ASSESSING THE COST-EFFECTIVENESS OF NON-PHARMACOLOGICAL THERAPIES FOR DEMENTIA IN THE COMMUNITY

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DECLARATION

I certify that the work contained in this thesis, or any part of it, has not been accepted in substance for any previous degree awarded to me or any other person, and is not concurrently being submitted for any other degree other than that of (Doctor of Philosophy) which has been studied at the University of Greenwich, London, UK.

I also declare that the work contained in this thesis is the result of my own investigations, except where otherwise identified and acknowledged by references. I further declare that no aspects of the contents of this thesis are the outcome of any form of research misconduct.

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ABSTRACT

Background

This thesis explores the cost-effectiveness of non-pharmacological therapies (NPTs) for people living with dementia (PLwD). NPTs aim to reduce symptoms and improve cognitive function or quality of life, alongside pharmacological therapies. However, their economic value remains unclear.

Aims

The thesis aimed to generate evidence to support decision-making around NPTs for PLwD and people with mild cognitive impairment (MCI). Specific objectives included:

a) conducting a systematic review and review of reviews on the cost-effectiveness of NPTs;

b) involving people with lived experience of dementia in prioritising the selection of community-based NPTs for further research;

c) analysing mental health service use and costs pre- and post-diagnosis; and

d) developing economic models to evaluate selected NPTs.

Methods

A systematic review of economic evaluations of community-based NPTs was conducted. A survey (n=50) involving caregivers, PLwD, and professionals identified priority interventions for further research. Two decision-tree models were developed to assess the cost-effectiveness of these interventions. A dataset of 16,081 patients was analysed to determine mental health service use and costs of these patients before and after a dementia diagnosis.

Results

The systematic review revealed limited economic evaluations of NPTs, despite growing interest. Survey participants prioritised music therapy (MT) and caregiver training programmes (CTP) for further research in this thesis. Economic modelling indicated that MT improved cognitive outcomes and reduced costs over six months, proving cost-effective. CTPs were cost-effective in the longer-term, to reduce behavioural symptoms in PLwD, and improve caregiver well-being, leading to being able to remain living at home for longer. Sensitivity analyses confirmed the robustness of findings.

Analysis of mental health service use for PLwD showed higher costs and increased service use after diagnosis than before diagnosis.

Conclusion

This thesis provides new evidence supporting the cost-effectiveness of MT and CTPs for PLwD in UK community settings. While findings are promising, further research using robust epidemiological methods is needed to strengthen the evidence base.

Keywords

Dementia, mild cognitive impairment, psychosocial, economic evaluation, cost, non-pharmacological therapies, music therapy, carers, caregiver training

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ABBREVIATIONS

Abbreviation	Description
AD	Alzheimer's disease
ADAS-Cog	Alzheimer's Disease Assessment Scale-Cognitive Subscale
AMSTAR 2	A Measurement Tool to Assess Systematic Reviews
ARC	Applied Research Collaboration
BPSD	Behavioural and Psychological Symptoms of Dementia
CBA	Cost-benefit Analysis
CBT	Cognitive Behavioural Therapy
CCA	Capital Consumption Allowance
CDR	Clinical Dementia Rating
CEA	Cost-effectiveness Analysis
CHEERS	Consolidated Health Economic Evaluation Reporting Standards
CMAI-SF	Cohen-Mansfield Agitation Inventory – short form
COVID-19	Coronavirus Disease 2019
CRIS	Clinical Records Interactive Search database
CST	Cognitive Stimulation Therapy
CT for CNLTC	Criterion Time for Certification of Needed Long-Term Care
CTI	Carer Training Intervention
CUA	Cost-utility Analysis
DCM	Dementia Care Mapping
DEEP	Dementia Engagement and Empowerment Thesis
DEMQOL	Dementia Quality of Life
DOH	Department of Health
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders
EQ-5D	EuroQol 5 Dimensions
EQ-VAS	Visual Analogue Scale
F2F contacts	Face-to face-contacts
FIM	Functional Independence Measure
FREC	Faculty Research Degrees Committee
GAIN	Alzheimer's Care Instrument
GP	General Practitioner
GRIPP2	Guidance for Reporting Involvement of Patients and the Public
HADS	Hospital Anxiety and Depression Scale
HCP	Healthcare Provider
HRQoL	Health-related Quality of Life
HSC/H&SC	Health and Social Care
ICD-10	International Classification of Disease
ICER	Incremental Cost-effectiveness Ratio
INT	Intervention
JDR	Join Dementia Research
MAUIs	Multi-attribute utility instruments
MC	Memory Clinic

MCI	Mild Cognitive Impairment
MMSE	Mini-Mental State Examination
MT	Music Therapy
NHP	Nursing Home Placement
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
NPI	Neuropsychiatric Inventory
NPTs	Non-pharmacological Therapies
PARO	Name of the toy in the PARO intervention
PBM	Preference-based measures
PCDC	Primary Care Dementia Clinic
PE	Physical Exercise
PICOS	Participants, Intervention, Comparison, Outcomes Study
PLwD	People Living with Dementia
PPI	Patient and Public Involvement
PRISMA	Preferred Reporting Items for Systematic review and Meta-Analysis
PROSPERO	International Prospective Register of Systematic Reviews
QALYs	Quality-adjusted Life Years
QoL	Quality of Life
QoL-AD	Quality of Life in Alzheimer Disease
QUALID	Quality of Life in Late-stage Dementia
RAID	Rating Anxiety in Dementia
RCT	Randomised Controlled Trial
SA	Sensitivity analysis
SF-6D	Short Form 6-Dimension utility index
SG	Standard gamble method
SLaM	South London and Maudsley NHS Foundation Trust
SPPB	Short Physical Performance Battery
START	STrAtegies for RelaTives intervention
TAU	Treatment as Usual
TTO	Time trade-off
UC	Usual Care
UK	United Kingdom
UREB	University Research Ethics Board
UREC	University Research Ethics Committee
US	United States
WHO	World Health Organisation
WTP	Willingness-to-Pay

List of publications arising from PhD

Eaglestone, G., Gkaintatzi, E., Jiang, H. *et al.* Cost-Effectiveness of Non-pharmacological Interventions for Mild Cognitive Impairment and Dementia: A Systematic Review of Economic Evaluations and a Review of Reviews. PharmacoEconomics Open (2023). https://doi.org/10.1007/s41669-023-00440-z

Chapter 1 Introduction

1.1 Background

This thesis sits at the intersection of health economics, dementia care, and non-pharmacological therapies (NPTs), with a specific focus on decision-analytic modelling in the United Kingdom (UK) context. There is an acknowledged lack of robust economic evaluations of NPTs for dementia (Alves *et al.*, 2013; Clarkson *et al.*, 2017). The work performed for this thesis has addressed this knowledge gap by providing rigorous economic evidence regarding NPTs that can be used to support national policy and commissioning decisions.

This first chapter summarises the context, background, and scope of the thesis. It then contains a description of the research questions, aims, objectives and framework used to guide the research. Finally, an outline of the thesis chapters is presented to guide the reader through the structure and progression of the research.

1.2 Context

Research as part of this thesis began during the pandemic caused by coronavirus disease 2019 (COVID-19). During this period, healthcare spending increased significantly, particularly in the context of providing care for people living with dementia (PLwD). In the UK National Health Service (NHS), budgets and resources became even more constrained than they had been previously during 2019 to 2022, as COVID-19 caused the deepest global recession for decades (Naseer *et al.,* 2023). COVID-19 increased the healthcare burden and demand on healthcare resources (Vysochyna *et al.,* 2023).

The pressure on healthcare systems during the pandemic particularly affected PLwD, who were especially vulnerable during the pandemic due to being particularly susceptible to infectious disease and having poor autonomy. They also had a higher rate of mortality from COVID-19 than did individuals without dementia (Liu *et al.*, 2020; Axenhus *et al.*, 2022; Office for National Statistics (ONS), 2023). PLwD were indirectly affected by the pandemic due to worsening quality of care and a refocus of healthcare services (Axenhus *et al.,* 2022). Cognitive function and quality of life declined as

access to services was reduced and people struggled with social isolation (Tuijt *et al.,* 2021). The vulnerability of PLwD or with mild cognitive impairment (MCI) also increased their reliance on support and care from informal caregivers during the pandemic (Tsapanou *et al.,* 2021). This increased reliance on informal caregivers highlighted the urgent need for accessible, effective support options. The pandemic has had lasting effects on healthcare services; for example, diagnosis rates fell during the pandemic and have not fully recovered. Additionally, some memory clinics have a backlog of referrals for dementia assessment (Royal College of Psychiatrists, 2024).

As this PhD thesis was conducted during this period, the need to evaluate the cost-effectiveness and acceptability of NPTs and to identify cost-effective interventions was highlighted. These interventions could potentially enhance support for PLwD, improve quality of life and reduce symptoms. The term ‘intervention’ refers to a deliberate action or treatment administered to individuals or groups to observe its effects on a particular outcome or condition. The goal of an intervention is typically to bring about a desired change or improvement for the targeted population. Despite the need for interventions to support PLwD, little research has been done in the UK to determine whether NPTs improve their health outcomes or reduce costs.

Furthermore, a broad global need was identified for cost-effectiveness research of NPTs for dementia, as existing evidence has highlighted significant gaps in the economic evaluation of such NPTs (Alves *et al.,* 2013; Clarkson *et al.,* 2017). The identified lack of cost-effectiveness evidence established the need for a thorough economic evaluation, particularly in the context of ongoing austerity and the rising number of PLwD/MCI. This PhD thesis contributes to the body of evidence on the cost-effectiveness of offering specific NPTs to PLwD.

1.3 Dementia background

Dementia is a progressive, neurodegenerative disease characterised by a decline in cognitive function beyond what might be expected from normal ageing (World Health Organization (WHO), 2025), and at present, it has no cure. Dementia is an umbrella term that is used to refer to multiple conditions affecting memory, cognition, and social functioning (WHO, 2025). Globally, around 50 million people currently live with dementia, and this number is expected to rise to 152 million by 2050 (WHO, 2017).

While dementia represents the more advanced stages of cognitive decline, it is often preceded by a related condition, MCI, which is defined as a state of reduced cognitive function between normal cognition and dementia, that is not severe enough to affect daily life significantly (Petersen, 2016). Worldwide, over 15% of people aged over 50 years and living in the community are estimated to have MCI (Bai *et al.*, 2022).

Dementia is a significant global public health challenge with substantial economic implications, largely driven by the increasing care needs of PLwD/MCI (Ward *et al.*, 2022). The global costs of dementia were estimated at US$1313.4 billion in 2019, which corresponded to US$23,796 per person with dementia per year, and this is expected to rise as the number of PLwD increases (Wimo *et al.*, 2023).

At present, treatment options for dementia remain limited; pharmacological therapies developed specifically for dementia are currently available only for Alzheimer's disease (AD), they can modestly slow the progression of dementia but do not cure it (WHO, 2025). NPTs are therapies that do not directly involve the use of medication, for example, music therapy, occupational therapy, art therapy and exercise therapy (Kooijmans *et al.*, 2025). There is growing evidence from randomised controlled trials and systematic reviews that NPTs are effective in reducing the behavioural and psychological symptoms of dementia (BPSD); for instance, they have been shown to reduce levels of agitation, depression and anxiety (Livingston *et al.*, 2014a) and to slow cognitive decline (Desai *et al.*, 2024). The National Institute for Health and Care Excellence (NICE) recommends that NPTs are used as complements to pharmacological therapies NICE, 2018a).

However, despite growing recognition of the clinical benefits of NPTs, their economic value remains under-explored (Alves, Magalhaes, and Thomas, 2013; Clarkson *et al.*, 2017). As the population of PLwD continues to grow and their care needs become more complex, there is an urgent need to assess the broad economic implications of NPTs. Projections of dementia-related costs at the population level are essential to inform policy priorities and to enable the effective allocation of limited resources (Bruck *et al.*, 2023). Economic evaluation plays a crucial role in improving efficiency in health production and finance by identifying cost-effective interventions. Incorporation of NPTs into economic evaluations is essential to determine their cost-effectiveness relative to pharmacological treatments and to support their integration into routine

dementia care. As a result, more healthcare therapies are being economically evaluated to support evidence-based decision-making regarding which should be funded (Kolovos *et al.*, 2017).

In this research, through the integration of data from a real-world cohort of mental health service users into model-based approaches, the aim is to provide a comprehensive model by which both short- and long-term economic outcomes of certain NPTs for PLwD can be assessed. This approach enables a structured comparison of interventions and facilitates evidence-based decision-making on resource allocation. Given the increasing financial pressures on the UK health and social care system, such evaluations are essential to identify interventions that deliver value for money and can be sustainably integrated into care pathways. The work undertaken in this thesis also sought to address knowledge gaps in the economic evaluation of NPTs and to inform national policy and commissioning decisions by providing rigorous economic evidence for non-pharmacological dementia care options.

1.4 Scope of the thesis

This thesis is focused on PLwD/MCI, with findings that can be applied to a UK population within the context of the NHS. The findings therefore reflect the interests and decision making of UK healthcare provision and the costs ascribed to it. For the purposes of this thesis, MCI was treated as a distinct condition and not merely as a subset of mild cognitive impairment within dementia. The scope was narrowed to NPTs that were delivered in the community to PLwD/MCI in the UK. In the context of this thesis, the term community referred to non-acute, non-hospital settings, including private homes, community-based facilities (day centres, memory cafés, libraries) and residential care settings (care homes, nursing homes).

NPT is a broad concept, but for this review it was defined narrowly as structured, manualised therapies delivered with a clear therapeutic intent such as improving cognitive function or improving quality of life. Broader interventions such as oral nutritional supplements, day care programmes, and multi-domain prevention trials were excluded because they focus on general wellbeing or dementia risk reduction rather than providing structured therapeutic input for PLwD/MCI. This narrower focus

was intended to generate context-specific evidence to inform dementia care policy and resource allocation.

There is an extensive range of NPTs, and it was not feasible to evaluate the cost-effectiveness of all within the scope of the thesis. Therefore, two therapies were selected for evaluation. This choice was informed by the preferences of a survey of individuals with lived experience of dementia. Purpose-built models were designed for each therapy, with the modelling concepts being transferable to other NPTs. The aim of the evaluation was to provide valuable evidence for decision-makers and potentially to support the wider adoption of NPTs in routine practice. The findings may help to support the wider adoption of NPTs for PLwD, offering greater choice in routine care.

The important role of caregivers is discussed in the thesis. In this case, caregivers include peer supporters – individuals with lived experience of dementia who support others on a similar journey. Peer supporters can have a meaningful impact on well-being and social inclusion for PLwD. Whilst their role is acknowledged, it is not discussed further in this thesis, as it falls outside the scope of the analysis.

1.5 Significance

This research has important implications for PLwD, their caregivers, and health policy and decision-makers in the UK. The aim was to generate robust evidence on the cost-effectiveness of specific NPTs that could help these decision-makers to maximise health benefits and to allocate limited healthcare resources efficiently.

The research findings can be used to determine the most effective NPTs for adoption into routine dementia care practice. They narrow the gap in the literature regarding the cost-effectiveness of NPTs for dementia. Addressing this gap was a key objective of the work for this thesis. The findings, though not necessarily generalisable to all settings, are likely to hold significance for countries experiencing similar pressures from dementia care demands.

1.6 Epistemological framework

To establish a clear philosophical foundation for this research, a theoretical framework was adopted to guide its design and interpretation. The research paradigm that underpinned the work was positivism. This theoretical approach was developed by

Comte in the early to mid-nineteenth century (Lenzer, 2017). Positivism is based on the belief that societies operate according to their own scientific principles and laws. It assumes that there are truths about society that can be discovered through scientific studies based on data and evidence (Brown, 1994).

The thesis framework was also informed by a realist perspective. Realism is a philosophical perspective that emphasises the representation of reality as it really is, with the assumption that entities exist independently of beliefs or perceptions about them (Bhaskar, 2008). Adopting a realist ontology led to the selection of an etic epistemology, which assumes that reality can be measured in an objective way by taking an external perspective to minimise bias and to maintain distance from the research subject (Bhaskar, 2008).

Adoption of a positivist framework for the thesis involved consideration of the following factors.

- Research questions: Should be clearly defined and structured, and addressed using measurable variables.
- Design: Literature reviews should focus on empirical studies and randomised controlled trials that have collected quantitative data, providing measurable outcomes to address the research questions.
- Data collection: The research design was selected to enable the collection of specific variables through a structured survey methodology. A quantitative methodological approach was adopted that combined primary data collection via surveys with secondary analysis of existing datasets. This approach was chosen to enable objective, systematic data collection and to minimise potential bias in the analysis.
- Analysis: Statistical and random-sampling techniques were employed to establish an objective relationship with the data, to ensure that the analysis was focused on measurable, numerical data. The use of quantitative methods was well-suited to the economic focus of the thesis, as they provided an appropriate framework for the evaluation of objective and numerical datasets.
- Findings: Are discussed in relation to existing evidence to produce a well-supported conclusion.

Systematic application of the positivist framework to the thesis enabled the production of objective and generalisable knowledge, and therefore effective addressing of the research questions.

1.7 Ethical approval

Ethical approval of the work performed for the thesis was granted by the University of Greenwich Research Ethics Board (UREB). Approvals for individual components of the thesis are discussed within the relevant chapters.

1.8 Research aims

The main aims of the research were to address gaps in existing economic knowledge about community-based NPTs for MCI/dementia by producing economic simulation models that could be used to evaluate the cost-effectiveness of NPTs in the UK.

To address the aims, four research questions were developed, which led to the focus of the thesis.

1. Which NPTs for PLwD are evidenced to be cost-effective?
2. How cost-effective are the selected NPTs for PLwD?
3. What are the predictors of NHS mental health service use and the costs for PLwD in a UK setting?
4. What NPTs do people with lived experience of dementia value and prioritise?

To address the research questions, five specific objectives were developed, each of which forms a key component of the thesis.

1. Review the literature systematically on the existing evidence regarding the cost-effectiveness of NPTs for PLwD/MCI and identify the gaps in the existing economic knowledge about community-based NPTs for these people.
2. Review the clinical effectiveness of NPTs for PLwD/MCI. The results of the systematic review of economic evaluations, together with the results of the clinical effectiveness review, were used to inform the list of therapies to be included in the survey of people with lived experience.

3. Develop a survey that would lead to the inclusion of the voices of people with lived experience in decision-making processes, by involving a PPI group and then adapting the survey to ensure it is accessible.
4. Conduct the survey mentioned in point 3 to set the priorities for the research and to inform the choice of NPTs for economic evaluation.
5. Analyse an existing dataset of the use of mental health services by PLwD/MCI and compute the costs associated with this use, in order to determine patterns of service use pre- and post-diagnosis, which will inform an economic evaluation.
6. Produce decision-tree economic simulation models by which to evaluate the cost-effectiveness of selected community-based NPTs and hence to address the economic knowledge gap regarding such NPTs for PLwD/MCI.

The aim was to identify therapies that offered value for money, improved quality of life effectively, managed symptoms or improved cognition, and that individuals found acceptable and motivating to use, while acknowledging that not all outcomes may be achieved equally. By increasing the body of evidence regarding the cost-effectiveness of NPTs for PLwD, this thesis not only provided decision-makers with data from economic evaluations but also represented a step towards improving the overall acceptability of NPTs. This, in turn, supported the widening of the choice of effective NPTs for PLwD.

1.9 Thesis outline

The literature review in Chapter 2 begins with some clinical background of dementia, which is followed by a discussion of dementia care, policy, and NPTs. It concludes with an exploration of the economic burden of dementia. This chapter provides a comprehensive explanation of the scope of the issue and lays the foundation for exploration of the research questions. Chapter 3 presents a systematic literature review, which has been published as a peer-reviewed paper, on the economic evaluations of NPTs for dementia. In the chapter, the cost-effectiveness of dementia NPTs is explored, gaps in the current economic evidence are identified, and the findings are situated within a discussion of the broad literature and thesis context.

In Chapter 4, a review of the clinical effectiveness of NPTs is intended to identify gaps in existing knowledge by finding clinically effective therapies that lack cost-effectiveness evaluation. Chapter 5 contains a description of the development of a survey with the involvement of a PPI group to include the voices of people with lived experience of dementia or MCI in the processes that would lead to decisions on the choice of NPTs to be economically evaluated. The findings from the survey are also presented.

Chapter 6 contains an analysis of an existing dataset regarding mental health service use by a cohort of patients and the associated costs, in order to determine patterns of service use pre- and post-diagnosis in the UK. Chapter 7 presents an economic evaluation of music therapy (MT) to assess its cost-effectiveness for improving cognitive function in PLwD in the UK community setting. Chapter 8 then presents an economic evaluation of caregiver training programmes (CTPs) to assess their cost-effectiveness in reducing BPSD. Finally, Chapter 9 summarises the thesis, discusses the strengths and limitations of the research, and explores the implications of the research and potential future work. Details of presentations and publications arising directly from this thesis are shown in Appendix 5, along with one co-authored publication on dementia not directly related to the thesis project to illustrate professional development and broader engagement with the field.

1.10 Chapter summary

Chapter 1 has introduced the background, context and scope of the thesis. It contains the research questions along with aims and objectives. An outline of the thesis chapters has been presented to guide the reader through the structure and progression of the thesis.

The next chapter contains a review of existing literature on dementia with a particular focus on care and support within the UK context. This provides context and background for the thesis.

Chapter 2 Literature review of dementia, including care and support, policies, economic impact and economic evaluation

2.1 Introduction

This chapter begins with a review of the literature on dementia that is focused on care and support within the UK context. It examines current approaches to dementia care in UK health and social care settings. Section 2.3 outlines the global and national policy landscape that shapes the provision of dementia care. Section 2.4 explores the role of NPTs in dementia care and highlights their therapeutic potential and clinical benefits for PLwD. Section 2.5 addresses the economic impact of dementia and introduces key principles of healthcare economic evaluation to identify which NPT interventions may offer sustainable and cost-effective improvements in care. Section 2.6 discusses the application of economic modelling in dementia research and its importance in the evaluation of the cost-effectiveness of NPTs. The chapter concludes with a summary and identification of a key gap in the current literature, which is the limited number of economic evaluations of NPTs for dementia that have been performed; this thesis aims to address this gap.

2.2 Understanding dementia

2.2.1 Epidemiology

An estimated 57.4 million people worldwide live with dementia, and this number is expected to rise to 152.8 million by 2050 (Nichols *et al.*, 2022). As of 2024, there were approximately 982,000 PLwD in the UK (Carnall Farrar, 2024). The incidence of dementia is reported to double every five years among those over the age of 65 years (Prince, Bryce and Ferri, 2011). In the UK, dementia prevalence rises from approximately 2-5% in individuals aged 65-74 years to over 30% in those over 85 years (Matthews *et al.*, 2013). While dementia typically affects older adults, early or young-onset dementia (before age 65) affects approximately 3.9 million people globally (Hendriks *et al.*, 2021).

2.2.2 Risk factors

Several risk factors for dementia have been identified, including non-modifiable risk factors such as age, gender, ethnicity and genetics, and modifiable factors such as lifestyle and behaviour factors (Livingston *et al.*, 2024). Management of risk factors can help to prevent or delay the onset of dementia (Department of Health, 2015b). These factors are discussed in the next sections.

2.2.2.1 Non-modifiable risk factors for dementia

Advancing age is a significant risk factor for dementia (WHO, 2017). Prevalence has been estimated at 3% in people aged 65-69 years, 6% for those aged 70-74, 12% for 75-79, 24% for those aged 80-84 and 40-50% for those aged 80 years and over (Nichols *et al.*, 2022). However, it is important to note that dementia is a disease and is not an inevitable consequence of ageing (Vinay and Biller-Andorno, 2023).

Dementia prevalence is higher in females than in males (Prince *et al.*, 2013; Nichols *et al.*, 2022), particularly in AD, in which approximately two-thirds of diagnoses are for women (Mielke, 2018). The higher prevalence in women is due to factors including longer life expectancy and biological factors such as hormonal changes (Cao *et al.*, 2020). However, a recent study of risk in cisgender, transgender, and non-binary adults found that people who had been assigned as female at birth had a lower mid-life dementia risk but a higher late-life AD risk than did those assigned as male at birth (Brady *et al.*, 2024). Additionally, transgender men, transgender women, and non-binary adults exhibited a higher late-life AD risk than did cisgender men and women. Differences were also observed in the incidence of specific risk and protective factors for dementia and AD across these groups (Brady *et al.*, 2024).

Ethnicity affects dementia risk and outcomes due to a mix of genetic, health, and social factors. Research has shown that certain racial and ethnic groups have higher rates of dementia compared with other populations (Shiekh *et al.*, 2021). This difference may be due to dementia risk factors such as hypertension and diabetes, which are more common in Black, Asian and other ethnic minorities (Shiekh *et al.*, 2021). Socioeconomic factors, including access to good quality healthcare, education, and income, also influence dementia rates (Cha *et al.*, 2024). People from minority groups are often diagnosed later than those from the majority or have missed diagnoses, and

their dementia may be at a more advanced stage when they are diagnosed (Lin *et al.*, 2021). Genetic factors may also affect dementia risk and outcomes, but their effects vary among populations (Mukadam, Basit and Livingston, 2011). To reduce these inequalities, public health efforts should prioritise ethnic minority and underrepresented communities to provide better access to healthcare, early diagnosis, and culturally sensitive support (Lin *et al.*, 2021).

2.2.2.2 Modifiable risk factors for dementia

Modifiable risk factors, including cardiovascular disease, diabetes, hypertension, high cholesterol levels, smoking, obesity and inactivity, alongside genetic risk factors have been linked to increased risk of dementia (Patterson *et al.*, 2008; Vinay and Biller-Andorno, 2023). Social isolation and lack of social support are also associated with an increased risk of developing the disease (Zhou, Wang and Fang, 2018; Shafighi *et al.*, 2023). In line with this finding, research has shown that people with hearing loss are more likely to develop dementia than are people with normal hearing, and hearing aid use has been associated with a lower prevalence of dementia (Thomson *et al.*, 2017; Livingston *et al.*, 2024). This highlights the importance of regular hearing assessments and timely interventions to manage hearing loss, both to improve hearing and as a potential strategy to reduce the risk of dementia. Conversely, higher education levels (Cha *et al.*, 2024; Livingston *et al.*, 2024), engagement in mental and physical activities (Duffner *et al.*, 2022), and a rich social life (Chen *et al.*, 2024) are all associated with a reduced risk of dementia.

Understanding the risk and protective factors is essential for both individuals and public health strategies. Addressing modifiable risk factors, including managing cardiovascular health, maintaining an active lifestyle, and fostering social connections, can potentially delay or prevent dementia.

2.2.3 Types of dementia

There are several different types of dementia; each type has its own pathophysiology and range of symptoms, and the causes of some types are unknown. For the purposes of this thesis, the term ‘dementia’ will be used as an umbrella term that encompasses all forms of dementia. AD is the most prevalent form and accounts for 60-70% of dementia cases (WHO, 2025). Other types are vascular dementia (15-20%) or

dementia with Lewy bodies (5%); a rarer form is frontotemporal dementia, which includes Pick's disease (2-5%); other types, including Huntington's and Creutzfeldt-Jakob disease, make up the rest (Alzheimer's Disease International, 2018). Next, the various types of dementia are explained in further detail.

2.2.3.1 Mild cognitive impairment

MCI is a term that is used to describe minor impairments to memory and cognitive function that exceed what is expected for normal age, but do not significantly impact daily life (Petersen *et al.*, 1999). While MCI is not a type of dementia, there is a higher risk of progression to dementia in people with MCI than in those who age normally; however, MCI may not progress to dementia, as many people recover or remain with a diagnosis of MCI (Petersen *et al.*, 1999).

MCI arises from one of multiple underlying causes, including neurodegenerative, vascular, and psychiatric factors, and co-morbid conditions such as anxiety and depression, which can contribute to or exacerbate cognitive deficits (Petersen *et al.*, 2014). Common symptoms include memory loss, and difficulties with concentration, planning and decision-making (NICE, 2018a).

2.2.3.2 Alzheimer's disease

AD is caused by abnormal structures in the brain, specifically beta-amyloid plaques and tau tangles, which damage and kill nerve cells, causing degeneration of the neural pathways. In certain cases, there may be a link to genetic mutations (Ridge, Ebbert and Kauwe, 2013). Symptoms include short-term memory loss, difficulty finding words and understanding language, changes in mood and personality and disorientation in terms of time and place (Karantzoulis and Galvin, 2011).

2.2.3.3 Vascular dementia

Vascular dementia is caused by a reduction in the flow of blood to the brain due to cardiovascular events or chronic vascular damage (Karantzoulis and Galvin, 2011). Symptoms include difficulty solving problems, making decisions or concentrating. These symptoms may appear suddenly, for example, after a stroke (WHO, 2023).

2.2.3.4 Mixed dementia

Mixed dementia refers to cases where the brain changes due to the effects of more than one type of dementia (WHO, 2023). These changes often include abnormal protein deposits, as seen in AD, alongside vascular abnormalities which are commonly associated with vascular dementia (WHO, 2023).

2.2.3.5 Dementia with Lewy bodies

Dementia with Lewy bodies is a type of progressive dementia that leads to a decline in thinking, reasoning and the ability to live independently (WHO, 2023). It is caused by the presence of abnormal protein deposits in the brain (WHO, 2023). Symptoms include disturbance of multiple higher cortical functions, such as memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement, along with motor symptoms such as tremors or rigidity that are commonly associated with Parkinson's disease (McKeith *et al.*, 2017).

2.2.3.6 Frontotemporal dementia

Frontotemporal dementia is caused by clumps of abnormal proteins that damage the frontal and temporal lobes of the brain, impairing their function. In many cases, there is a genetic component (WHO, 2023). Memory loss is not usually seen in the early stages; instead, there may be personality changes, impulsive behaviour, apathy and loss of empathy as well as language difficulties (WHO, 2023).

2.2.3.7 Early-onset dementia

Dementia symptoms and diagnosis before the age of 65 years are known as early-onset or young-onset dementia. This type accounts for 5-10% of cases (Rossor *et al.*, 2010). People with early-onset dementia are more likely to have frontotemporal dementia or a genetic or metabolic cause for their dementia than to have AD, which is more common in late-onset onset (Rossor *et al.*, 2010).

2.2.4 Symptoms and progression

Decline in usual activities of daily living (ADLs) and instrumental activities of daily living (IADLs) are key markers of functional deterioration for PLwD. ADLs are basic tasks of self-care such as bathing, dressing, eating, toileting, and mobility. They are usually the last skills to be lost as dementia progresses (Giebel, Challis and Montaldi, 2015).

IADLs are more complex, higher-level functions that are necessary for independent living. Examples are management of medications, handling finances, shopping, cooking, and using transportation. These skills are usually affected earlier in dementia than are ADLs as they require executive functioning, memory, and decision-making skills. Giebel, Challis and Montaldi (2015) found that as dementia progressed, individuals typically experienced a gradual loss of independence in both IADLs and basic ADLs. Therefore, changes in ADLs and IADLs must be monitored to assess disease progression, to determine the level of support required and to plan care needs (Giebel, Challis and Montaldi, 2015).

In addition to functional loss, many PLwD experience a range of cognitive and behavioural symptoms (BPSD). These include memory loss, agitation, depression, euphoria and sleep disturbance (Beeri *et al.*, 2002; Lian *et al.*, 2017). BPSD can significantly diminish the quality of PLwD's lives (Lian *et al.*, 2017). The Department of Health (DOH) has recognised improving the quality of life for PLwD as a key priority in the *National Dementia Strategy* (DOH, 2009).

2.2.5 Diagnosis

There have been significant advances in the detection, diagnosis, and treatment of dementia, particularly for AD. Advances in neuroscience, imaging and pharmacology have enabled early identification and diagnosis, and the development of disease-modifying treatments (Anderson *et al.*, 2018; Laurell *et al.*, 2023). In the UK, the diagnostic journey for people suspected of having dementia or MCI typically begins in primary care, where individuals consult their general practitioner (GP) before being referred to a memory clinic for further assessment and diagnosis. Dementia diagnosis involves the application of a variety of tests, including biomarker searches, scans, and screening tools. The mini-mental state examination (MMSE) (Folstein, Folstein and McHugh, 1975) is an assessment of cognitive decline that provides a score that is used to aid diagnosis. The MMSE is the most popular and best-known tool in research studies to measure the level of cognitive impairment (Arevalo-Rodriguez *et al.*, 2021).

The MMSE is used to categorise dementia severity and disease progression as well as to aid in diagnosis. NICE guidelines (2018) categorise stages of AD severity according to cognitive impairment, which is measured by the MMSE score. The four

stages of AD are categorised as mild, moderate, moderately severe, and severe based on MMSE score, as detailed below (NICE, 2018b).

- Severe AD: MMSE score less than 10
- Moderately severe AD: MMSE 10-14
- Moderate AD: MMSE 10-20
- Mild AD: MMSE 21-26

Early detection and diagnosis of dementia were promoted in the Prime Minister's Challenge on Dementia 2020. Early diagnosis can lead to earlier implementation of strategies to delay the progression of dementia (DOH, 2015a). After diagnosis, most PLwD are managed in the community by their GP until they have unmanaged behavioural symptoms, when they may be referred to specialist dementia practitioners (Koychev *et al.*, 2024). However, the progression of the condition means that many PLwD eventually require long-term care; recent evidence shows that over half of PLwD in the UK move to a nursing home within five years of their diagnosis (Bruck *et al.*, 2023).

2.3 Dementia care and support in the UK

2.3.1 Informal caregiving

There is currently a shortage of community caregivers in the UK; the demand for caregivers is high, but the role is poorly paid (UK Parliament, 2024). As a result, many family members and friends provide informal care and support for PLwD. The term 'informal carer/caregiver' is used for an unpaid family member, friend or community member who provides help, support, and care for another person (Patel *et al.*, 2023). Within this group, a 'family caregiver' is a term used to describe an informal caregiver who is related to the PLwD. Support and care for older people is a major public health issue. Informal caregivers fill this role and supply a vital care resource (Schulz and Sherwood, 2008). These caregivers provide care and support for large numbers of PLwD worldwide. In the UK alone, there are an estimated 700,000 informal providers of care to PLwD (Lewis *et al.*, 2014).

2.3.2 Psychological impact of caregiving

Many caregivers feel unsupported and unprepared for the responsibility of their role (Gomes da Rocha, Perrenoud and Ramelet, 2022; Hazzan *et al.*, 2022). The BPSD are particularly challenging, often contributing to caregiver burden (Chiao, Wu and Hsiao, 2015) as well as stress, depression and declines in caregivers' own health (Sadavoy, Sajedinejad and Chiu, 2022; Chakraborty, Jana and Vibhute, 2023).

Caregiver burden that negatively impacts caregivers' health can in turn affect the health of the PLwD, and this often results in more rapid placement in care or nursing homes (Beeri *et al.*, 2002; Etters, Goodall and Harrison, 2008). Support for caregivers that reduces their levels of stress may lead to improved care and, in turn, improved quality of life for the person they care for (Tanner *et al.*, 2014). Many caregivers are required to take on increasing levels of responsibility as the dementia progresses and the condition of the PLwD deteriorates (Chiao, Wu and Hsiao, 2015). However, despite the reported challenges, caregivers report positive experiences. As summarised by Schult and Sherwood (2008), caregiving can foster a sense of purpose, emotional fulfilment and personal growth. Beyond these individual benefits, many caregivers are motivated by a sense of familial obligation, love and commitment that can bring meaning and satisfaction and strengthen existing relationships (Zarzycki and Morrison, 2021).

Nonetheless, addressing caregiver burden is essential for the well-being of both caregivers and of PLwD. There is evidence of inadequate support after diagnosis and wide variation in service provision that particularly affects certain groups, such as ethnic minority communities (Prince *et al.*, 2016). Therefore, the identification of effective and cost-effective methods to support informal caregivers of PLwD remains a key priority (Dowd *et al.*, 2018). Yet there are few model-based economic evaluations of NPTs, whether targeted at PLwD or their caregivers. This broad knowledge gap underscores the need for comprehensive evaluations of specific NPTs, and this thesis seeks to address this issue.

2.3.3 Economic impact of caregiving

Many informal caregivers are the primary source of care and support services, offering assistance that would otherwise incur significant costs if obtained through formal

channels (Lewis *et al.*, 2014). The economic cost of informal care for older people in England was £54.2 billion in 2019 (Hu *et al.*, 2024). A study by Wittenberg *et al.* (2019) estimated the total annual cost of dementia in England at £24.2 billion (in 2015), with 42% of that figure (£10.1 billion) attributed to informal care (Wittenberg *et al.*, 2019). Over 50% of the total costs of dementia care are attributed to unpaid care by family members and friends (WHO, 2025).

Informal caregiving can reduce usage of formal health services and can delay the transfer of PLwD to long-term care (Gallagher-Thompson *et al.*, 2012). By enabling individuals to remain at home, informal caregiving not only supports PLwD well-being but also alleviates pressure on health and social care systems. The cost of provision of dementia care at home by informal caregivers is significantly lower than the cost of care in a long-term institutional setting (Wubker *et al.*, 2015). However, there are indirect costs of caregiving for caregivers and society, through reductions in work hours and lost income (O'Shea, 2003; Ekman *et al.*, 2021). Many caregivers are reported to give up work, reduce their hours or decline promotion to undertake caring responsibilities (O'Shea, 2003).

2.3.4 Long-term and residential care

There is a high probability that PLwD will have to move into care/nursing homes as their disease progresses. Research indicates that most would prefer to remain in their own homes, provided that they can maintain a good quality of life with adequate support *(*Rapaport *et al.,* 2020; Jutkowitz *et al.,* 2023). Early nursing home placement may become necessary when caregivers are unable to manage the demands of caregiving, which exacerbates the challenges for PLwD and reduces their overall well-being. Research indicates that PLwD who live at home and receive care tend to report better quality of life than do those who live in institutional settings (Nikmat, Hawthorne and Al-Mashoor, 2015; Jing, Willis and Feng, 2016; Olsen *et al.*, 2016). Older people with dementia who live in institutions are more likely to report low quality of life, be less physically active and receive more medications than those living in the community (Jing, Willis and Feng, 2016; Olsen *et al.*, 2016). Individuals with severe dementia have reported a lower quality of life than people with mild dementia, needing higher levels of care and higher expenditures to meet their needs (Wittenberg *et al.*, 2019). Many people in care homes are prescribed high doses of psychotropic medications

(McCowan *et al.*, 2013) and have low levels of physical activity (Alphen *et al.*, 2016), both of which can lead to a lower quality of life for people in long-term care than is enjoyed by people living in the community. Notably, cognitive impairment alone is not the main driver of admission to care homes for PLwD; rather, it is the presence of BPSD and care needs that cannot be met by community-based caregivers (Gaugler *et al.*, 2009).

2.3.5 Use of health and social care services

Many PLwD rely on social care services to manage their daily activities and maintain their quality of life. Social care comprises a range of support services that are offered in residential or home care (Nuffield Trust, 2024). In the UK there is currently a poor distinction between healthcare needs and social needs. Additionally, there are long-standing issues within the social care sector, including workforce shortages, lack of funding and insufficient integration with health services. As a result, responsibility for long-term care often falls on families, as dementia care is only partially integrated into the broader healthcare system.

The Better Care Fund was developed in 2013 between NHS England, the Department of Health and Social Care, the Ministry for Housing, Communities and Local Government and the Local Government Association (NHS England, 2013). Its aim was to promote the integration of health and social care services across the UK, to enhance the co-ordination and quality of local care and support services. It incorporated elements of integrated care, which is an approach to healthcare through which different health and social care providers work together to meet the holistic needs of people with complex health conditions such as dementia. Integrated healthcare systems have been associated with improved PLwD outcomes, including reductions in hospital admissions and shorter lengths of stay (Liljas *et al.,* 2019). By fostering collaboration across services, integrated care also helps to minimise duplication of efforts. However, some critics argue that integration may lead to increased service utilisation, as people gain access to a wider range of services, potentially driving up overall costs (Wilberforce *et al.*, 2016).

In 2021, the Department of Health and Social Care introduced a comprehensive 10-year strategy titled *People at the Heart of Care*, aimed at reforming adult social care in the UK (Department of Health and Social Care, 2024). This plan included

commitments to additional funding on top of existing budgets (Department of Health and Social Care, 2024). However, in 2023, many of the short-term parts of the plan were scaled back, less funding was allocated, and key initiatives were delayed. This has led to insufficient resources being allocated to community care in the UK, which has exacerbated the pressure on local councils, care providers and families who rely on these services (Samuel, 2024; UK Parliament, 2024). While the Government has reaffirmed its long-term intentions, revised implementation timelines and concrete delivery plans have not yet been fully outlined. The absence of a reliable, long-term funding plan, coupled with rising demand for social care services, has led to uncertainty for care providers and people who rely on these services.

As dementia progresses, PLwD may require increased engagement with health services, including specialist mental health care and memory clinics. They may also need more frequent face-to-face interaction with clinicians and experience a higher rate of inpatient admissions, often triggered by incidents such as falls. Chapter 6 explores service use and associated costs for PLwD/MCI, focusing on mental health service use within a UK-based cohort.

2.4 Policy context for dementia

2.4.1 Global dementia policies and frameworks

Countries around the world are developing strategies and policies to address the growing demand for dementia care and its rising costs, which pose a significant global challenge. In 2017, the WHO developed a *Global action plan on the public health response to dementia, 2017–2025* (WHO, 2017). This included targets for governments to advance dementia research, increase disease awareness, reduce risk, improve diagnosis, care and treatment, and provide support for informal caregivers (WHO, 2017). The WHO encourages countries to acknowledge dementia as a public health priority and to integrate dementia care into their national health policies.

Many countries have developed strategies for addressing dementia that follow the WHO guidelines; these include Australia, Canada, China and the United States (US) (WHO, 2017). Global organisations such as Alzheimer's Disease International encourage collaboration between countries and promote the sharing of best practice

(Alzheimer's Disease International, 2015). These strategies aim to improve the quality of life for PLwD and their caregivers and to integrate dementia care into wider healthcare systems (WHO, 2017).

Many countries do not consider dementia a national health priority, particularly those low- and middle-income countries in which health systems are overburdened and underfunded (Kenne Malaha *et al.*, 2023). As a result, resources for dementia care, including staffing, equipment, and training, are frequently limited (Kenne Malaha *et al.*, 2023).

2.4.2 UK dementia strategies and policy initiatives

The UK Government has responded to the growing dementia challenge by investing in research aimed at reducing the incidence of the disease, raising public awareness, and enhancing the quality of life and outcomes for PLwD. The Government's first national strategy on dementia, *Living Well with Dementia: A National Dementia Strategy*, was launched in 2009. It aimed to achieve 'better awareness of dementia, early diagnosis and high-quality treatment at whatever stage of the illness and in whatever setting' (DOH, 2009). The guidelines offered practical tools for service development and redesign. They included a framework for delivery of integrated care, prioritisation of person-centred services, achievement of enhanced outcomes, and maximised returns on investment.

The *Dementia Commissioning Pack* was later published as a guide for commissioners, those responsible for planning and funding local services, to raise awareness of the economic impact of dementia and improve returns on investment in care services (Department of Health and Social Care, 2011). In 2012, the Prime Minister's Dementia Challenge was launched, with the aim to deliver major improvements in dementia care and research by 2015 (DOH, 2012). This was followed up in 2015 by the 2020 version of the challenge, which committed to invest £300 million in dementia research (DOH, 2015a). Historically, dementia research in the UK has received significantly less funding compared to other major diseases, despite its growing prevalence and societal impact (Luengo-Fernandez, Leal and Gray, 2015). In 2012, cancer received 64% of research funding, coronary heart disease 19%, dementia 11%, and stroke 7% (Luengo-Fernandez, Leal and Gray, 2015).

A UK Government initiative was launched in 2015 to develop dementia-friendly communities. It encouraged local areas to adapt services and environments better to support people with dementia. It also aimed to reduce the stigma that is often associated with dementia (Department of Health and Social Care, 2015). Then, in 2018, NICE published guidance regarding the care and support of PLwD and their caregivers in England and Wales (NICE, 2018a). These guidelines aimed to provide health and social care professionals, PLwD and informal caregivers with up-to-date, evidence-based information about dementia care. It also provided important guidelines about pharmacological treatments and NPTs, and summarised evidence on effectiveness and cost-effectiveness.

In 2019, the *NHS Long Term Plan* was published. This document showed further commitment to improving the quality of life of PLwD and their caregivers (NHS England, 2019). After the UK 2019 general election, the Labour Party proposed several measures for improving dementia care and support in its report, *Towards the National Care Service* (Labour Party, 2019). Measures included a commitment to provide free personal care, such as help with washing, dressing, and eating, for older people with dementia, and to extend it to all working-age adults with the disease. There were also pledges to address the long waiting lists for dementia assessment and to offer greater support after dementia diagnosis. The party also emphasised the importance of improving the NHS, including increasing the number of GPs and ensuring the availability of face-to-face appointments, which could benefit people with dementia.

Later, in 2021, the UK Government stated an intention to advance research in the UK into life-changing diseases such as obesity, cancer and dementia through its *Life Sciences Vision* policy paper (UK Government, 2021). In 2022, the Westminster Health Forum was held to coincide with the development of the new Government strategy for dementia. The forum enabled key stakeholders and policymakers to engage in discussions. The *NHS Operating Framework* mandates that the NHS collaborates with local authorities to fund and resource services appropriately for PLwD, ensuring that commissioned services respect these clients' dignity and recognise their value (DOH, 2010).

2.5 Therapeutic approaches in dementia

2.5.1 Pharmacological therapies for dementia

Pharmacological therapies for dementia fall into two categories: disease-modifying treatments, which are currently available only for AD; and symptomatic treatments, which are designed to alleviate cognitive symptoms or BPSD (WHO, 2025).

Current NICE guidelines on pharmacological therapies for AD recommend acetylcholinesterase inhibitors to delay the progression of memory loss in people with mild to moderate AD (NICE, 2018a). Examples of acetylcholinesterase inhibitors are donepezil, rivastigmine and galantamine. N-methyl-D-aspartate (NMDA) receptor antagonists such as memantine and Namzaric can be used to regulate glutamate levels and protect brain cells. Memantine can be used to treat memory loss in severe AD or in people who cannot tolerate acetylcholinesterase inhibitors (NICE, 2018a). In addition to symptomatic treatments, new disease-modifying treatments have emerged that slow disease progression by targeting the amyloid plaques that otherwise build up in the brain. These include aducanumab, lecanemab and donanemab. While lecanemab and donanemab have been approved for use in the UK, they are not currently available due to concerns about cost-effectiveness and limited evidence regarding their long-term benefits (National Institute for Health and Care Excellence (NICE), 2024a, 2024b). Aducanumab has not been approved in the UK, and is being phased out in the US and Europe due to concerns over its effectiveness, safety and high cost.

Pharmacological therapies have limited effect on BPSD, such as confusion, distress, aggression, and agitation, and can cause unpleasant side effects (Lin *et al.*, 2023). NICE recommends the use of NPTs as complements to pharmacological therapies (NICE, 2018a). It is common for older people with multiple comorbidities to be prescribed multiple medications to manage health conditions (Masnoon *et al.*, 2017). Polypharmacy is a term for the taking of five or more medications, and it has been associated with adverse outcomes such as increased risk of mortality, hospitalisation (Chang *et al.*, 2020) and falls (Zaninotto *et al.*, 2020). Some authors claim that appropriate polypharmacy is often necessary in older people to manage multiple health conditions and that it can prevent unplanned hospital admissions (Varghese *et al.*, 2024). For example, a study by Poudel *et al.* (2016) showed that polypharmacy

was not an independent predictor of adverse outcomes, but that it might be an indicator of the need for a medication review. The study showed that severe cognitive impairment was significantly associated with non-polypharmacy when compared with polypharmacy groups.

2.5.2 NPTs

NPTs do not directly involve medication. Due to the progressive nature of dementia and the lack of a cure, many NPTs for PLwD aim to improve quality of life or reduce symptoms (Robinson *et al.*, 2007; Livingston, Kelly, *et al.*, 2014). NPTs may be used as complementary therapies alongside pharmacological therapies, and more than one type of therapy may be used, for example, MT with occupational therapy. NPTs may be organised in a variety of community-based settings and are not restricted to healthcare. Nursing and care homes have the potential to provide services that might not be available in private homes, for example they can develop and implement innovative psychosocial therapies aimed at alleviating symptoms and enhancing the quality of life for residents (Vernooij-Dassen *et al.*, 2010). Psychosocial therapy is a type of NPT that uses a psychological process as its main treatment method. Examples include reminiscence therapy, counselling, problem-solving therapy, cognitive-behavioural therapy (CBT), support groups, psychotherapy (Kasl-Godley and Gatz, 2000; Huibers *et al.*, 2003), and cognitive stimulation therapy (CST) (NICE, 2018a). Psychosocial therapies may target cognitive function, quality of life, or both. Some interventions, such as CST, are specifically designed to improve cognition in the short term.

There is growing evidence of the effectiveness of NPTs. Effectiveness can be evaluated in terms of improving quality of life or cognition, or reducing BPSD. Recent systematic reviews have reported the effectiveness of NPTs in terms of improved cognitive function, quality of life, and reduced levels of depression and agitation (Abraha *et al.*, 2017; Vilela *et al.*, 2017). In 2018, NICE dementia guidelines reviewed the effectiveness of dementia NPTs and gave clear guidance on their use (NICE, 2018a). Four NPTs were recommended by NICE to improve cognition, independence, and well-being in people with mild- or moderate-stage dementia. These were occupational therapy and three psychosocial therapies: CST, reminiscence therapy (group sessions), and cognitive rehabilitation. It reported that many NPTs were

delivered as part of research studies rather than as part of routine care. An example of a psychosocial intervention is *Well-being and Health for People Living with Dementia* (WHELD), a person-centred care and psychosocial intervention that incorporated reviews of antipsychotic medication with PLwD (Ballard *et al.*, 2018a). Another example of a therapy evaluated within a research study was *STrAtegies for RelaTives* (START), which was intended to reduce depression and anxiety among family caregivers of PLwD (Livingston *et al.*, 2014b).

Other research, including work by Brodaty and Arasaratnam (2012), has demonstrated that such interventions not only improve well-being but can also provide economic advantages by potentially slowing disease progression and alleviating caregiver strain. Cost-effectiveness studies, such as that by Livingston *et al.* (2017), have shown that these strategies, especially when paired with caregiver support, contribute to reduced healthcare expenditure and may delay the need for institutional care. These approaches are often preferred over pharmacological treatments alone, as they offer a more comprehensive approach, in that they address both social and emotional needs of PLwD while fostering a supportive care environment.

2.5.3 Barriers to therapy uptake

The Government document *Living Well with Dementia: A National Dementia Strategy* (2009) states that equal access for all to dementia treatments should be a priority (DOH, 2009). However, there are inequalities in service provision and access to dementia support services and therapies. Inequalities in provision and availability of funds for services and therapies vary among countries, cities or even between postcode areas within a city (Giebel *et al.*, 2021a). Services vary according to geographical location, with people living in rural areas reporting difficulties in accessing formal care. Factors that affect uptake of dementia services by caregivers and PLwD include ethnicity, stigma surrounding diagnosis, lack of transport, lack of awareness regarding the services, acceptability of the services, and financial barriers (Morgan *et al.*, 2002; Giebel *et al.*, 2021a).

Ethnicity can also be a barrier to the uptake of NPTs. Individuals from minority ethnic backgrounds are often diagnosed at later stages of dementia and are less likely than those from majority groups to access anti-dementia medication, participate in research trials, or receive 24-hour care services (Cooper *et al.*, 2010). Language differences

may further hinder access to dementia-related services and delay diagnosis (Sorrentino *et al.*, 2025).

People from lower socioeconomic groups have a higher risk of developing early-onset dementia compared to people from higher socioeconomic backgrounds (Li *et al.*, 2023). Socioeconomic status has also been shown to influence individuals' ability or willingness to engage in dementia prevention, seek timely diagnoses, and access healthcare services (Livingston *et al.*, 2024). Financial barriers can significantly limit access to dementia care for those with lower incomes (Giebel *et al.*, 2021c). For example, a cohort study of caregivers in Canada found that individuals from lower socioeconomic backgrounds face greater difficulty in obtaining anti-dementia medications (Cooper *et al.*, 2010).

The acceptability of NPTs for PLwD/MCI is a critical factor in their effectiveness. Most NPTs require consistent attendance across multiple sessions, and individuals who do not find the intervention acceptable or engaging are unlikely to continue participating. Moreover, preferences for activities vary widely among individuals, highlighting the need for personalised approaches. Ultimately, even the most cost-effective therapies offer little value if they are not taken up by the people they are intended to support. This is particularly evident among people with young-onset dementia, who often underuse formal community dementia services. Research suggests that these services frequently fail to meet their personal and psychological needs, with many reporting difficulties in finding age-appropriate activities (Cations *et al.*, 2017). In the work for this thesis, the acceptability of therapies was considered through the inclusion of a survey that determined the preferences of PLwD/MCI and caregivers. The results of this survey are discussed in Chapter 3. It was assumed that PLwD and caregivers would opt for therapies that they would either enjoy or find beneficial.

Geographical location of the therapies can be a barrier to accessing community-based sessions such as support groups or activity clubs. In rural or remote areas, access to services may be limited or absent (Wittenberg *et al.*, 2019). A lack of public transport, reliance on others to provide transport or difficulties with parking may be additional barriers to participation (Choi *et al.*, 2025). There is a lack of structured groups and activities in which PLwD can safely participate without their caregivers (Mental Health Foundation, no date), and this reduces their autonomy. In these situations, caregivers

are required to attend the groups with the PLwD and do not have meaningful respite from their caring responsibilities (Alzheimer's Association, 2025). It is important that these issues are addressed, as attendance at support groups has been shown to reduce depression and improve quality of life for PLwD (Leung, Orrell and Orgeta, 2015).

The format in which the therapies are offered can also be challenging for some people. Group therapies may deter people who dislike group situations, due to excess, noise or anxiety (Cohen-Mansfield and Jensen, 2022). Tailoring activities to individual preferences can enhance engagement and improve outcomes (Cohen-Mansfield, 2018).

Funding for NPTs is limited due to budget constraints that restrict their widespread implementation within public healthcare systems (Wittenberg *et al.*, 2019). The range of NPTs that are commissioned by the NHS remains limited despite government guidelines recommending their use. Commissioning is the ongoing process of planning, agreeing upon, and monitoring services, and it involves continuous quality assessment (NHS England, no date). To be able to expand the range of therapies offered and implement new NPTs, decision and policymakers require clear evidence of their effects and costs to ensure value for money. There is an increasing need to provide reliable economic evaluations of NPTs as the population ages and healthcare resources (and other provider resources) are stretched (Sopina and Sørensen, 2018).

2.6 Economic impact of dementia

The regional costs of dementia vary significantly; Europe has the highest costs of dementia care, followed by the US, the Western Pacific, South-east Asia, the Eastern Mediterranean and Africa (Wimo *et al.*, 2023). High-income countries account for 91.6% of direct costs and 69.2% of informal care costs despite having only 37.3% of dementia cases (Wimo *et al.*, 2023). Low- and middle-income countries are experiencing faster ageing populations than are high-income countries, and this situation is expected to lead to an increased economic burden for those countries (Prince *et al.*, 2016).

While global figures highlight the widespread and growing costs of dementia, it is equally important to consider the national context. In the UK, dementia is one of the

costliest health conditions (Wittenberg *et al.*, 2019) and has a significant impact on inpatient services. It is estimated that the UK cost of dementia in 2015 was approximately £24.2 billion a year (Wittenberg *et al.*, 2019). Of this figure, social care took £10.2 billion, unpaid care £10.1 billion, and healthcare costs were approximately £3.8 billion (Wittenberg *et al.*, 2019). These figures highlight the substantial economic burden of dementia, with unpaid care and social care requiring most of the spending.

The significant cost of dementia in the UK is not limited to unpaid and social care; it also places increasing strain on the healthcare system, particularly due to the combination of health issues and care needs that commonly affect PLwD. Recent research on healthcare costs has shown that one in four hospital beds in the UK is occupied by a person with dementia at any one time (NICE, 2024). UK hospitals are under pressure to keep people in hospital when they no longer need medical treatment due to inadequate or shortages of community care provision and adult social services (Foster, 2023).

2.6.1 Healthcare economic evaluations

Economic analyses of healthcare are used to compare intervention options, such as NPTs, in terms of their costs and consequences (Briggs, Sculpher and Claxton, 2006). These analyses help evaluate the value of various healthcare options, including medications, surgical procedures, screening programmes, and health promotion initiatives. Common methods include cost-effectiveness analysis, cost-utility analysis, and cost-benefit analysis (see section 2.6.4).

Evaluations often extend beyond direct healthcare costs to include social care, informal caregiving, and broader non-health sector impacts. Typical cost categories encompass healthcare resources (i.e., staffing, buildings and equipment), consumables such as medications, and broader societal costs like productivity losses and informal care (Briggs, Sculpher and Claxton, 2006).

There is increasing reliance on economic evaluations to inform policymaking and funding decisions, partly because limited resources must be targeted as efficiently as possible to meet the increasing disease burden. Decision-makers are increasingly having to choose which interventions to fund, particularly with advances in medical

technology and pharmaceuticals. As a result, economic evaluations have become essential tools for assessing the cost-effectiveness of healthcare interventions.

In the UK, the publicly funded nature of the NHS, combined with increasing pressure on resources and limited funding to cover all possible treatments, means that the need for economic evaluations to inform cost-effective and evidence-based national responses has become increasingly urgent (WHO, 2017). The establishment of health technology assessment (HTA) bodies has also increased the popularity of economic evaluations. HTAs include NICE, which uses economic evaluation to inform its decisions about whether or not to license pharmaceuticals for use in the UK, as well as medical devices, diagnostic technologies and surgical procedures (Briggs, Sculpher and Claxton, 2006).

As healthcare systems strive to fund innovations while managing constrained budgets, economic evaluation has evolved from a specialist academic discipline into a core part of health policy and planning. It now plays a key role in shaping clinical guidelines, pricing negotiations, and public health strategies (Ryan, Saha and Trépel, 2024), offering a framework to weigh clinical benefits, affordability, and population-level impact.

While economic evaluations are widely used in high-income countries with universal healthcare, such as the UK, Australia, Germany and Canada, their application varies globally due to differences in infrastructure, policies, and healthcare priorities. For example, their use is more limited in the US, where legal restrictions prevent Medicare and Medicaid from applying cost-effectiveness thresholds.

Despite their growing importance, there remains a significant gap in economic evaluations of NPTs for dementia care (Alves *et al.*, 2013; Clarkson *et al.*, 2017). This significant knowledge gap is explored further in Chapter 3 through a systematic review and review of reviews focused on the economic evaluation of NPTs for PLwD.

2.6.2 Key concepts in economic evaluations

Key concepts used in economic evaluations are the incremental cost-effectiveness ratio (ICER) and willingness-to-pay (WTP) thresholds. These metrics help determine whether an intervention provides good value for money relative to its cost. The cost-

effectiveness plane is another commonly used tool to visually represent uncertainty around cost-effectiveness estimates. However, it was not employed in the analyses conducted for this thesis due to the nature of the available data and the scope of the analysis.

An ICER is calculated by dividing the difference in cost between two alternative interventions by the difference in their effects. This ratio helps assess the additional cost incurred for each unit of additional benefit gained, such as a QALY, when comparing interventions. WTP represents the monetary value individuals or society place on a health benefit. It is often used to estimate how much people are prepared to invest in goods, services, or activities that enhance their health and well-being. In economic evaluations, WTP is commonly associated with the value placed on a year of additional life or an additional QALY (Sloan and Hsieh, 2017). The primary aim of measuring WTP is to establish social value using preference-based approaches, thereby informing decisions about the allocation of healthcare resources.

2.6.3 Cost-of-illness studies

Cost-of-illness studies are a type of economic study that is designed to identify and measure the total costs of a particular illness and to estimate its total cost to society (Segel, 2006). The total costs include:

- direct costs such as healthcare and non-healthcare costs directly related to medical care and treatment; and
- indirect costs, such as lost productivity or income due to absence or illness.

These studies are intended to provide a comprehensive guide for policymakers, health professionals and researchers and essential data for the assessment of the economic impact of disease. They can aid in resource allocation, healthcare planning and the development of policies. They can also be used to justify investments in disease prevention and treatment. However, some economists argue that they are not as reliable as economic evaluations. Many are simplistic and are focused on identifying areas of high costs without giving sufficient attention to important health gains that can be made at a lower cost (Byford, Torgerson and Raftery, 2000).

Several cost-of-illness studies on dementia have been conducted. Such a study that was performed across Europe and North America demonstrated that costs increased

with the stage of dementia severity; they were almost twice as high for people with severe stage dementia as for people with mild stage (Quentin *et al.*, 2010). More recently, a retrospective study conducted in Peru in 2015 demonstrated that dementia was a substantial socioeconomic challenge for the country (Custodio *et al.*, 2015). At the time, this was important as there were few studies of the economic burden of dementia in low- and middle-income countries, and it recognised that dementia was not just an economic burden in high-income countries. Also, a cost-of-illness study has highlighted the high global economic burden of schizophrenia (Lin, Zhang and Jin, 2023), which is a serious mental illness that is associated with an increased risk of developing dementia (Cai and Huang, 2018).

2.6.4 Types of economic evaluation

Guinness and Wiseman (2011) describe four types of economic evaluation in healthcare: cost-benefit analysis (CBA), cost-effectiveness analysis (CEA), cost-utility analysis (CUA), and cost-minimisation analysis (CMA). These approaches differ in how they measure and value health outcomes.

CBA expresses both the costs and benefits in monetary terms. If the benefits are worth more than the costs, then the treatment is seen as worthwhile. It can be difficult to apply this type of analysis to conditions such as dementia, as it can be hard to value concepts such as well-being or reduced caregiver burden.

CEA assesses the cost per unit of outcome, for example, in life years or QALYs saved (Sloan and Hsieh, 2017). It is the method most used by organisations such as NICE. A commonly used tool in calculating QALYs is the EuroQol 5-dimension questionnaire (EQ-5D), which is a standardised measure of health-related quality of life developed by the EuroQol Group (Herdman *et al.*, 2011). The EQ-5D captures five dimensions of health: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. It generates a utility score that can be used in economic evaluations. However, the EQ-5D may not fully capture important areas of memory, communication, and emotional well-being, which are especially important for PLwD, particularly in the early stages of the disease. It may also be challenging for PLwD to rate their own health, making it harder to collect accurate data.

CUA and CMA are described by Briggs *et al.* (2007). CUA is used for two treatments that have the same outcomes, to determine the cheaper one. Outcomes are expressed in health units to capture the quantity and quality of life. CUA uses a measure of utility to determine the value or worth of goods or services. Utility is a measure of preference or value that is assigned by an individual or society to a specific health state. Typically, it is represented by a numerical value between 0 (death) and 1 (perfect health). CMA is a type of CEA. It is used to measure and compare input across alternatives that have identical outcomes. This method is not often used in dementia because treatments usually have different effects.

2.6.5 Valuation of healthcare costs and outcomes

Over recent years, CUA has been increasingly used to guide resource allocation decisions by government agencies such as NICE in England and Wales (Rowen *et al.*, 2012). CUA is appealing to NICE because its use of a standardised, generic measure enables the comparison of very different clinical areas. A focus on long-term outcomes may not be appropriate due to the deteriorating nature of the disease; instead, measurement of short-term, temporary changes that improve quality of life may be more relevant (Mittelman, 2008). For this reason, many NPTs have been designed to reduce the rate of cognitive decline or to improve quality of life rather than to improve cognition directly.

There is ongoing debate over which type of utility measure is most appropriate for use in economic evaluations in dementia. Surrogate endpoints are indirect measures that are used to predict a clinically meaningful outcome. For example, changes in blood pressure are used as a surrogate measure of the risk of cardiovascular events, or blood glucose levels as a predictor of diabetes-related complications. However, in CUAs, clinical endpoints are generally preferred, as they more directly reflect peoples' experiences, including their symptoms, functional status, and life expectancy (NICE, 2022).

In dementia research, clinically specific outcomes such as MMSE scores and Clinical Dementia Ratings (CDRs) are often used to assess disease progression and treatment effectiveness. These measures provide a more direct indication of cognitive and functional decline, making them more suitable for evaluating interventions in this context. However, their use in economic evaluations is debated. While they can be

used independently, they only allow comparisons within the same clinical area and may not fully capture outcomes that are meaningful to people (Baker, 2018). Moreover, their value is difficult to quantify, limiting their usefulness for policymakers (Sopina and Sørensen, 2018). Some researchers argue that clinical outcomes should not be used at all in cost-utility analyses (Solomon *et al.*, 2015), although they may be justified when the intervention explicitly targets a specific clinical change.

2.6.5.1 Cost valuation

Calculation of the total cost of dementia care involves accounting for direct and indirect costs. Direct costs are services or materials for which money is paid, including diagnosis, consultant visits, hospital visits and stays, medications, paid caregivers and transportation (Wimo *et al.*, 2023). Indirect costs can be attributed to both PLwD and their caregivers. For PLwD these might include loss of earnings due to reduced working capacity or early retirement (Wimo and Prince, 2010). For caregivers, they could be caregiving without payment (loss of earnings, loss of leisure time) or the cost of replacing the unpaid caregiver with a professional, paid caregiver (Wimo and Prince, 2010). Whilst both types of costs are important for the economic analysis of the cost of dementia, for the purposes of this thesis only direct costs are considered.

Informal care provided by family members can be considered within economic evaluations as consisting of both direct and indirect costs. Direct costs involve out-of-pocket expenses and indirect costs are those that result in lost productivity or time. The value of informal care can be estimated in different ways as either opportunity costs (which value the time spent on caregiving based on lost wages or usual daily activities), or the replacement cost (which estimates what it would have cost for a professional to provide this care) (Briggs, Sculpher and Claxton, 2006). The choice of method can significantly influence outcomes of cost-effectiveness, especially in dementia, which involves substantial amounts of informal care.

2.6.5.2 Health outcome valuation and utility weights

Preference-based measures (PBMs) (also known as preference-based outcomes) are used in health economics to measure how desirable or undesirable a particular health state is to individuals. They measure utility, which can be used to calculate QALYs. These measures are often used in economic evaluations to compare healthcare

treatments. There are three main methods to generate PBMs: standard gamble (SG), time trade-off (TTO) and multi-attribute utility instruments (MAUIs) (Drummond *et al.*, 2015). The SG method gives people a hypothetical choice between living with a health condition or taking a risk that might result in either perfect health or death. This approach is based on decision-making in a state of uncertainty and can be difficult for people to understand. The TTO approach is more widely used and involves asking people how many years of life they would be willing to give up to spend a shorter period of life in perfect health, rather than living longer in a poorer health state (Torrance, 1986). In contrast, MAUIs are calculated from short questionnaires that cover different areas of health, such as mobility, pain and mental well-being. People rate their current health, and this is converted into a single utility value using data obtained from population-based studies. These questionnaires are commonly used in health policy and research as they are simple to use and allow comparison between different health conditions. Examples of MAUIs are the EQ-5D and the short form 6-dimension utility index (SF-6D).

The use of EQ-5D is widely recommended by HTA bodies such as NICE for the assessment of health-related quality of life (HRQoL) as it is easy to use, has a standardised format and can be used to compare across a range of conditions (NICE, 2013). Its use is often recommended in economic evaluations (Devlin, Parkin, and Janssen, 2020). It measures HRQoL across the five key dimensions of mobility, self-care, usual activities, pain/discomfort and anxiety/depression (EuroQol Group, 1990). Respondents rate each dimension according to its severity in their situation. The scores are converted into single utility scores. However, the EQ-5D has been criticised for having limited sensitivity in some conditions, including dementia, especially in the early stages of the disease or with non-physical domains such as psychological aspects, mental health, well-being and cognition (Mulhern *et al.,* 2013). Therefore, condition-specific PBMs or mapping techniques are sometimes used alongside the EQ-5D.

The health of the nation outcome scale (HoNOS) is a clinical tool designed to assess the health and social functioning of people with severe mental illness (Harris *et al.*, 2018). The tool consists of 12 items that evaluate behaviour, impairment, symptoms and social functioning. The assessment uses a Likert scale to give a total score ranging from zero to 48, which reflects the severity of an individual's mental health and

social difficulties (Gale and Boland, 2019). Higher HoNOS scores indicate greater impairment in daily functioning and poorer mental health outcomes (Gale and Boland, 2019). HoNOS 65+ was developed based on the original HoNOS tool. It retains the same scale but has been adapted specifically to target the mental health needs of people aged 65 years and over (Burns *et al.*, 1999). It is typically completed by physicians rather than the person themselves, emphasising its clinical focus.

In health economic evaluations, health states may be converted into utility scores using preference weights that are derived from surveys of the general population. These are often obtained using methods such as TTO or discrete choice experiments. Utility scores are usually on a scale from 1, which represents full health, to 0, which represents death. Negative scores indicate those that are considered worse than death. HRQoL is commonly used as a proxy measure for utility. Each method for calculating PBMs has its strengths and limitations, and the way in which health outcomes are measured can influence the estimated effectiveness and cost-effectiveness of interventions, particularly in complex conditions such as dementia.

2.6.5.3 QALYs

QALYs are not PBMs, but they are calculated using PBMs. They are a generic measure of disease burden that considers the quality and quantity of life lived. One QALY equates to one year in perfect health. QALYs are calculated by multiplying the duration spent in a particular health state by the utility score associated with that health state. Quality of life is frequently expressed in policymaking as QALYs (Bruck *et al.*, 2023). QALYs are used in economic evaluations to assess the value of medical interventions. Projections of QALYs are useful to policy- and decision-makers to view how the burden of dementia will develop. QALYs are the most used utility in international economic evaluations (Solomon *et al.*, 2015). a widely used metric in health economic evaluations across many countries, particularly in high-income settings such as the UK, Canada, and Sweden.

Limitations of QALYs include their underlying assumptions, which may not match real-world values, and ethical concerns (Carlson *et al.*, 2020). Critics have argued that QALYs can oversimplify complex experiences of well-being, especially in complicated health conditions such as dementia. In the US, QALYs have received criticism regarding ethics. Some argue that they overlook important moral issues such as the

idea of helping those in urgent need, ensuring that everyone receives a fair chance at a healthy life and treating people equally when their health needs are the same (Ubel, 2001; Neumann *et al.,* 2018). Others argue that the use of QALYs can unfairly undervalue care for people with disabilities, serious illness, or those who are older (Harris, 1987; Williams and Bryan, 2007). There are also concerns that the values used to calculate QALYs often come from the general public and not from people living with the health conditions being studied (Dolan, 2000). However, supporters of QALYs say they are a useful tool as they combine measures of quality and length of life, which can help in the comparison of the value of different treatments rather than the value of different people (Brazier, 2001).There is no strong evidence that QALYs have been used in a way that has led to discrimination in real-world healthcare decisions (Carlson *et al.,* 2020).

2.6.5.4 Utility weights

Mapping can be used to weight an outcome measure and convert it to another, more useful outcome measure. Mapping techniques use algorithms to create true, meaningful endpoints and allow the drawing of conclusions about effects (Baker, 2018). There is debate over whether generic outcome measures or disease-specific measures should be used in economic evaluations. Generic outcome measures such as the EQ-5D can be used to generate utilities that simplify the comparison of effects across different studies and health conditions (Whitehead and Ali, 2010). However, although generic instruments generate utilities, many are not sensitive enough to record disease-specific effects (Whitehead and Ali, 2010). It has been argued that disease-specific measures for dementia, such as the dementia quality of life measure (DEMQOL), which was developed and validated in a cognitively impaired population, should be used instead (Rowen *et al.,* 2012).

2.7 Healthcare economic modelling in dementia

2.7.1 Overview of modelling approaches

A healthcare economic model is a mathematical framework that enables the prediction of the possible consequences of a healthcare decision (Briggs, Sculpher and Claxton, 2006). Economic modelling provides a way to compare the cost-effectiveness of interventions by bringing together published data from various sources of evidence to

predict costs and outcomes. It is often used in cases in which economic evaluation was not included in a trial, or when an alternative economic evaluation is considered necessary (Briggs, Sculpher and Claxton, 2006; Drummond *et al.*, 2015). Some economists see economic modelling as superior to trial-based evaluation as it enables the synthesis of evidence from multiple sources, which in modelling trial data may be used selectively, to inform specific model parameters, rather than being the sole basis for decision-making (Briggs, Sculpher and Claxton, 2006).

Model-based CEAs are being used increasingly to inform healthcare policy decisions (Caro *et al.*, 2012). A recent systematic review by Darab *et al.* (2024) found that there had been a recent increase in model-based economic evaluations for dementia. However, the methodology and reporting quality of many such evaluations showed weaknesses, indicating a lack of justification for model assumptions and data input (Darab *et al.*, 2024). Additionally, a review of dementia modelling studies by Nguyen, Comans and Green (2018) found that they largely consisted of evaluations of pharmacological products; there were fewer models to evaluate prevention/diagnosis and NPTs (Nguyen, Comans and Green, 2018). This lack of model-based evaluations of NPTs for dementia highlights a significant knowledge gap that this thesis is intended to address.

There are clear recommendations regarding best practice in the design of economic decision models, and methods should be detailed and transparent to allow replication (Caro *et al.*, 2012). In the UK, NICE has produced guidelines (2022) for the performance of health technology economic evaluations. The document sets out a rigorous and transparent process for evaluation of the cost-effectiveness of health technologies for use in the NHS so that decision-makers can ensure efficient allocation of resources that benefit patients (NICE, 2022). It recommends assessment of cost-effectiveness against a threshold of £20,000-30,000 per QALY. A report from the Modelling Good Research Practices Taskforce, part of ISPOR, the leading professional society for health economics and outcomes research (Eddy *et al.*, 2012) makes a number of key recommendations to develop robust economic models. It emphasises the need for transparent, evidence-based models that are well-structured and validated with appropriate consideration of uncertainty. Several types of modelling techniques exist in healthcare evaluation: Markov models, discrete-event simulation (DES) and decision-tree models. These are described next.

2.7.2 Markov model

A Markov model is a tool commonly used in decision analysis in cases in which there are multiple possible consequences (Briggs, Sculpher and Claxton, 2006). In healthcare, the model simulates how patients move between different health states over time (Briggs, Sculpher and Claxton, 2006). In the model, time is divided into discrete time periods (cycles), and in each cycle, individuals may stay in the same state, move to another state (e.g., progress from mild to moderate dementia), or die. Each state is assigned a cost and a quality-of-life value, and this method allows researchers to estimate the long-term costs and health outcomes of different interventions. It can be particularly useful for chronic conditions such as dementia, in which there is often a gradual decline in health. Markov models have been used to evaluate dementia interventions (Jones, McCrone and Guilhaume, 2004; Zhang *et al.,* 2011; Saito *et al.,* 2014; Tahami Monfared *et al.*, 2023).

2.7.3 Discrete-event simulation

DES is an approach to the modelling of complex healthcare systems and patient pathways that is structured around how long an individual remains in a state, rather than focusing on the probability of moving to another state (Briggs, Sculpher and Claxton, 2006). By imitating how a real-world system evolves, the use of DES allows researchers to predict the impact of decisions within healthcare systems and to evaluate alternative scenarios in a risk-free, controlled environment (Vázquez-Serrano, Peimbert-García and Cárdenas-Barrón, 2021).

It is a patient-level simulation, which means that patients are tracked individually so that the model can reflect the medical history of a patient (Briggs, Sculpher and Claxton, 2006). Traditional models use fixed-time cycles, but DES tracks individual patients through a series of events that occur at specific time points. This tracking enables a more accurate representation of real-world variability in disease progression, treatment responses, and healthcare interventions. This modelling approach is widely used to address healthcare systems (Vázquez-Serrano, Peimbert-García and Cárdenas-Barrón, 2021)

Patient-level modelling is particularly valuable when timing, resource constraints, or patient heterogeneity significantly affect outcomes. DES is suitable for informing policy

decisions in which precision and realism are essential, especially in scenarios involving capacity limitations, care coordination, or personalised care strategies (Vázquez-Serrano, Peimbert-García and Cárdenas-Barrón, 2021). However, it can be time-consuming to develop a DES model and there is little evidence of the implementation of these models after their development (Vázquez-Serrano, Peimbert-García and Cárdenas-Barrón, 2021). Patient-level simulation models enable the representation of individual variation in disease progression and treatment pathways; however, they have several limitations. They may be demanding, complex and time-consuming to construct, especially for large populations or with probabilistic sensitivity analyses. This complexity can make them less transparent or harder to validate than cohort models.

2.7.4 Decision-tree models

A decision-tree or decision-analytic model compares alternative courses of action by showing outcomes and costs under different treatment scenarios (Cohen and Neumann, 2008). Decision-tree models, as described by Briggs, Sculpher and Claxton (2006), range from relatively simple to highly complex structures. A square, decision node typically represents a decision point, in which two or more strategies are considered. A round, chance node represents points of uncertainty, after which multiple possible outcomes may occur, each associated with a specific probability. These probabilities show the likelihood of an event happening at a chance node and are fundamental to the model structure. The terminal points of each pathway are shown as triangles, which represent final model outcomes. Each pathway through the tree shows a mutually exclusive sequence of events. Probabilities along a given pathway are usually conditional on prior events, but in some models they may be independent. The pathway probability result is read along each pathway and is calculated by multiplying the probabilities along the branch to give an estimated joint probability of that sequence of events (Briggs, Sculpher and Claxton, 2006).

Decision tree models are appropriate for short-term time evaluations where events occur within clearly defined timeframes. However, dementia is a chronic and progressive condition where costs and outcomes evolve over time and a limitation of these types of models is that they cannot capture gradual cognitive decline or evolving care needs. For longer-term economic evaluations in dementia, Markov models can

be used as they can allow individuals to move between disease states over time and capture the cumulative impact of interventions on costs, quality of life, and care pathways.

2.7.5 Existing models for dementia

Several models of different types have been used to study NPTs. Markov models are among the most commonly used. For example, Budd *et al.* (2011) developed a hypothetical disease-modification treatment for MCI. Similarly, Martikainen, Valtonen and Pirttilä (2004) applied a Markov model to evaluate a cognitive-behavioural family-based programme for people with AD. Gannon *et al.* (2025) also utilised a Markov model to evaluate a home-based intervention aimed at reducing BPSD. Another example is the Markov decision-analytic model, which was developed by Mirsaeedi-Farahani *et al.* (2015) to evaluate the cost-effectiveness of deep brain stimulation for people with AD, with the outcomes projected over five years. A Markov model was also developed to analyse the cost-utility of group living versus living at home or in long-term care (Wimo *et al.*, 1995).

Beyond Markov models, other modelling techniques have also been applied. Dowd *et al.* (2018) developed a trial-based modelling approach to assess a multi-component health promotion programme for people with mild dementia. A model-based CUA by Vandepitte *et al.* (2020) evaluated the cost-effectiveness of an in-home respite service for PLwD, which reported cost-effectiveness in terms of QALYs and costs. More recently, Knapp *et al.* (2022) used a population-level simulation model to predict the potential costs and outcomes of upscaling CST across the UK. These diverse modelling approaches provide valuable insights into the cost-effectiveness and potential impact of various NPTs for dementia care.

2.8 Chapter summary

This literature review has highlighted that dementia is a significant global public health and economic challenge, primarily due to population ageing. The increasing prevalence of dementia is placing huge pressure on healthcare systems, families and national economies. Dementia presents not just a significant clinical burden but also

huge social and economic costs, which affect both PLwD and caregivers and broader communities.

NPTs such as CST, caregiver training and education, and structured activities have shown promising benefits and are especially effective in maintaining function and improving quality of life for PLwD. However, despite their potential, there are few economic evaluations of NPTs. This is important because, as healthcare systems face constrained budgets, policymakers rely more heavily on economic evidence to guide funding and policy decisions. This lack of comprehensive economic evaluations limits the ability of decision-makers to allocate resources effectively. Addressing this gap is a central aim of this thesis, which seeks to contribute valuable economic evidence on the value and impact of NPTs in dementia care.

The next chapter presents a systematic review and review of reviews of economic evaluations of community-based NPTs for PLwD or MCI. Together, these reviews aim to identify the strengths, limitations, and gaps in published literature and evaluate the methodological quality and relevance of economic evaluations in this field. This approach provides a comprehensive foundation for the economic components of this thesis and directly informs the development of the decision-analytic modelling presented in later chapters. By critically appraising the existing evidence, this chapter will help to establish the rationale for further economic analysis of NPTs in the context of dementia care in the UK.

Chapter 3 Publication: Cost-effectiveness of non-pharmacological interventions for mild cognitive impairment and dementia: a systematic review of economic evaluations and a review of reviews

3.1 Introduction

As has been outlined in Chapter 2, there is evidence that NPTs can be effective in terms of improving quality of life, symptom management and well-being for PLwD. However, before new NPTs can be introduced into routine practice, economic data and evidence of clinical effectiveness are required to determine their cost-effectiveness. This chapter contains a dual-review approach (systematic review and review of reviews) of economic evaluations of NPTs for dementia and MCI to provide a broad understanding of the economic evidence base. The systematic review synthesises primary economic evaluation studies that have assessed the cost-effectiveness of specific NPTs, while the review of reviews collates and analyses findings from published reviews. Through this critical appraisal of the existing evidence, this chapter helps to establish the rationale for further economic analysis of NPTs in the context of dementia care in the UK.

3.2 Publication details

The following paper was published in *PharmacoEconomics Open* in 2023. The format of figures and tables has been modified to enable inclusion in the thesis. The published version is available at: https://doi.org/10.1007/s41669-023-00440-z

Gillian Eaglestone (GE), Professor Paul McCrone (PM) and Professor Rosana Pacella (RP) were responsible for the conception and design of the systematic review. GE developed the protocol with advice from PM. Searches and screening were carried out by GE and reviewed by PM, Evdoxia Gkaintatzi (EG) and Harmony Jiang (HJ). Data extraction and quality appraisal were conducted by GE and reviewed by EG and HJ. GE drafted the manuscript. PM, RP, Doctor Charlotte Stoner (CS) and EG critically

reviewed the manuscript and revised it for important intellectual content; all authors approved the final version to be published.

Cost-effectiveness of non-pharmacological interventions for mild cognitive impairment and dementia: a systematic review of economic evaluations and a review of reviews

(Eaglestone, Gkaintatzi, Jiang, Stoner, Pacella, McCrone, 2023)

3.3 Abstract

Background: Dementia prevalence is increasing, with no cure at present. Drug therapies have potential side effects and risk of mortality. People with dementia are frequently offered non-pharmacological interventions to improve quality of life and relieve symptoms. Identifying which interventions are cost-effective is important due to finite resources in healthcare services.

Aims: The aims were to review published economic evaluations of community and nursing home non-pharmacological interventions for people with mild cognitive impairment or dementia and assess the usefulness of these evaluations for decision making in health services, for use by policy and local and national decision makers.

Methods: We conducted a systematic review (PROSPERO CRD42021252999) of economic evaluations of non-pharmacological interventions for dementia or mild cognitive impairment with a narrative approach to data synthesis. Exclusions: interventions for dementia prevention/early detection/end of life care. Databases searched: Academic Search Premier, MEDLINE, Web of Science, EMBASE, Google Scholar, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycInfo, Psychology and Behavioural Sciences Collection, PsycArticles, Cochrane Database of Systematic Reviews, Business Source Premier and Regional Business News; timeframe 1 January 2011–11 May 2023. Reporting quality was assessed using the Consolidated Health Economic Evaluation Reporting Standards (CHEERS).

Results: The review included 37 economic evaluations and four reviews worldwide across several distinct forms of care: physical activity, cognition, training, multicomponent, assistive technology and other (specialist dementia care, group living, home care vs care home). The intervention with the strongest evidence of cost-effectiveness was maintenance cognitive stimulation therapy. Case management,

occupational therapy and dementia care management also showed good evidence of cost-effectiveness.

Conclusion: More economic evidence on the cost-effectiveness of specific dementia care interventions is needed, with consistency of methods and outcome measures. This could improve local and national decision makers' confidence to promote future cost-effective dementia interventions.

3.4 Key points for decision makers

This review found that maintenance cognitive stimulation therapy showed the strongest evidence of being cost-effective, but with a small number of economic evaluations; case management, occupational therapy and dementia care management also showed good evidence of cost-effectiveness.

More economic evidence about the cost-effectiveness of dementia care interventions is needed, and researchers need to be consistent with study methods and outcome measures to allow comparison across interventions. Increased economic information and consistency would increase confidence of policy and local and national decision makers when they are planning and implementing dementia care interventions in the future.

3.5 Introduction

The worldwide economic burden of dementia care is high at US$815 billion (Alzheimer's Disease International, 2015). The total annual cost of dementia in the UK is estimated at £24.2 billion (Wittenberg *et al.*, 2019). With the increase in numbers of people being diagnosed with dementia and the high costs of dementia care, economic evaluations are needed to ensure that non-pharmacological interventions which are offered are cost-effective, however, economic evidence of these interventions remains limited (Nickel, Barth and Kolominsky-Rabas, 2018).

By 2050 the number of people with dementia is projected to rise to 152 million due to population growth and an increasingly ageing population (Nichols *et al.*, 2022). There is currently no cure for dementia; existing drug therapies are either symptomatic therapies to relieve symptoms of dementia or are primarily indicated for Alzheimer's Disease (World Health Organisation, 2025). Drug therapies have potential for serious

side-effects including mortality (Meads *et al.*, 2020). Non-pharmacological therapies may be considered as complements to pharmacological treatments.

The National Institute for Health and Care Excellence guideline for dementia care (National Institute for Health and Care Excellence (NICE), 2018a) recommends four non-pharmacological interventions: group cognitive stimulation therapy, group reminiscence therapy and cognitive rehabilitation or occupational therapy. The main aim of these types of dementia interventions is to reduce symptoms including cognitive decline, promote independence and wellbeing and improve quality of life.

Existing systematic reviews of economic evidence commonly focus on a particular intervention (Pimouguet *et al.*, 2010; Alves, Magalhaes and Thomas, 2013) or dementia symptom (Robinson *et al.*, 2007; Livingston *et al.*, 2014a). Previous reviews have also included interventions to improve the quality of life of caregivers as well as people with dementia (PLwD) (Clarkson *et al.*, 2017; Nickel, Barth and Kolominsky-Rabas, 2018). The term 'carer' here refers to anyone supporting a family member, partner or friend and not receiving payment for providing this care (NHS England, 2023a).

3.6 Aim

The aim of this review was to provide a comprehensive summary of existing economic evaluations of non-pharmacological interventions delivered in the community and nursing homes, evaluating a wide range of dementia symptoms and interventions which measured the impact on the PLwD and not solely their carer. The intended audience of the review is policy makers and key decision makers including health care providers and managers at a local and national level.

3.7 Methods

The protocol for this systematic review was established before work commenced and was registered on PROSPERO (CRD42021252999). Preferred Reporting Items for Systematic review and Meta-Analysis (PRISMA) guidelines were followed throughout (Page *et al.*, 2021).

3.8 Eligibility criteria

Inclusion criteria (detailed in Table 3.1) stated that papers should be trial-based economic evaluations, observational studies or modelling simulations; the population under observation was people with dementia or mild cognitive impairment. People with mild cognitive impairment (MCI) were included as a high percentage go on to later develop dementia (Gauthier *et al.*, 2006). To be eligible interventions needed to aim to delay progression of the disease or improve quality of life. Papers could have evaluated dementia interventions throughout the dementia pathway, ranging in severity from recent diagnosis to advanced dementia, but prevention/early detection of dementia or end of life care interventions were excluded. Both narrative and systematic reviews of economic studies were also eligible for inclusion.

Table 3.1 Eligibility criteria

Inclusion criteria	Exclusion criteria
Population with dementia (including Alzheimer's disease) or mild cognitive impairment	Studies of intervention purely for the carers of people with dementia
Trial-based economic evaluations, observational or simulation studies	Interventions focusing solely on homeopathic or herbal remedies
Non-pharmacological community and nursing home-based interventions designed to either delay progression of the disease or to improve/maintain health-related quality of life	End-of-life care interventions
All study designs including reviews and systematic reviews	Interventions aimed at prevention/early detection of dementia
Papers in any language, both abstracts and full texts will be translated	Studies without costings/outcomes data
	Letters, commentaries, study protocol papers and conference abstracts

3.8.1 Search strategy

The databases searched were Academic Search Premier, Google Scholar, Web of Science, Cochrane Database of Systematic Reviews, MEDLINE, Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsycInfo, Psychology and Behavioural Sciences Collection, PsycArticles, Business Source Premier and Regional Business News. Papers published between 1 January 2011 and 11 May 2023 were included to search only recent articles. Articles published in any languages were eligible.

The search terms used within the databases were the disease-specific terms ‘dementia’, ‘Alzheimer’s’ and ‘mild cognitive impairment’ combined with the economic terms ‘cost*’ or ‘econ*’, with additional search terms to identify interventions: ‘intervention’ or ‘therapy’. The reference lists of primary studies and review articles that met the inclusion criteria were manually searched for other relevant articles for inclusion.

3.8.2 Study selection

Titles and abstracts were screened according to inclusion/exclusion criteria by author Gillian Eaglestone (GE) and results were verified by EG/HJ. Any disputes were resolved by PM. Full texts of selected articles were retrieved and reviewed by GE and EG/HJ and any disputes were resolved by PM.

3.8.3 Data extraction

Extracted data included intervention description, participant numbers, follow-up period, study design, economic evaluation type, main economic outcome measure, primary outcome (PLwD only) and perspective (see Table 3.2). Data extraction was performed by GE, with EG/HJ independently undertaking data extraction for 40% of the included articles. Any disagreement was resolved by PM.

Table 3.2 Data characteristics of economic evaluation

Author[a], country[b]	INT	INT description	No.[a]	Time horizon[a]	Study design[b]	EE[a]	Main economic outcome measure	Primary outcome[a]	Perspective[a]
Brown *et al.* (2019a), UK	Cog	Maintenance cognitive stimulation therapy with a group that had previously received cognitive stimulation therapy	INT 123, TAU 113	6	RCT	CUA	QALYs	EQ-5D (self and proxy), DEMQOL (self and proxy)	Societal
D'Amico *et al.* (2015), UK	Cog	Maintenance cognitive stimulation therapy in addition to usual care	INT 64 dyads, TAU 67 dyads	6	RCT	CUA	QALYs	ADAS-Cog, QoL-AD	H&SC
Laakkonen et al. (2016), Finland	Cog	Separate group rehabilitation sessions run for PLwD and for spouses	INT 67 TAU 69	24	RCT	CEA	Patient HRQoL	15D	Not stated

Mervin *et al.* (2018), Australia	Cog	Individual, non-facilitated sessions with a soft toy. Received either a toy with artificial intelligence (PARO) or a soft toy	PARO 138, soft toy 140, TAU 137	2.5	RCT	CEA	Patient agitation level	CMAI-SF	HCP
Orgeta *et al.* (2015), UK	Cog	Home-based, individual cognitive stimulation therapy, led by own carer. Up to three 30-minute activity sessions/week over 25 weeks. Initial training and ongoing support provided	INT 180, TAU 176	6.5	RCT	CUA	QALYs	ADAS-Cog, QoL-AD	H&SC/ Societal
Sado *et al.* (2020), Japan	Cog	A learning therapy intervention carried out in nursing homes. A combination of cognitive training and stimulation	INT 30, TAU 27	12	Non-randomised matched control	CBA	CT for CNLTC	CT for CNLTC	HCP
Soggard *et al.* (2014), Denmark	Cog	Intensive, multi-component, semi-tailored, psychosocial INT programme with counselling, education and support	INT 163 dyads TAU 167 dyads	36	RCT	CUA	QALYs	EQ-5D-5L	Societal
Spector *et al.* (2015), UK	Cog	A CBT manual developed for anxiety in dementia and trialled in sessions with participant/carer dyads	INT 25, TAU 25	6	RCT	CEA	Patient anxiety	RAID score	H&SC

Woods *et al*. (2012), UK	Cog	Group reminiscence therapy for participants and with carers	INT 196, TAU 140	10	RCT	CUA	QALYs	QoL-AD	Public sector
Ballard *et al*. (2018a), UK	Train	Staff training programme on person-centred care for care staff, promoting tailored activities, antipsychotic medication review	INT 404, TAU 443	9	RCT	CEA	Patient quality of life	DEMQOL-(Proxy)	Not stated
El Alili *et al*. (2020), Netherlands	Train	Multicomponent care programme for nursing home residents with advanced dementia	INT 116, TAU 115	12	RCT	CUA	QALYs	QUALID, GAIN	Societal
Livingston *et al*. (2019), UK	Train	Evidence-based, manualised, intervention, delivered to staff in 6 interactive sessions. Comprising training getting to know and understand residents	INT 189, TAU 215	8	RCT	CUA	QALYs	CMAI	Not stated
Meads *et al*. (2020), UK	Train	Dementia Care Mapping: a care-home staff training intervention aimed to embed person-centred care, improve care quality and health outcomes for residents	INT 418, TAU 308	16	RCT	CUA	QALYs	EQ-5D-5L	HCP

Menn *et al*. (2012), Germany	Train	GPs in 3 groups (A, B, C) trained in dementia care. At different timepoints groups B and C actively recommended support groups and promoted caregiver counselling	B 88, C 108, TAU 107	48	RCT	CEA	Time to institutionalisation	Remaining time the patient lived at home	Societal
Romeo *et al*. (2019), UK	Train	Person-centred care intervention delivered by staff in nursing homes. Staff were trained in person-centred care, management of agitation, and psychosocial approaches	INT 404, TAU 443	9	RCT	CUA	QALYs	QoL measured by DEMQOL	H&SC
Van de Ven *et al*. (2014), Netherlands	Train	Dementia care mapping, multi-component INT. Staff from participating nursing homes attended training, then assessed residents' needs and implemented care INT.	INT 154, TAU 164	18	RCT	CBA	Health care consumption, falls and psychotropic drug use and staff absenteeism	Health care consumption, falls	HCP
Williams *et al*. (2017), USA	Train	Staff training INT to improve communication with residents by encouraging staff to stop using 'childish' language/way of speaking and	INT 42 dyads, TAU unstated	36	Observational	CEA	% Time staff used elderspeak, % time residents resistive to care	% Time staff used elderspeak, % time residents resistive to care	Not stated

		interacting (elderspeak)							
Henderson *et al*. (2021), Italy, Poland, UK	Multi-dimension	Meeting centre support programme; person-centred, psychosocial approach combining day centre services with support for carers	INT 83, TAU 69	6	Non-randomised matched control	CUA	QALYs	QoL-AD	H&SC /societal
Jennings *et al*. (2019), USA	Multi-dimension	Dementia care programme co-managed by nurse practitioners and physicians, comprising structured assessments, individualised care plans, referral to community support/advice services, and 24h access to a clinician	INT 1083, TAU 2186	36	RCT	CEA	Patient health care utilisation	Admission to long-term care, health care utilisation	Not stated
Jutkowitz *et al*. (2023) USA	Multi-dimension	Modelling simulation on interventions designed to reduce admissions to nursing homes. Using 2 carer support/education interventions and 2 Dementia Care Management interventions	INT 5,000, TAU 5,000 (simulation)	24	Modelling	CBA	QALYs	Admission to long-term care	Societal
MacNeil Vroomen *et al.* (2016) Netherlands	Multi-dimension	Comparison of 2 types of case management. Intensive Case	Intensive 234, Linkage 214, TAU 73	24	Non-randomised observationa	CUA	QALYs	NPI score	Societal

		Management Model: carried out within one care organization, and Linkage Model where care was provided by different care organisations within 1 region			I controlled, cohort study				
Michalowsky *et al*. (2019a), Germany	Multi-dimension	Dementia care management INT using multi-disciplinary care to assess and support the dementia patient and carer	INT 315, TAU 129	24	RCT	CUA	QALYs	SF-12	Societal
Mostardt *et al.* (2012), Germany	Multi-dimension	Case management INT aiming to improve support networks and quality of care and enable PLwD to stay at home for longer	INT 38, TAU 76	12	Non-randomised matched control	CEA	Additional time in the home environment	Time in the home environment	HCP
Pizzi *et al*. (2022), USA	Multi-dimension	Assessment by occupational therapist and advanced nurse practitioner. Falls prevention strategies, medication review and carer education. Plan to increase physical activity and engagement	INT 130, TAU 120 (dyads)	12	RCT	CBA	Healthcare resource utilisation costs	Healthcare resource utilisation	Healthcare provider
Pizzi *et al*. (2023), USA	Multi-dimension	Occupational therapist assessment.	INT 93, TAU 83	6	RCT	CBA	Healthcare utilisation costs	Caregiver reported health care utilisation	Healthcare and societal

		Activities tailored to assessment profiles and instructed caregivers in their daily use along with providing disease education and stress reduction techniques							
Pizzo *et al*.(2022), UK	Multi-dimension	A community-based occupational therapy INT. Assesses and agrees goals. One hour a week for 10 weeks	INT 249, TAU 219	6	RCT	CUA	QALYs	Bristol Activities of Daily Living Scale	UK NHS and personal social services
Radke *et al*. (2020), Germany	Multi-dimension	Dementia care management intervention, delivered in participant's homes by dementia-trained nurses. Focus on interprofessional treatment and care, medication management and support/education of carers	INT 315, TAU 129	24	Cluster randomised	CEA	Patient functional independence	SF-12	HCP
Rosenvall *et al*. (2020), Finland	Multi-dimension	Three INTs for people with Alzheimer's: care-management, family support and physical activity. Analysed using existing data then a modelling simulation was carried out	924 (simulation)	48	Modelling	CBA	Use of health and care services, clinical outcome measures	Delay in transition to long-term care	Not stated

Saxena *et al*.(2018), Singapore	Multicomponent	PCDC compared with a hospital-based MC. PCDC was run by GPs and nurses assisted by the MC team	MC 101, PCDC 99, TAU 63	12	Non-randomised quasi-experimental design	CUA	QALYs	EQ-5D-5L	Societal
D'Amico *et al*. (2016), UK	PE	Individually tailored dyadic regime, walking daily for 12 weeks	INT 30, TAU 22	3	RCT	CUA	QALYs	NPI score	H&SC/ societal
Davis *et al*.(2013), Canada	PE	Twice-weekly group classes for older women, comparing resistance or aerobic training with balance and tone classes	Resistance 28, Aerobic 30, Balance & Tone 28	6	RCT	CEA	Patient executive cognitive function	Stroop test	HCP
Lamb *et al*. (2018), UK	PE	Weekly group exercise programme of aerobic and resistance training led by a physio	INT 294, TAU 141	12	RCT	CUA	QALYs	EQ-5D-3L	HCP/ societal
Pitkala *et al*. (2013), Finland	PE	Group-based exercise sessions twice a week compared to home-based exercise	Home 70, Group 70, TAU 70	12	RCT	CEA	FIM score changes and SPPB score changes	FIM, SPPB	H&SC
Sopina *et al*. (2017), Denmark	PE	Supervised, hour-long group sessions of aerobic exercise, three times a week	INT 107, TAU 93	4	RCT	CUA	QALYs	EQ-5D-5L, EQ-VAS	Danish healthcare perspective
Van Santen *et al*. (2022), Netherlands	PE	Exergaming – an interactive cycling system which mimics outdoor cycling whilst on a stationary bike	INT 53, TAU 29 (dyads)	6	RCT	CUA	QALYs	EQ-5D-3L	Societal

Ghani *et al*. (2022), UK	Assist tech	Tablet app with medication reminders, photos, cognitive games	INT 173, TAU 172	6	RCT	CUA	QALYs	EQ-5D-3L	Healthcare provider
Howard *et al*. (2021), UK	Assist tech	Assistive technology and telecare assessment followed by installation of all appropriate devices	INT 248, TAU 247	24	RCT	CUA	QALYs	Time to institutionalisation	H&SC /societal

ADAS-Cog - Alzheimer's Disease Assessment Scale–Cognitive Subscale, Assist tech – assistive technology, CBA – cost-benefit analysis, CBT – cognitive behavioural therapy, CEA – cost-effectiveness analysis, CMAI-SF – Cohen-Mansfield Agitation Inventory – short form, Cog – cognitive, CT for CNLTC - Criterion Time for Certification of Needed Long-Term Care, CUA – cost-utility analysis, DEMQOL - Dementia Quality of Life, EE – method of economic evaluation, EQ-5D - health related quality of life measure, EQ-VAS - EQ-Visual Analogue Scale, FIM - Functional Independence Measure, GAIN - Alzheimer's care instrument, GP – general practitioner, H&SC – health and social care, HCP – healthcare provider, HRQol - health-related quality of life, INT - intervention, MC – memory clinic, NHS – National Health Service, NPI - neuropsychiatric Inventory, PCDC – primary care dementia clinic, PE – physical exercise, PLwD – person(s) with dementia, QALY – quality-adjusted life year, QoL – quality of life, QoL-AD - Quality of Life in Alzheimer Disease, QUALID - Quality of Life in Late-stage Dementia, RCT – randomised controlled trial, SF-12 - Short Form Health Survey, SPPB - Short Physical Performance Battery, TAU – treatment as usual, Train – training interventions

a Data for the economic evaluation, b Data for original study

Separate data extraction was conducted for the review of reviews by GE (see Table 3.3). Extracted data included: interventions reviewed, number of studies included in the review and databases used.

Table 3.3 Review characteristics

Study	Review method	Interventions reviewed	Intervention descriptions	No. studies included	Databases used
Alves, Magalhaes and Thomas (2013)	Systematic	Cognitive	Cognitive stimulation, cognitive training or cognitive rehabilitation	5	PubMed, PsychINFO, the Cochrane Library, EMBASE, metaRegister of Clinical Trials, OVID, EBM Reviews
Clarkson *et al*. (2017)	Systematic	Multicomponent	Home support interventions	8	British NHSEED
Livingston *et al*. (2014)	Systematic	Cognitive/multicomponent	Blended inpatient and outpatient programme to reduce	2	MEDLINE, Web of Knowledge; EMBASE; British Nursing Index; the Health Technology, NHSEED, the HTA programme database and the DARE Assessment programme database; PsycINFO; NHS Evidence; System for Information on Grey

			hospitalisation. Also, an Australian comparison of dementia care mapping and person-centred care programmes		Literature; the Stationery Office Official Documents website; the Stationery National Technical Information Service; Cumulative Index to Nursing and Allied Health Literature (CINAHL); and the Cochrane Library.
Nickel, Barth and Kolominsky-Rabas, (2018)	Systematic	Physical exercise/cognitive	Physical exercise, cognitive interventions	16	Centre for Reviews and Dissemination, EconLit, Embase, Cochrane Library, PsycINFO and PubMed

3.8.4 Data synthesis

A narrative approach to data synthesis was used to summarise and allow comparison of the methods and results of the included evaluations whilst demonstrating heterogeneity. A narrative reporting approach was used as meta-analysis could not be carried out due to the context specific nature of the economic evaluations and the numerous outcomes used in studies.

Interventions were classified according to the following categories representing distinct forms of care: physical activity, cognitive interventions, training interventions, multicomponent interventions, assistive technology and other interventions (specialist dementia care, group living, home care vs care home).

3.8.5 Quality appraisal

Quality appraisal was conducted using the Consolidated Health Economic Evaluation Reporting Standards (CHEERS) statement (Husereau *et al.*, 2013) (see Table 3.7). CHEERS is designed to assess reporting quality rather than the quality of the evaluation. The statements relate to the following aspects: title, abstract, introduction, methods, results, discussion and disclosure. Statements which related only to modelling evaluations were excluded for non-modelling evaluations and resulting scores adjusted accordingly. Each was assigned a score, based on the number of statements met on the CHEERS checklist (0 = unmet, 0.5 = partially met, and 1 = met), the total was then translated into a percentage of items met. Quality appraisal was carried out by GE, EG/HJ undertook an independent appraisal of 30% of the articles and any disagreement was resolved by PM.

In the review of reviews, A Measurement Tool to Assess Systematic Reviews (AMSTAR 2) (Shea *et al.*, 2017) (see Table 3.4) was used to critically appraise the quality of the reviews. GE undertook the initial assessment and EG independently undertook assessment for 60% of the included articles. The tool includes an assessment of potential bias, assessing each area or domain of the review, with certain domains being defined as critical. An overall rating of confidence in quality was calculated based on the total number of weaknesses in critical domains. These weaknesses were defined by unmet/partial met statements on the AMSTAR 2 checklist according to the following criteria:

- *High confidence* None or one non-critical weakness
- *Moderate confidence* More than one non-critical weakness but no critical flaws
- *Low confidence* One critical flaw with or without noncritical weaknesses
- *Critically low confidence* More than one critical flaw with or without non-critical weaknesses

Table 3.4 Quality assessment of systematic reviews using AMSTAR 2 (Shea *et al.*, 2017)

Study	**Alves et al** (2013)	**Clarkson et al** (2017)	**Livingston et al** (2014 a)	**Nickel et al** (2018)
1. Did the research questions and inclusion criteria for the review include the components of PICO?	met	met	met	unmet
2. **Did the report of the review contain an explicit statement that the review methods were established prior to the conduct of the review and did the report justify any significant deviations from the protocol?**	unmet	unmet	met	partial met
3. Did the review authors explain their selection of the study designs for inclusion in the review?	unmet	unmet	met	met
4. Did the review authors use a comprehensive literature search strategy?	partial met	partial met	met	partial met
5. Did the review authors perform study selection in duplicate?	unmet	met	unmet	unmet
6. Did the review authors perform data extraction in duplicate?	met	met	met	unmet
7**. Did the review authors provide a list of excluded studies and justify the exclusions?**	unmet	partial met	met	partial met
8. Did the review authors describe the included studies in adequate detail?	met	met	met	met
9. **Did the review authors use a satisfactory technique for assessing the risk of bias (RoB) in individual studies that were included in the review?**	met	partial met	met	unmet
10. Did the review authors report on the sources of funding for the studies included in the review?	met	met	met	unmet
11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	met	N/A	met	N/A
12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	met	N/A	met	N/A
13. Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review?	met	unmet	met	met
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	met	met	met	met
15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	met	N/A	met	N/A
16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?	partial met	partial met	met	met
Overall rating	**Critically low confidence**	**Critically low confidence**	**High confidence**	**Critically low confidence**

Questions with bolded text denote critical domains

AMSTAR 2 A Measurement Tool to Assess Systematic Reviews, N/A not applicable, RoB risk of bias

3.8.6 Usefulness of economic evaluations to decision making

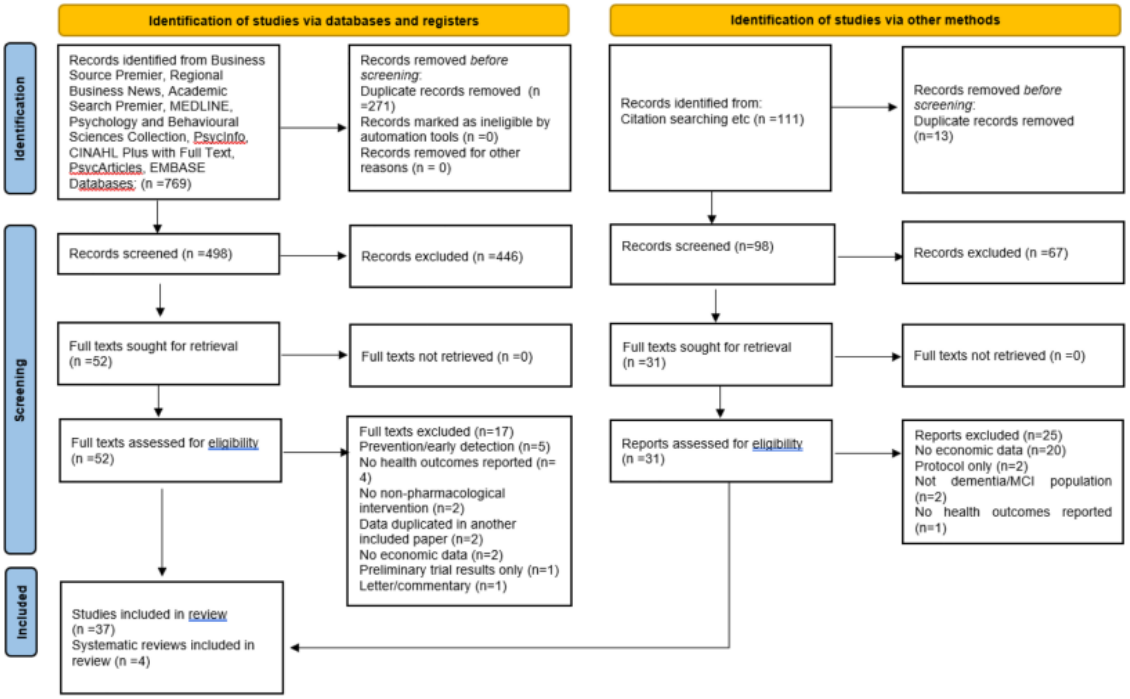
A score of usefulness of the economic evaluations to decision making was calculated for each included evaluation. The scoring system was based on an existing method of assessing usefulness of economic evaluations based on data extraction and assessment of reporting quality (Cheng, Graves and Pacella, 2018). Usefulness was then categorised according to these scores: limited ≤ 4, moderate 4.5–5, strong 5.5–6 (details in Table 3.5).

Table 3.5 Usefulness of economic evaluations to decision making

Study	Usefulness level	Primary reasons
El Alili *et al.* (2020)	Strong	Appropriate statistical analysis including sensitivity analysis, long time horizon
Howard *et al.* (2021)	Strong	Appropriate statistical analysis including sensitivity analysis, long time horizon
Jutkowitz *et al.* (2023)	Strong	Appropriate statistical analysis, model parameter uncertainty described, long time horizon
Lamb *et al.* (2018)	Strong	Appropriate statistical analysis including sensitivity analysis, long time horizon
Meads *et al.* (2020)	Strong	Appropriate statistical analysis including sensitivity analysis, long time horizon
Michalowsky *et al.* (2019a)	Strong	Appropriate statistical analysis including sensitivity analysis, long time horizon
Radke *et al.* (2020)	Strong	Appropriate statistical analysis including sensitivity analysis, long time horizon
Rosenvall *et al.* (2020)	Strong	Appropriate statistical analysis, model parameter uncertainty long 4-year time horizon
MacNeil Vroomen *et al.* (2016)	Moderate	Appropriate statistical analysis including sensitivity analysis, long time horizon, study design
Mostardt *et al.* (2012)	Moderate	Appropriate statistical analysis including sensitivity analysis, long time horizon, study design
D'Amico *et al.* (2015)	Moderate	Appropriate statistical analysis including sensitivity analysis, short time horizon
D'Amico *et al.* (2016)	Moderate	Appropriate statistical analysis including sensitivity analysis, short time horizon
Ghani *et al.* (2022)	Moderate	Appropriate statistical analysis including sensitivity analysis, short time horizon
Livingston *et al.* (2019)	Moderate	Appropriate statistical analysis including sensitivity analysis, short time horizon
Orgeta *et al.* (2015)	Moderate	Appropriate statistical analysis including sensitivity analysis, short time horizon
Pitkala *et al.* (2013)	Moderate	Appropriate statistical analysis including sensitivity analysis, no ICER reported
Pizzi *et al.* (2022)	Moderate	Appropriate statistical analysis including sensitivity analysis, no ICER reported
Romeo *et al.* (2019)	Moderate	Appropriate statistical analysis including sensitivity analysis, short time horizon
Sogaard *et al.* (2014)	Moderate	Appropriate statistical analysis including sensitivity analysis, no ICER reported
Sopina *et al.* (2017)	Moderate	Appropriate statistical analysis including sensitivity analysis, short time horizon
Woods *et al.* (2012)	Moderate	Appropriate statistical analysis including sensitivity analysis, short time horizon
Van Santen *et al.* (2022)	Moderate	Appropriate statistical analysis including sensitivity analysis, short time horizon
Brown *et al.* (2019b)	Moderate	Boot strapping, short time horizon
Laakkonen *et al.* (2016)	Moderate	Sensitivity analysis performed, long time horizon, no ICER reported
Williams *et al.* (2017)	Moderate	Sensitivity analysis performed, long time horizon
Henderson *et al.* (2021)	Limited	Appropriate statistical analysis including sensitivity analysis, short time horizon, study design
Sado *et al.* (2020)	Limited	Appropriate statistical analysis including sensitivity analysis, no ICER reported, long time horizon, study design
Saxena *et al.* (2018)	Limited	Long time horizon, ICER not reported for all comparison groups, study design
Ballard *et al.* (2018a)	Limited	No ICER reported, short time horizon,
Davis *et al.* (2013)	Limited	No ICER reported, short time horizon,
Pizzi *et al.* (2023)	Limited	No ICER reported, short time horizon,
Spector *et al.* (2015)	Limited	No ICER reported, short time horizon,
Jennings *et al.* (2019)	Limited	No sensitivity analysis, no ICER reported
Van de Ven *et al.* (2014)	Limited	No sensitivity analysis, no ICER reported
Pizzo *et al.* (2022)	Limited	Not all parameters used were reported, short time horizon
Menn *et al.* (2012)	Limited	Statistical analysis methods not appropriate, no ICER reported
Mervin *et al.* (2018)	Limited	No sensitivity analysis, short time horizon, no ICER reported

3.9 Results

The systematic literature review identified 769 publications, duplicates were manually removed, and 489 articles were screened. A list of papers excluded after full text screening is included with reasons for exclusion (Appendix 6.1). Forty-one papers were included in the final review. The articles selected for inclusion comprised 37 single economic evaluations and four reviews. The search strategy has been reported using a PRISMA (Page *et al.*, 2021) flow diagram (Figure 3.1). The literature search revealed a lack of economic evaluations on the cost-effectiveness of creative therapies such as art, music, drama, creative writing and dance and sensory therapies such as aromatherapy and massage.



MCI mild cognitive impairment, PRISMA Preferred Reporting Items for Systematic review and Meta-Analysis

Figure 3.1 PRISMA flow diagram showing inclusion process of articles in the systematic review (Page *et al.*, 2021)

3.9.1 Study characteristics

The specific conditions being studied included: people with dementia (n=29), Alzheimer's disease (n=2), MCI (n=2), and mixed populations of MCI/Alzheimer's disease/dementia (n=4). Types of interventions reviewed were exercise (n=6), cognitive (n=9), multicomponent (n=12), training (n=8), assistive technology (n=2). Studies recruited participants living in a variety of settings: 27 studies were for

community dwelling participants, nine were for people in nursing homes and two were for people living either in a nursing home or the community. Studies used varying criteria to define dementia/MCI in their inclusion criteria, ranging from having symptoms of dementia (n=1) to a formal diagnosis of dementia (n=11). A number of studies defined specific Clinical Dementia Rating scores (n=3) and/or used Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) assessment criteria in their inclusion criteria (n=8).

The majority of studies evaluated were randomised controlled trials (n=30), followed by non-randomised studies (n=5) and two modelling studies. Sample size varied greatly, ranging from 50 to 3269 (10,000 in a modelling evaluation). International reach of the studies was UK (n=14) (Woods *et al.*, 2012; D'Amico *et al.*, 2015; Orgeta *et al.*, 2015; Spector *et al.*, 2015; D'Amico *et al.*, 2016; Ballard *et al.*, 2018a; Lamb *et al.*, 2018; Brown *et al.*, 2019b; Livingston *et al.*, 2019; Romeo *et al.*, 2019; Meads *et al.*, 2020; Howard *et al.*, 2021; Pizzo *et al.*, 2022), Germany (n=4) (Menn *et al*., 2012; Mostardt *et al*., 2012; Michalowsky *et al*., 2019a; Radke *et al*., 2020), Netherlands (n=4) (van de Ven *et al*., 2014; MacNeil Vroomen *et al*., 2016; El Alili *et al*., 2020; Van Santen *et al*., 2022), United States (n=5) (Williams *et al*., 2017; Jennings *et al*., 2019; Pizzi *et al*., 2022, 2023; Jutkowitz *et al*., 2023) Finland (n=3) (PitkäÏa *et al*., 2013; Laakkonen *et al*., 2016; Rosenvall *et al*., 2020), Denmark (n=2) (Sogaard *et al*., 2014; Sopina *et al*., 2017), Australia (n=1) (Mervin *et al*., 2018), Japan (n=1) (Sado *et al*., 2020), Canada (n=1) (Davis *et al*., 2013), Singapore (n=1 (Saxena *et al*., 2018), Sweden (n=1) (Ghani *et al*., 2022) and a multi-national study involving Italy, Poland and the UK (Henderson *et al*., 2021).

A range of interventions were identified, which focused on improving the behavioural and psychological symptoms of dementia (BPSD), as well as interventions to prevent decline in cognitive function and mobility. In total 27 different primary outcome measures were used across the included 37 studies. Outcomes included generic, dementia specific and utility-based quality-of-life scales.

Over half of the evaluations employed a cost-utility analysis (n=20), followed by cost-effectiveness analysis (n=10) and cost-benefit analysis (n=4), quality-adjusted life years (QALYs) were the most frequently used measure of benefit (n=20). Costs and outcomes are reported in Table 3.6. It was noted that where studies compared an

intervention to treatment as usual (TAU) the meaning and content of TAU varied between studies potentially affecting the relative effectiveness and cost-effectiveness of interventions.

Fourteen economic evaluations took a societal perspective. A societal perspective takes into account all costs and effects of the intervention on the whole of society and is often favoured by health economists (Drost *et al.*, 2017). The perspective taken when conducting an economic evaluation could affect the analyses and results (Drost *et al.*, 2017).

Table 3.6 Economic evaluation results

Author, country	INT	Intervention group cost[a]	Comparison group cost	INT group outcome	Comparison group outcome	Main result
Brown *et al.* (2019b), UK	Cog	Care home £18,635; lives alone £9,053; lives with someone £18,853; low ADAS-Cog 18,675; high ADAS-Cog £15,266	Care home £17,485; Lives alone £9,155; lives with someone £15,026; low ADAS-Cog £16,398; high ADAS-Cog £13,791	0.07 QALYs (EQ-5D) lives alone		INT dominant over TAU in terms of QALYs for the subgroup living alone
D'Amico *et al.* (2015), UK	Cog	£11,306	£11,440		Incremental effect: 0.0176 QALYs (calculated with Proxy EQ-5D)	ICER = £26,835/QALYs (calculated by Proxy EQ-5D)
Laakkonen *et al.* (2016), Finland	Cog	€8,947	€9,383	-0.03 HRQoL mean score	-0.04 mean change in HRQoL	There was no change between the groups in HRQoL according to 15D. However, the INT had beneficial effects on cognitive function without increasing total costs
Mervin *et al.* (2018), Australia	Cog	$13,827 (PARO, interactive toy); $12,078 (soft toy)	$6,862	-2.66 CMAI-SF mean change (PARO), -1.68 CMAI-SF mean change (soft toy)	1.22 CMAI-SF mean change	Incremental cost per unit improvement in CMAI-SF was $13.01 for the PARO group and $12.85 for the soft toy group relative to usual care
Orgeta *et al.* (2015), UK	Cog	£4,740 (HSC); £9770 (societal)	£4,670 (HSC); £10,630 (societal)	ADAS-Cog 20.53, QoL-AD 37.96	21.19 ADAS-Cog, 37.71 QoL-AD	INT dominated by TAU in terms of ADAS-Cog, no differences in primary outcomes of cognition or quality of life
Sado *et al.* (2020), Japan	Cog	$795	not stated	68.4 CT for CNLTC mean score	83.3 mean score CT for CNLTC	INT showed $21 per month cost-saving/unit of CT for CNLTC for avoiding increased long-term care costs
Sogaard *et al.* (2014), Denmark	Cog	€ 84,142 per dyad	€ 80,741	3.26 QALYs	3.46 QALYs	INT dominated by TAU in terms of QALYs
Spector *et al.* (2015), UK	Cog	£2,344	£1,259	-4.59 mean score Rating anxiety in dementia for PLwD		INT was cost neutral
Woods *et al.* (2012), UK	Cog	£5,853	£4,309	37.013 QoL-AD, 0.644 QALYs	36.416 QoL-AD, 0.643 QALYs	ICER = £2,586/per 0.597 change in QoL-AD score (no ICER expressed in £/QALYs)
Ballard *et al.* (2018a), UK	Train	£2,713 (INT cost); £29702 (total HSC costs)	£0 (INT cost); £34,442 (total HSC costs)	4.78-point improvement in DEMQOL	2.54-point improvement in DEMQOL (mean difference)	INT demonstrates benefits in terms of quality of life, agitation, and neuropsychiatric symptoms, as well as cost savings
El Alili *et al.* (2020), Netherlands	Train	£7,173 (total societal costs)	£7,484 (total societal costs)	Incremental effect: 0.40 QALYs	0.39 QALYs	INT dominant over TAU in terms of QALYs
Livingston *et al.* (2019), UK	Train	£1,379	£1,175	0.346 QALYs	0.332 QALYs	ICER = £14,064/QALYs gained
Meads *et al.* (2020), UK	Train	£3,539	£2,060	0.718 QALYs	0.708 QALYs	ICER = £64,380/QALYs gained

Menn *et al.* (2012), Germany	Train	€80,361 (Group B); €75,754 (Group C)	Group A €82,745	x	x	Group B = 0.858 Hazard rate on time to institutionalisation over 4 years Group C = 1.133 Hazard rate on time to institutionalisation over 4 years
Romeo *et al.* (2019), UK	Train	£32,112	£34,215	1.96 DEMQOL proxy score (mean change)	x	INT dominant over TAU in terms of QALYs gained
Van de Ven *et al.* (2014), Netherlands	Train	$0.63 per resident/day	not stated	3.33 falls (mean annual no.), $3.50 per resident/day (total healthcare consumption), $0.13 per resident/day (psychotropic drug use)	1.81 falls (mean annual no.), $3.23 per resident/day (total healthcare consumption), $0.25 per resident/day (psychotropic drug use)	INT was cost neutral
Williams *et al.* (2017), USA	Train	$79.69/per staff member (elderspeak); $39.84/per resident (resistive to care)	x	11.80% (reduction in time staff used elderspeak), 9.24 % reduction in time residents resistive to care		ICER = $4/resident per one percentage point reduction in Resistiveness to care ICER = $7/staff member per one percentage point reduction in elderspeak
Henderson *et al.* (2021), Italy, Poland, UK	Multicomponent	£10,650 (total health & social care costs)	£4,709 (total health & social care costs)	Incremental effect 0.40 QALYs	0.40 QALYs, mean difference 0.01 QALYs	ICER = £832,636/QALYs gained for PLwD. For QALYs the probability of c/e was 0 at WTP of £0 to £350,000. For QOL-AD, the probability of c/e of intervention was 50% at WTP of €5,000 for a 1-point increase
Jennings *et al.* (2019), USA	Multicomponent	$317 per quarter	not stated	not stated	not stated	Hazard ratio of 0.60, program participants less likely to be admitted to long-term care facility than TAU
Jutkowitz *et al.* (2023), USA	Multicomponent					All 4 INT showed small QALY improvements and delayed transition to long-term care
MacNeil Vroomen *et al.* (2016), Netherlands	Multicomponent	€69,435 (ICMM); €84,155 (LM)	€107,627	1.25 QALYS (ICMM), 1.18 QALYs (LM)	1.27 QALYs	ICER (ICMM vs LM) = ICMM dominates ICER (LM vs control) = €460,135 ICER (ICMM vs control) = unstated
Michalowsky *et al.* (2019a), Germany	Multicomponent	€24,046	€ 24,615	1.349 QALYs	1.300 QALYs	INT dominant over TAU in terms of QALYs
Mostardt *et al.* (2012), Germany	Multicomponent	€1,409	€ 1,292	16.4 (months in home environment)	12.2 (months in home environment)	ICER= €53 per additional month in a home environment
Pizzi *et al.* (2022), USA	Multicomponent	$2,047 mean per dyad	$0.3 mean per dyad	N/A	N/A	Mean cost savings for COPE $2354 per dyad compared to TAU
Pizzi *et al.* (2023), USA	Multicomponent	$1,707 mean per dyad	$864 mean per dyad	N/A	N/A	Mean cost savings for TAP compared with TAU: $1299 per dyad (healthcare perspective), $8611 per dyad (societal perspective)
Pizzo *et al.* (2022),UK	Multicomponent	£2,689	£1,919	0.00664 QALYs	Not reported	INT was dominated by TAU
Radke *et al.* (2020), Germany	Multicomponent	unavailable	unavailable	+0.05 QALYs	Incremental effect: +0.049 QALYs	INT dominant over TAU in terms of QALYs gained

Rosenvall *et al.* (2020), UK	Multicomponent	€527 (CM); €8,000 (Rehabilitative); €341 (SFS) All costs per pt/year	N/A	x	N/A	Economic break-even points reached if a patient's transition to long-term care is delayed by: CM = 2.8 days SFS = 1.8 days Rehabilitative cognitive, physical and social activation = 43.0 days
Saxena *et al.* (2018), Singapore	Multicomponent	$15,308 (MC); $13,275 (PCDC); $15,766 (Other clinics)	x	0.78 (PCDC), 0.76 (Other polyclinics clinics) (EQ-5D scores)	x	ICER = S$29,042/QALYs for the PCDC group when compared with the MC group
D'Amico *et al.* (2016), UK	PE	£10,533	£7,805	N/A	Incremental effect: 0.0055 QALYs	ICER = £286,440 QALYS (calculated by DEMQOL-Proxy) Not C/E when outcomes are calculated by QALYs
Davis *et al.* (2013), Canada	PE	$2,255 (CAD) (resistance); $1,417.15 (CAD) (aerobic)	$2,387 (CAD) (balance and tone)	44.61 (resistance), 48.27 (aerobic) (seconds gained/lost on Stroop test)	54.69 (balance and tone) (seconds gained/lost on Stroop test)	Both the aerobic and the resistance classes dominate balance and tone classes in terms of seconds gained/lost on Stroop test
Lamb *et al.* (2018), UK	PE	£5,580	£3,917	0.787 QALYs	0.826 QALYs	INT dominated by TAU in terms of QALYs
Pitkäla *et al.* (2013), Finland	PE	$25,112 per dyad/per year (HE group); $2,2066 per dyad/per year (GE group)	$34,121per dyad/per year (Control group)	-7.1 (HE group), -10.3 (GE group) (FIM change)	-14.4 (control group) (FIM change)	INTs had beneficial effects on the physical functioning of patients with Alzheimer's disease, without increasing the total costs of health and social services
Sopina *et al.* (2017), Denmark	PE	£608 (including transport)	Not stated	Not stated	Not stated	ICER= €158,520/QALYs gained
Van Santen *et al.* (2022), Netherlands	PE	€2,877	€2,750	0.36 QALYs	0.42 QALYs	INT dominated by TAU in terms of QALYs
Ghani *et al.* (2022), UK	Assist tech	€8,188	€8,175	-0.03 EQ-5D-3L mean change	-0.01 EQ-5D-3L mean change	INT dominated by TAU
Howard *et al.* (2021), UK	Assist tech	£19,649 (HSC), £56,000 (societal)	£15,186 (HSC), £53,378 (societal)	1.201 QALYs	1.306 QALYs	ICER= £8,635/QALYs (HSC), £33,672/QALYs (societal)

All dollar values are in US$ unless otherwise indicated

ADAS-Cog - Alzheimer's Disease Assessment Scale–Cognitive Subscale, Assist tech – Assistive technology, C/E – cost-effectiveness, CAD – Canadian dollars, CMAI-SF - Cohen-Mansfield Agitation Inventory – short form, Cog – cognitive, CT for CNLTC - Criterion Time for Certification of Needed Long-Term-Care, DEMQOL - Dementia Quality of Life, EQ-5D – health related quality of life measure, FIM - Functional Independence Measure, GE – group-based exercise, HE – tailored home-based exercise, HRQol - Health related quality-of-life, HSC – health and social care, ICER – incremental cost effectiveness ratio, ICMM – Intensive Care Management Model, INT – intervention, LM – linkage model, MC – memory clinic, PCDC – primary care dementia clinic, PE – physical exercise, PLwD – person(s) with dementia, QALY – quality-adjusted life year, QoL-AD – Quality of Life in Alzheimer Disease, S$ - Singapore dollars, SFS – structured family support, TAU – treatment as usual, Train – training interventions, WTP – willingness to pay

a - Mean cost per person over the length of the INT unless otherwise stated

3.9.2 Quality appraisal of economic evaluations

Individual evaluations met between 62 and 98% of criteria items in assessment of CHEERS reporting quality (mean 81%). Twenty-one evaluations met over 80% of total assessed items. In terms of scores for categories of interventions: the highest was for the ‘other’ category which scored of 89% (mean), however, it should be noted that this category only evaluated two interventions. Exercise interventions ranked next highest with 84% (mean); training interventions scored the lowest overall with 76% (mean).

3.9.3 Usefulness of economic evaluations to decision making

Scores for level of usefulness were as follows: evaluations rated as having ‘strong’ usefulness (n=8), ‘moderate’ (n=17) and ‘limited’ (n=12). The results showed that a high CHEERS quality assessment score did not necessarily translate to a high usefulness score for aiding decision making (see Table 3.5).

Table 3.7 Quality assessment of studies using CHEERS (Husereau *et al.*, 2013)

Study	Title/abstract (2 items)	Introduction (2 items)	Methods (10[a] items)	Results (4[b] items)	Discussion (1 item)	Disclosure (2 items)	Total	% Items met
Cognitive								
Brown *et al.* (2019b)	1.5	2	6.5	3	0.5	2	15.5	74%
D'Amico *et al.* (2015)	2	1.5	9	4	1	2	19.5	93%
Laakkonen *et al.* (2016)	1.5	2	6.5	3.5	1	1	15.5	74%
Mervin *et al.* (2018)	1.5	2	8	1	1	2	15.5	74%
Orgeta *et al.* (2015)	1.5	2	9	3	2	1	18.5	88%
Sado *et al.* (2020)	1	2	9	3	1	2	18	86%
Sogaard *et al.* (2014)	2	2	8.5	3	1	2	18.5	88%
Spector *et al.*(2015)	1.5	2	6	2	1	2	14.5	69%
Woods *et al.* (2012)	1.5	2	8	4	1	2	18.5	88%
Means	**1.6**	**1.9**	**7.8**	**2.9**	**0.9**	**1.9**	**17.1**	**81%**
Training								
Ballard *et al.* (2018a)	1.5	2	4	3	1	2	13.5	64%
El Alili *et al.* (2020)	2	1.5	8.5	3	1	2	18	86%
Livingston *et al.* (2019)	2	2	8.5	4	1	1	18.5	88%
Meads *et al.* (2020)	2	2	8	3	1	2	18	86%
Menn *et al.* (2012)	1.5	2	9.5	1	1	1	16	76%
Romeo *et al.* (2019)	1.5	2	8.5	3	0.5	1	16.5	79%
Van de Ven *et al.* (2014)	1	2	7	1	0.5	2	13.5	64%
Williams *et al.* (2017)	1	1.5	7	1.5	1	2	14	67%
Means	**1.6**	**1.9**	**7.6**	**2.4**	**0.9**	**1.6**	**16.0**	**76%**
Multicomponent								
Henderson et al. (2021)	2	2	9.5	4	1	2	20.5	98%
Jennings et al. (2019)	1.5	2	6	2	1	2	14.5	69%
Jutkowitz et al. (2023)	1	1	12	3	2	1	20	83%
MacNeil Vroomen *et al.* (2016)	1.5	2	9	3	1	2	18.5	88%
Michalowsky *et al.* (2019a)	1.5	2	9	4	1	1.5	19	90%

Mostardt *et al.* (2012)	1	1	6.5	3	0.5	1	13	62%
Pizzi *et al.* (2022)	2	1.5	7	3	1	2	16.5	79%
Pizzi *et al.* (2023)	1.5	1.5	6	3	1	2	15	58%
Pizzo *et al.* (2022)	2	2	9	2	0.5	2	17.5	65%
Radke *et al.* (2020)	1	2	8.5	4	1	2	18.5	88%
Rosenvall *et al.* (2020)	1	2	6.5	4	2	1	16.5	69%
Saxena *et al.* (2018)	2	2	8.5	2	0.5	2	17	81%
Means	**1.5**	**1.8**	**8.1**	**3.1**	**0.9**	**1.9**	**17.2**	**80%**
Exercise								
D'Amico *et al.* (2016)	1.5	1.5	9	3	1	2	18	86%
Davis *et al.* (2013)	2	2	10	3	1	2	20	95%
Lamb *et al.* (2018)	1.5	2	9	4	1	2	19.5	93%
Pitkala *et al.* (2013)	1.5	2	8.5	3	1	2	18	86%
Sopina *et al.* (2017)	1	1.5	7.5	3	1	0	14	67%
Van Santen *et al.* (2022)	1.5	2	7	3	0.5	2	16	76%
Means	**1.5**	**1.8**	**8.5**	**3.2**	**0.9**	**1.7**	**17.6**	**84%**
Other								
Ghani *et al.* (2022)	2	2	8.5	4	0.5	2	19	90%
Howard *et al.* (2021)	2	2	8.5	4	1	1	18.5	88%
Means	**2.0**	**2.0**	**8.5**	**4.0**	**0.8**	**1.5**	**18.8**	**89%**

CHEERS Consolidated Health Economic Evaluation Reporting Standards
a - 13 items assessed for Rosenvall et al and Jutkowitz et al modelling studies
b - 4 items assessed for Rosenvall et al and Jutkowitz et al modelling studies

3.9.4 Intervention specific results

3.9.4.1 Cognitive interventions

Nine evaluations explored interventions focused on cognition (Table 3.2). Study populations comprised community dwelling PLwD (Woods *et al.*, 2012; Sogaard *et al.*, 2014; Orgeta *et al.*, 2015; Spector *et al.*, 2015; Laakkonen *et al.*, 2016), nursing home residents (Mervin *et al.*, 2018; Sado *et al.*, 2020) and a combination of both populations (D'Amico *et al.*, 2015; Brown *et al.*, 2019b).

CST's were evaluated in three papers: one evaluating cognitive stimulation for participants new to CST (Orgeta *et al.*, 2015) and two evaluating maintenance cognitive stimulation therapy (MCST) (D'Amico *et al.*, 2015; Brown *et al.*, 2019b). The D'Amico *et al* evaluation reported that MCST dominated TAU with a 40% probability of being cost-effective at WTP threshold of £20,000 for cost per QALY using proxy EQ-5D ratings (D'Amico *et al.*, 2015). In the Brown *et al* evaluation, MCST dominated TAU in terms of QALYs for a sub-group of people living alone (Brown *et al.*, 2019b). However, this evaluation used a small secondary dataset which may not have been representative of the general population and was not powered to detect sub-group changes, therefore results should be interpreted with caution. The CST intervention was not evaluated as cost-effective though, it did not improve cognition or quality of life for PLwD and was dominated by TAU (Orgeta *et al.*, 2015).

Cognitive multi-component interventions were evaluated in two papers (Sogaard *et al.*, 2014; Sado *et al.*, 2020). Sado *et al* evaluated a combination of cognitive training and stimulation in a nursing home population (Sado *et al.*, 2020) while Sogaard *et al* assessed a community counselling/education and support intervention (Sogaard *et al.*, 2014). Both followed up participants for significant periods of time (Sogaard *et al.*, 2014; Sado *et al.*, 2020). Although the Sado *et al* evaluated intervention reported significant cost savings compared to TAU (Sado *et al.*, 2020) the non-randomised matched control design was not gold-standard, such designs risk introducing bias and confounding (Rose and Laan, 2009). The Sogaard *et al* evaluated intervention was not cost-effective and was dominated by TAU in terms of QALYs (Sogaard *et al.*, 2014).

The remaining four cognitive papers all evaluated different types of cognitive interventions. Laakkonen *et al* evaluated cognitive rehabilitation with promotion of self-management skills for people recently diagnosed (Laakkonen *et al.*, 2016). Participants in the intervention group showed significantly less decline in verbal fluency scores compared with TAU, without increasing total costs (Laakkonen *et al.*, 2016). Spector *et al* evaluated cognitive behavioural therapy (CBT) to reduce anxiety in PLwD (Spector *et al.*, 2015). Significant improvements in depression were reported by the intervention group; improvements in anxiety scores were also reported but this failed to reach statistical significance (Spector *et al.*, 2015). Mervin *et al* evaluated an intervention to improve levels of agitation using soft toys and interactive toys with artificial intelligence; no statistically significant between-group differences in agitation were found between the soft toy and the interactive toy groups and the intervention was not cost-effective (Mervin *et al.*, 2018). Woods *et al* evaluated joint reminiscence therapy groups with carers and PLwD (Woods *et al.*, 2012). It reported no significant difference in outcomes or service use between the intervention group and TAU (Woods *et al.*, 2012).

3.9.4.2 Training interventions

There were eight evaluations of specialised dementia training for staff caring for PLwD (Table 2.2). Seven of the eight interventions involved nursing home staff training with one community-based training intervention for general practitioners (GPs). The training intervention evaluation with the longest follow up period was evaluated by Williams *et al* at 36 months (mean=15.4, SD 9.83) (Williams *et al.*, 2017).

Four training interventions were evaluated as cost-effective in terms of QALYs (Williams *et al.*, 2017; Ballard *et al.*, 2018a; Livingston *et al.*, 2019; El Alili *et al.*, 2020). Ballard *et al* reported the staff training intervention demonstrated benefits in terms of quality of life, agitation, and neuropsychiatric symptoms, as well as cost savings (Ballard *et al.*, 2018a). The staff training intervention Livingston *et al* evaluated was cost-effective in terms of QALYs with a 62% probability of cost-effectiveness at a WTP of £20,000/QALY (Livingston *et al.*, 2019). The multi-component training intervention for people with severe dementia evaluated by El Alili *et al* was reported to dominate TAU in terms of QALYs (El Alili *et al.*, 2020). Williams *et al* evaluated staff communication with residents, and this intervention was found to be cost-effective,

however the evaluation lacked appropriate statistical analysis, as no incremental cost-effectiveness ratio (ICER) in terms of QALYs was reported; direct comparison with other studies is difficult (Williams *et al.*, 2017). A strength of this evaluation was its long time-horizon of 36 months; it was limited by the small sample size and generalisability was also limited due to the small geographical location of the nursing homes.

An evaluation of the cost-effectiveness of a programme which provided GP training in dementia care, carer counselling and promotion of support groups was carried out by Menn *et al* (Menn *et al.*, 2012). Despite having the longest of all follow up periods at 48 months it showed no significant reduction in time to institutionalisation (Menn *et al.*, 2012). Meads *et al* and van de Ven *et al* both evaluated dementia care mapping interventions in nursing homes, they were evaluated as not cost-effective and cost-neutral respectively (van de Ven *et al.*, 2014; Meads *et al.*, 2020).

3.9.4.3 Multicomponent interventions

Twelve papers evaluated a range of multicomponent dementia care programmes. Dementia care management evaluations by Jennings *et al*, Michalowsky *et al* and Radke *et al* looked at multicomponent community dementia care for assessment, management and support (Jennings *et al*., 2019; Michalowsky *et al*., 2019b; Radke *et al*., 2020).

Only two of the three dementia care management interventions evaluated showed evidence of cost-effectiveness and TAU was dominated in terms of QALYs (Michalowsky *et al.*, 2019a; Radke *et al.*, 2020). Radke *et al* undertook sub-group analysis to determine which group of participants benefitted most (Radke *et al.*, 2020). A higher probability of cost-effectiveness was reported in people aged <80 years compared to >80 years; females compared to males, PLwD living alone compared to people not living alone and in people with more co-morbidity than less co-morbidity (Radke *et al.*, 2020). The authors suggest that the high probability of cost-effectiveness in females and people living alone could be attributed to these groups having fewer relatives or carers to provide care and support and therefore having a higher number of unmet needs, meaning that they are more likely to benefit from a multicomponent management programme (Radke *et al.*, 2020).

Case management, supporting the person with dementia and their carer in conjunction in a multicomponent team approach, was evaluated by MacNeil Vroomen *et al* and Mostardt *et al* (Mostardt *et al.*, 2012; MacNeil Vroomen *et al.*, 2016). Mostardt *et al* reported a significant difference in average additional months spent in the home environment for intervention group participants, although no limitations were discussed in the evaluation, which also used a non-randomised matched controlled study design. MacNeil Vroomen *et al* evaluated an intensive care management model which dominated TAU in terms of QALYs with 99% WTP at €30,000/QALY (MacNeil Vroomen *et al.*, 2016). However, the observational, non-randomised design may have introduced selection bias and more heterogeneity into the study population.

Three occupational therapy based interventions were evaluated which involved PLwD assessment and carer/PLwD education (Pizzi *et al.*, 2022, 2023; Pizzo *et al.*, 2022). While cost-benefit analysis showed cost savings for two of these interventions (Pizzi *et al.*, 2022, 2023), the third intervention was dominated by TAU (Pizzo *et al.*, 2022).

Rosenvall *et al* and Jutkowitz *et al* each undertook modelling simulation evaluating interventions to delay transition to long-term care (Rosenvall *et al*., 2020; Jutkowitz *et al*., 2023). Rosenvall *et al* demonstrated potential cost-effectiveness through care management, family support and rehabilitation interventions to delay cognitive decline and transition to long-term care (Rosenvall *et al*., 2020). The Jutkowitz *et al* modelling simulation also demonstrated potential cost-effectiveness; they modelled four interventions including two targeting caregivers' education/support and two targeting assessment/management of PLwD and found that all showed small QALY improvements and increased time spent at home (Jutkowitz *et al*., 2023).

Saxena *et al* undertook an evaluation comparing a primary care dementia clinic with a hospital-based memory clinic in Singapore (Saxena *et al.*, 2018). QALYs were higher for the primary care clinic and the ICER at 12 months was S$29,042 (Singapore Dollars) per QALY (less than the assumed threshold of S$78,690). The authors concluded that the care provided by the primary care clinic had similar effectiveness to that provided by a hospital clinic, suggesting that these clinics could be cost-effectively set up elsewhere in primary care.

Henderson *et al* conducted an evaluation on a non-randomised study of meeting centres providing day support (Henderson *et al.*, 2021). The evaluation had a short 6-

month time horizon, it was rated highest for reporting quality by CHEERS at 98% but was not cost-effective in terms of QALYs.

3.9.4.4 Exercise interventions

Six RCTs on the effect of physical activity on PLwD were evaluated. One intervention included people living in nursing homes (D'Amico *et al.*, 2016), the rest focused on people living in the community (Davis *et al.*, 2013; PitkäÏa *et al.*, 2013; Sopina *et al.*, 2017; Lamb *et al.*, 2018; Van Santen *et al.*, 2022). The majority of evaluations were of group-based exercise outside of the home.

None of the interventions demonstrated cost-effectiveness in terms of QALYs; however, two showed improvements in primary outcomes (Davis *et al.*, 2013; PitkäÏa *et al.*, 2013). Davis *et al* reported that resistance and aerobics dominated balance and toning in terms of seconds gained/lost on Stroop test of cognitive function and were less costly (Davis *et al.*, 2013). In PitkäÏa *et al* both home exercise and group exercise intervention groups demonstrated significantly slower decline in functioning measured by Functional Independence Measure (FIM) (-7.1 and -10.3 FIM change, respectively) than the control group (-14.4 FIM change) without increasing the total costs of health and social services (PitkäÏa *et al.*, 2013).

3.9.4.5 Assistive technology interventions

Howard *et al* evaluated a telecare and assistive technology intervention, which was not cost-effective in terms of QALYs and did not enable PLwD to live safely at home for longer (Howard *et al.*, 2021). Ghani *et al* evaluated an app for people with MCI and their carers (Ghani *et al.*, 2022). The results of the cost-effectiveness analysis were inconclusive but suggest the intervention may be more beneficial for carers than PLwD.

3.10 Review of reviews

Alves *et al* undertook a systematic review of five RCTs on the efficacy and feasibility of cognitive interventions for people with Alzheimer's disease (Alves, Magalhaes and Thomas, 2013). The review included cognitive stimulation, cognitive training and cognitive rehabilitation. It was rated as critically low for confidence in quality using AMSTAR 2 with several critical domains not being fully met. Only one relevant

economic evaluation of cost-effectiveness was identified: in the cognitive intervention category, a programme of cognitive stimulation for PLwD living either at home or in nursing homes (participant numbers not stated). The intervention was not reported as cost-effective.

Home support interventions for PLwD living in the community were systematically reviewed by Clarkson *et al* (Clarkson *et al.*, 2017). The review included 14 economic evaluations, six of these evaluated only carer outcomes and as such were excluded here. The economic evaluation by PitkäÏa *et al* (PitkäÏa *et al.*, 2013) was reviewed by Clarkson *et al*, it has already been reviewed in this paper (see Sect. 3.4.4) and will be not be discussed here again to avoid duplication. The remaining seven relevant economic evaluations looked at interventions across several categories of intervention: training (dementia care mapping - DCM), cognitive (activity sessions), multicomponent (occupational therapy, dementia care management n=2) and other (specialist dementia day care, home care compared to care home). Only occupational therapy was reported to show cost-effectiveness. Confidence in the Clarkson *et al* review was rated as critically low for confidence in quality using AMSTAR 2 and did not fully me*et al*l critical domains.

As part of a systematic review of interventions to reduce agitation in older adults with dementia in any setting, Livingston *et al* (Livingston *et al.*, 2014a) identified an economic evaluation by Norman *et al* evaluating a comparison of DCM and person-centred care (Norman *et al.*, 2008). Economic outcomes were measured using Cohen-Mansfeld Agitation Inventory (CMAI) scores. Norman *et al* reported that for person-centred care relative to usual care there were costs of A$6.43 (Australian Dollars) per CMAI point averted, for the DCM intervention the costs were higher at A$46.89 (Norman *et al.*, 2008). The summary economic measure for this evaluation was cost per CMAI score change, further data on effectiveness of this intervention was not available within the review.

Additionally, as part of the review Livingston *et al* (2014) created a simulation model using the most effective strategies identified from an effectiveness review of 30 studies of wide-ranging dementia therapies and existing patient cohort data (Livingston *et al.*, 2014a). Modelling of a multi-component intervention for participants with mild to moderate dementia revealed 82% probability of cost-effectiveness at a maximum WTP

threshold of £20,000/QALY. However, due to the multi-component nature it was not possible to determine which particular component of the intervention was most effective. This review rated high for confidence in quality using AMSTAR 2.

The Nickel *et al* review (Nickel, Barth and Kolominsky-Rabas, 2018) of interventions for PLwD and their carers contained three evaluations in our physical activity intervention category (Davis *et al.*, 2013; PitkäÏa *et al.*, 2013; D'Amico *et al.*, 2016) and three cognitive interventions (Woods *et al.*, 2012; D'Amico *et al.*, 2015; Orgeta *et al.*, 2015) which were relevant to this systematic review. The evaluations contained in this review have already been individually identified through the literature review, and methods and results are discussed above. The review rated critically low for confidence in quality using AMSTAR 2.

3.11 Discussion

3.11.1 Summary of main findings

This paper reviewed economic evaluations of a wide range of interventions for dementia and MCI. These interventions took place around the world in community and nursing home settings.

Of the 37 evaluations and four reviews evaluated in this paper, 16 interventions demonstrated evidence to favour interventions, although some of these had limitations. The category with the greatest number of interventions showing evidence of cost-effectiveness was multicomponent interventions. Eight of the 16 multicomponent interventions were cost-effective in terms of QALYs gained compared to TAU. Case management showed evidence of cost-effectiveness in both evaluations which were evaluated, both of these evaluations rated 'moderate' for usefulness (Mostardt *et al.*, 2012; MacNeil Vroomen *et al.*, 2016). However one of these was rated 'low' in CHEERS assessment of reporting quality and did not report cost-effectiveness in terms of QALYs (Mostardt *et al.*, 2012). Occupational therapy and dementia care management showed evidence of cost-effectiveness in over 60% of the evaluations (Jennings *et al.*, 2019; Rosenvall *et al.*, 2020).

MCST demonstrated strongest evidence of cost-effectiveness, and results were reported using QALYs. Both interventions were cost-effective in terms of QALYs compared to TAU (D'Amico *et al.*, 2015; Brown *et al.*, 2019b). They both scored

'moderate' for usefulness (D'Amico *et al.*, 2015; Brown *et al.*, 2019b) and D'Amico *et al* scored highly for CHEERS reporting quality (D'Amico *et al.*, 2015). Overall conclusions should be interpreted with caution however as only two evaluations of MCST were available. As previously mentioned, group CST is already recommended as an intervention (National Institute for Health and Care Excellence (NICE), 2018a) and has been proven to be cost-effective in a large-scale study outside of the timeframe of this review (Knapp *et al.*, 2006). However, the economic evaluation of CST was not found to be cost-effective (Orgeta *et al.*, 2015) and overall, the cognitive interventions category did not demonstrate good evidence of cost-effectiveness.

There was also evidence for care home and nursing home staff training interventions. 62% of training evaluations evaluated showed evidence of cost-effectiveness in terms of QALYs or showed significant patient benefits (Williams *et al.*, 2017; Ballard *et al.*, 2018a; Livingston *et al.*, 2019; Romeo *et al.*, 2019; El Alili *et al.*, 2020) and a sixth intervention was cost neutral (van de Ven *et al.*, 2014).

Limitations were identified in some of the evaluations, and evidence was weakened by small number of evaluations per intervention, small sample sizes, short timeline or reliability of evidence. Four of the evaluations reporting cost-effectiveness did not use an RCT design and this could have led to biased estimates of effect (Mostardt *et al.*, 2012; MacNeil Vroomen *et al.*, 2016; Saxena *et al.*, 2018; Sado *et al.*, 2020). The generalisability of the sample to the wider population was a potential issue in two evaluations as the study population was limited to a rural community (Michalowsky *et al.*, 2019a; Radke *et al.*, 2020). Five of the cognitive evaluations took place in the same country, which may lead to a geographical bias (Woods *et al.*, 2012; D'Amico *et al.*, 2015; Orgeta *et al.*, 2015; Spector *et al.*, 2015; Brown *et al.*, 2019b).

3.11.2 Limitations

Despite the broad search terms used, it is possible that some economic evaluations may have been missed. There may be an element of publication bias, as it is acknowledged that authors may be less willing to publish evaluations that do not demonstrate cost-effectiveness or cost savings.

Synthesising evidence from evaluations and reviews evaluating a wide range of interventions presented challenges. Due to the variety of outcome measures used, the

heterogeneity of the study methods and the variety of different interventions, it was difficult to compare the cost-effectiveness of different interventions. The lack of WTP thresholds for different countries made it difficult to compare the ICERs between countries.

The review was also hampered by lack of robust economic evidence generally for non-pharmacological studies. This in turn resulted in limited evidence for each category of intervention.

It is acknowledged that the revised AMSTAR 2 tool which evaluated the systematic reviews was not published until after several of the reviews had been published and this may have negatively impacted on the scores received.

3.12 Recommendations for future research

Our review excluded carer-targeted interventions, it is acknowledged that there may be interventions that improve health or quality of life of PLwD in ways considered to be cost-effective, even though the consequences would be secondary to the impact on carers. Also, if carer health and costs are considered then this could change results.

It was noted that evaluations tended not to analyse the distribution of costs, effects and cost-effectiveness across population subgroups. Given the wide inequalities in the experiences of people with dementia in terms of time to diagnosis, access to dementia services for example future research could focus on these areas.

The results of the review demonstrate gaps in the economic evidence on non-pharmacological interventions which could benefit from further research. There was limited evidence shown for multicomponent cognitive evaluations and CBT. Additionally economic evaluations of creative and sensory therapies were not found in the literature review. Further high-quality research would evaluate whether these interventions are cost-effective.

3.13 Conclusion

MCST was evaluated as having the strongest evidence of cost-effectiveness although the number of economic evaluations was small. Case management, occupational therapy and dementia care management also showed good evidence of cost-

effectiveness. More economic evidence on the cost-effectiveness of dementia care interventions is needed, with consistency of study methods and outcome measures, to inform policy and local and national decision makers future decision making. This could improve decision makers' confidence to promote cost-effective dementia interventions in the future.

End of published paper

3.14 Updated literature review of economic evaluations

3.14.1 Aim

This part of the thesis aims to provide an update to the original published systematic literature review and review of reviews with a focus on economic evaluations of NPTs for dementia. This update aimed to identify and assess any newly published studies that may offer relevant findings or additional insights relevant to the current research. The objective was not only to ensure that the latest evidence was incorporated, but also to evaluate whether this evidence had the potential to influence or refine the direction, assumptions, or conclusions of the thesis.

3.14.2 Method

A literature review was conducted to search for papers published between May 2023 and June 2025, to identify relevant economic evaluations of NPTs for PLwD. The search strategy applied the same predefined eligibility criteria as outlined in section 3.8, in order to maintain methodological consistency.

3.14.3 Results

Some recent reviews of NPTs have been published. A recent systematic review and meta-analysis of various interventions to reduce BPSD found that NPTs were effective for overall BPSD, depression and agitation (Yin *et al.*, 2024). These researchers found that the most effective intervention for improving overall BPSD was exercise plus TAU, however, they did not evaluate cost-effectiveness (Yin *et al.*, 2024).

Recent RCTs have also economically evaluated specific types of interventions for PLwD, including exercise (Harwood *et al.*, 2023), sleep disturbances (Gonzalez *et al.*, 2024) and MT (Gaviola, Searles and Dilworth, 2022; Riedl *et al.*, 2025). For example, the trial named promoting activity, independence, and stability in early dementia was a UK multi-centre RCT of a tailored exercise programme for individuals with mild dementia or MCI (Harwood *et al.*, 2023). A CUA was conducted, which concluded that the intervention did not offer better value for money compared with standard care, highlighting the challenges in demonstrating cost-effectiveness for certain NPTs. Another UK RCT, titled *Dementia-related manual for sleep; strategies for relatives*, investigated the effectiveness of an intervention to manage sleep disturbances in PLwD (Rapaport *et al.*, 2024). The intervention was evaluated as cost-effective in

improving sleep disturbances compared to TAU, suggesting potential benefits of such targeted NPTs (Gonzalez *et al.*, 2024).

For MT, a scoping review by Riedl *et al.* (2025) found that while some studies of MT indicated possible cost-effectiveness, there was a lack of evaluation and a need for more rigorous, standardised economic evaluations. These will be discussed further in subsequent chapters. Gaviola, Searles and Dilworth (2022) evaluated the cost of providing an individualised MT intervention for PLwD in care homes in Australia through the use of a simple cost analysis (Gaviola, Searles and Dilworth, 2022). It was shown to be a low-cost, feasible intervention; however, specific clinical outcomes were not measured in this study.

Model-based economic evaluations of dementia interventions were recently reviewed by Darab *et al.* (2024). The review included various interventions and noted that only in a few studies had the model assumptions and parameters been adequately justified. The authors emphasised the need for improved methodological quality in future evaluations (Darab *et al.*, 2024).

3.14.4 Conclusion

The results of the updated systematic review showed continued interest in NPTs for PLwD. However, there remains a limited number of studies that have evaluated the cost-effectiveness of these interventions, particularly those employing model-based economic evaluations. This is concerning given the growing need for healthcare providers and policymakers to allocate services efficiently amid ongoing budgetary constraints. Furthermore, the growing reliance on model-based economic evaluations to inform policy decisions highlights the urgent need for robust, high-quality research in this area. This thesis seeks to contribute to addressing this critical gap in the evidence base.

3.15 Chapter summary

NPTs for dementia have shown effectiveness in managing symptoms, improving quality of life, and in some cases, delaying the need for nursing home placement. However, the availability of NPTs within the NHS remains limited, largely due to a lack of robust economic evidence supporting their cost-effectiveness. Economic evaluations are essential for comparing interventions and identifying those that offer

the best value for money. Without such evidence, it is difficult to justify the expansion of NPT offerings within the healthcare system. The published literature review and its subsequent update highlight a persistent gap in economic evaluations of NPTs for dementia. This lack of evidence poses a significant barrier for healthcare commissioners and policymakers, making it challenging to shape dementia care policy or make informed decisions at both local and national levels. Strengthening the evidence base through high-quality economic evaluations would enhance confidence in promoting cost-effective dementia interventions.

3.16 Footnote

In the published systematic review and review of reviews of economic evaluations, CTPs were excluded if they assessed outcomes solely for caregivers, as the primary focus was on outcomes for PLwD. However, emerging evidence suggests that CTPs may offer significant clinical benefits for both PlwD and their caregivers. In light of this, the inclusion criteria were broadened to better reflect the interconnected nature of dementia care. To align the economic evidence base with this expanded perspective, articles from the original systematic review were re-screened to identify economic evaluations of CTPs that reported primary outcomes for both caregivers and PlwD. The findings from this updated review are presented in Chapter 8.

Chapter 4 Literature review of clinical effectiveness of community-based non-pharmacological therapies

4.1 Introduction

This chapter presents a review of clinical effectiveness of community-based NPTs for PLwD. The primary objective of the review was to identify therapies that demonstrated strong evidence of clinical effectiveness in the published studies but lacked sufficient evidence regarding their cost-effectiveness. The findings from this review were subsequently used to inform the selection of therapies included in a survey designed to establish research priorities for this thesis.

4.2 Background

Health-related interventions can be assessed in terms of their clinical effectiveness to evaluate how well they achieve the desired outcomes. Key measures of clinical effectiveness include clinical audit or assessment of clinical outcomes (such as blood pressure changes), service evaluation and benchmarking data. Effective clinical treatment has been categorised in various ways. One approach by Nasrallah *et al.* (2005) proposed four key ways to categorise dimensions of clinical treatment effectiveness: symptoms of disease, treatment burden, disease burden and health and wellness (Nasrallah *et al.*, 2005). Another, more formal approach by Guyatt *et al.* (2008) is the grading of recommendations assessment, development, and evaluation system (Guyatt *et al.*, 2008). This is often used by NICE and is focused on the quality of evidence and risk-benefit analysis, which is a key concept in the evaluation of clinical treatments. Another framework is economic, clinical, and humanistic outcomes (Kozma, Reeder and Schulz, 1993). This is commonly used in HTAs and economic evaluations. It has three dimensions: clinical, economic and humanistic outcomes (i.e. patient-reported outcomes and quality of life).

4.3 Aim

A review of published systematic reviews was conducted to evaluate the clinical effectiveness of community-based NPTs. This review focused specifically on clinical outcomes, building on the findings presented in Chapter 3, which examined economic evaluations through a systematic review and a review of reviews.

The current analysis aimed to synthesise evidence on clinical effectiveness to complement the earlier economic perspective, with the goal of identifying therapies that have demonstrated clinical benefit but have not yet been subjected to formal CEA.

4.4 Design

The review methodology was deliberately selected as part of a broader triangulation strategy. This approach was considered more appropriate than a systematic review due to the exploratory nature of the research and the breadth of the evidence base. It was carried out to ensure that any emerging therapies without evaluation of cost-effectiveness were not missed and were assessed for inclusion in the survey. Its purpose was to ensure comprehensive coverage of the evidence base, particularly to identify any emerging community-based NPTs that may not yet have undergone formal cost-effectiveness evaluation. By doing so, the review aimed to capture potentially valuable interventions that might otherwise be overlooked, in order to inform decisions about their inclusion in the subsequent survey phase.

Systematic reviews of community-based NPTs for dementia, excluding those focused on economic evaluations, were sourced to assess the evidence of clinical effectiveness. Papers published between 1 January 2012 and 23 March 2022 were included to search only recent articles. The EBSCO database was used for the search using the disease-specific search terms “dementia”, “Alzheimer’s”, “cognitive impairment” and “memory loss” combined with specific search terms to identify reviews of clinical effectiveness: “systematic review”, “effectiveness” and “non-pharmacological interventions”.

To ensure methodological rigour and transparency, the quality of reporting and risk of bias (RoB) in the included systematic reviews were assessed using the AMSTAR 2 tool, which had been developed by Shea *et al.* (2017). AMSTAR 2 is a validated instrument designed for use to appraise the methodological quality of systematic reviews of healthcare interventions. The findings from the included reviews were synthesised and presented narratively, allowing for a descriptive overview of the clinical effectiveness of community-based NPTs.

4.4.1 Inclusion/exclusion criteria

Inclusion criteria followed the participants, intervention, comparison, outcomes, and study (PICOS) criteria (Page *et al.*, 2021). These criteria were defined according to the following descriptions.

1. Population – PLwD/MCI.
2. Intervention – any NPT for MCI/dementia.
3. Comparison – control group which followed TAU.
4. Outcome – assessed effectiveness in terms of outcomes for PLwD/MCI.
5. Study design – systematic reviews or reviews of reviews.

To maintain a focused analysis on interventions that directly affected PLwD, reviews were excluded if they reported outcomes solely for caregivers. This ensured that the review remained centred on assessing the clinical effectiveness of interventions for the target population. Additionally, economic evaluations were excluded, as the primary objective was to examine clinical outcomes. However, it is acknowledged that some of the included systematic or other types of reviews may have incorporated economic data, these data which were not extracted or analysed within the scope of this review.

4.4.2 Analysis

Data extraction and analysis were conducted by a single reviewer, who independently extracted relevant information from each included review. The extracted data were organised and analysed using Microsoft Excel, focusing on key variables including number of primary studies included and the primary outcomes reported. Particular attention was given to the identifying the types of therapies that had been evaluated as clinically effective. These findings were then compared with the results of the published systematic review of economic evaluations (Chapter 3) to identify therapies that demonstrated clinical effectiveness but had not yet been subjected to formal CEA.

4.5 Results

The search strategy has been reported using a PRISMA (Page *et al.*, 2021) flow diagram (**Error! Reference source not found.**).

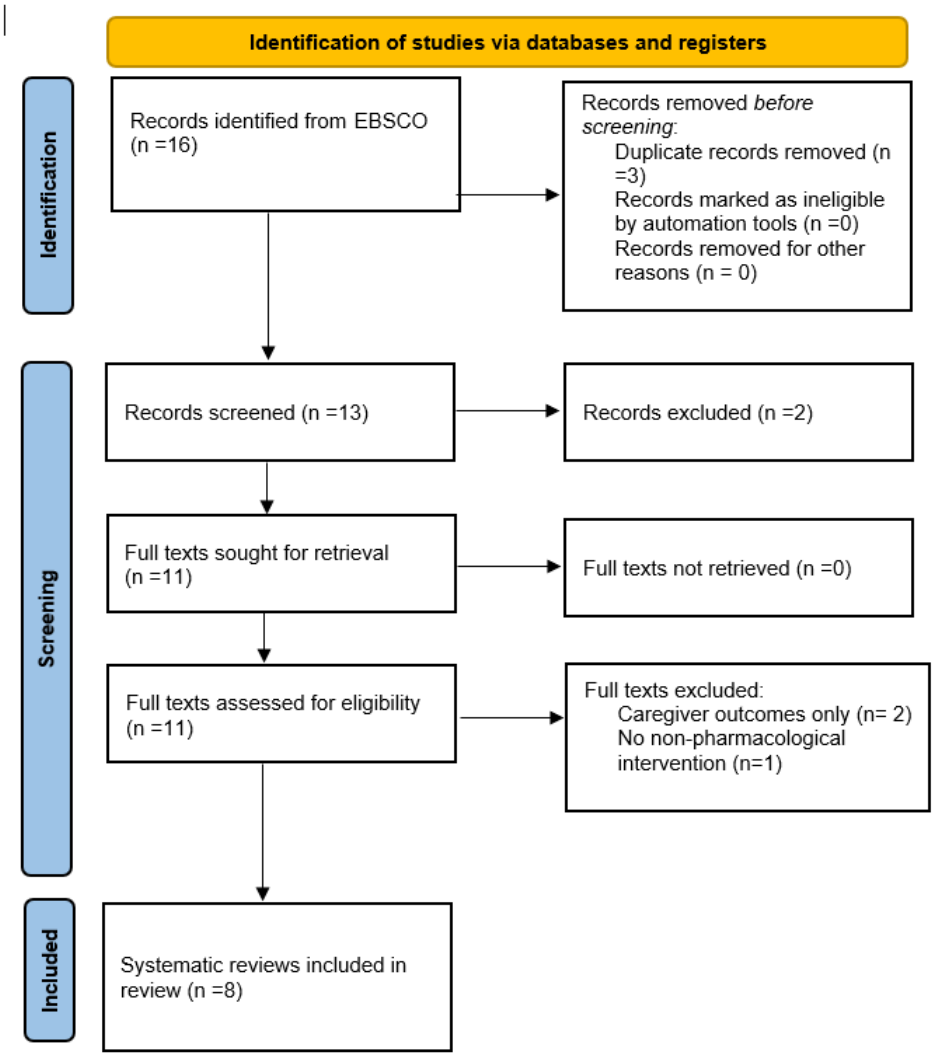


Figure 4.1 PRISMA flow diagram showing inclusion process of articles in the review of clinical effectiveness (Page et al., 2021)

A total of 16 systematic reviews were identified based on the predefined search parameters. Three papers were excluded: two papers were excluded as they focused on caregiver outcomes only (Jones, Edwards and Hounsome, 2012; Brooks *et al.*, 2018), a further paper was excluded as it reported only symptom-specific outcomes related to eating and mealtime functioning, and did not report the broader clinical outcomes required for inclusion (Li *et al.*, 2020). Following abstract screening, eight full-text articles met the screening criteria and were incorporated into the analysis. Of these, seven were systematic reviews, and one, by Cai *et al.* (2020), was a review of reviews. Three of the included reviews conducted meta-analyses (R. Lin *et al.*, 2021; Xu *et al.*, 2021, 2022). The study populations varied across reviews, five focused on

PLwD, two on individuals with MCI, and one on both MCI and mild dementia. Only one review explicitly stated that it examined community-based NPTs, while the remaining reviews did not specify the care setting.

The included reviews addressed a range of dementia symptoms, including apathy (Cai *et al.*, 2020), depression (Xu *et al.*, 2022), BPSD (Trivedi *et al.*, 2019; R. Lin *et al.*, 2021; Kouloutbani *et al.*, 2022), and quality of life (Cooper *et al.*, 2012). The number of primary studies included in each review varied considerably: nine (Cai *et al.*, 2020), 13-22 (Cooper *et al.*, 2012; Lin *et al.*, 2021; Kouloutbani *et al.*, 2022; Xu *et al.*, 2022), 48-50 (Trivedi *et al.*, 2019; Xu *et al.*, 2021) and 160 (Livingston *et al.*, 2014a). While most reviews examined a broad range of NPTs; two were more narrowly focused: one reviewed only physical exercise interventions (Kouloutbani *et al.*, 2022), while another concentrated on sensory, psychological and behavioural interventions specifically targeting BPSD (Livingston *et al.*, 2014a).

The AMSTAR 2 assessment revealed considerable variation in the methodological quality of the included studies, from high quality critically low quality. Two studies were rated as critically low quality due to significant methodological flaws that compromised their overall quality (Cooper *et al.*, 2012; Kouloutbani *et al.*, 2022), while three were rated low quality (Trivedi *et al.*, 2019; Cai *et al.*, 2020; Xu *et al.*, 2022). One review was assessed as moderate quality (R. Lin *et al.*, 2021) and two were assessed as high quality (Livingston *et al.*, 2014a; Xu *et al.*, 2021).

Table 4.1 Quality assessment of clinical effectiveness of systematic reviews using AMSTAR 2

Study	**Livingston *et al.*** (2014a)	**Xu *et al.*** (2021)	**Lin *et al.*** (2021)	**Trivedi *et al.*** (2019)	**Cai *et al.*** (2020)	**Xu *et al.*** (2022)	**Cooper *et al.*** (2012)	**Kouloutbani *et al.*** (2022)
1. Did the research questions and inclusion criteria for the review include the components of PICOS?	met	met	unmet	met	met	met	met	met
2. **Did the report of the review contain an explicit statement that the review methods had been established prior to the conduct of the review and did the report justify any significant deviations from the protocol?**	met	met	met	met	unmet	unmet	unmet	unmet
3. Did the review authors explain their selection of the study designs for inclusion in the review?	met	met	met	met	met	met	met	met
4. Did the review authors use a comprehensive literature search strategy?	met	met	met	met	met	met	met	met
5. Did the review authors perform study selection in duplicate?	unmet	met	met	met	met	met	met	met
6. Did the review authors perform data extraction in duplicate?	met	met	unmet	met	met	met	unmet	met
7**. Did the review authors provide a list of excluded studies and justify the exclusions?**	met	met	met	met	met	met	met	met
8. Did the review authors describe the included studies in adequate detail?	met	met	met	met	met	met	met	met
9. **Did the review authors use a satisfactory technique for assessing the risk of bias (RoB) in individual studies that were included in the review?**	met	met	met	met	met	met	unmet	met
10. Did the review authors report on the sources of funding for the studies included in the review?	met	unmet	unmet	unmet	met	unmet	unmet	unmet
11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	met	met	met	n/a	n/a	met	unmet	n/a
12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	met	met	met	n/a	n/a	met	unmet	n/a
13. Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review?	met	met	met	met	met	met	unmet	unmet
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	met	met	met	met	met	met	met	met
15. If they performed quantitative synthesis, did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	met	met	met	unmet	n/a	met	met	met
16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?	met	met	met	met	met	met	met	met
Overall rating	High	High	Moderate	Low	Low	Low	Critically low	Critically low

In the review, clinical effectiveness across the primary sources was assessed using a range of validated measurement instruments, each selected for its suitability to the specific outcomes being evaluated. These tools varied depending on the nature of the intervention and the characteristics of the target population, reflecting the methodological heterogeneity across studies. This approach enabled a comprehensive assessment of clinical effectiveness while also highlighting the diversity of outcome measures employed in the existing literature. One example of this is a systematic review by Livingston *et al.* (2014a) which evaluated the clinical effectiveness of NPTs for the management of agitation in older adults with dementia. Therapies involving touch, in particular, were found to be clinically effective in reducing agitation among care home residents (Livingston *et al.*, 2014a). Additionally, group-based interventions such as music, exercise, storytelling, and cooking were also associated with reductions in mean agitation levels.

Building on this, a review of reviews by Cai *et al.* (2020) focused on NPTs that were aimed at reducing apathy in PLwD (Cai *et al.*, 2020). The review identified several therapies that were clinically effective, including pet therapy and MT. Pet therapy showed relatively strong evidence for reducing apathy, with meaningful improvements in activity levels and emotional responsiveness (Cai *et al.*, 2020). MT also emerged as a particularly effective intervention, demonstrating relatively robust evidence across six studies. These studies highlighted improvements in mood, engagement and communication through both standalone and multi-sensory music-based approaches. The meta-analysis further confirmed that music-based interventions significantly reduced BPSD, with a moderate effect size (standardised mean difference [SMD] = -0.49, 95% confidence interval [CI]: -0.82 to -0.17) (Cai *et al.*, 2020). Subgroup analysis indicated that individualised music interventions were especially effective, with a larger effect size (SMD = -0.77, 95% CI: -1.50 to -0.04) (Cai *et al.*, 2020). The consistent positive outcomes across these studies support the clinical value of MT as a non-pharmacological approach in dementia care.

In addition to addressing apathy and agitation, several reviews examined the impact of NPTs on symptoms of depression in PLwD and individuals with MCI. Two systematic reviews (R. Lin *et al.*, 2021; Xu *et al.*, 2022) reported on the effectiveness of NPTs in reducing symptoms of depression. Physical activity was particularly beneficial for individuals with MCI (Xu *et al.*, 2022), while multi-modal interventions

combining cognitive, psycho-behavioural and educative components were effective at reducing levels of depression in individuals with pre-clinical and mild dementia (R. Lin *et al.*, 2021). These findings suggest that both targeted physical interventions and broad, integrative approaches can play a role in improving mental health outcomes in this population.

Cognitive function, particularly global cognition in adults with MCI, was the focus of another review by Xu *et al.* (2020). This review found that interventions combining physical exercise with cognitive stimulation, such as memory training, problem-solving tasks and attention exercises, were effective at improving cognition in older PLwD (Xu *et al.*, 2021). The dual approach of engaging both mind and body led to more significant cognitive benefits than either physical exercise or cognitive training alone (Xu *et al.*, 2021). This finding highlighted the value of integrated therapeutic strategies in dementia care.

Further evidence of the clinical effectiveness of NPTs was found in a systematic review by Cooper *et al.* (2012). It found that group cognitive stimulation in care homes improved quality of life for PLwD (Cooper *et al.*, 2012). This aligns with broader findings that structured group activities can enhance both cognitive and emotional well-being. Similarly, a systematic review of 48 RCTs by Trivedi *et al.* (2019) demonstrated that caregiver training and educational programmes improved BPSD in community-dwelling PLwD, underscoring the importance of caregiver involvement in therapeutic strategies (Trivedi *et al.*, 2019).

Finally, a review by Kouloutbani *et al*. (2022) which focused on physical exercise interventions found that behavioural symptoms were reduced in participants assessed using the Neuropsychiatric Inventory tool (NPI). These findings reinforce the role of physical activity not only in improving mood and cognition but also in mitigating behavioural symptoms associated with dementia (Kouloutbani *et al.*, 2022).

4.5.1 Economic evidence for clinically effective therapies

The therapies identified as clinically effective in this review were subsequently compared with findings from the economic evaluations presented in the previously published systematic review (see section 3.11.1). This comparison aimed to identify interventions that are not only clinically beneficial but also economically viable, thereby

supporting evidence-based decision-making in the development and implementation of community-based NPTs for dementia care. From the ten selected reviews, a diverse range of therapies were found to demonstrate clinical effectiveness, including sensory therapies (e.g., massage, multi-sensory stimulation), group activities (such as music, storytelling, and cooking), MT, multi-sensory stimulation, group CST, multi-modal interventions, pet therapy, physical activity, and training and education programmes for caregivers. The identification of these therapies provides a foundation for prioritising future research and investment in dementia care strategies that offer both clinical and economic value.

However, six of these therapies—sensory therapies, group activities, music, multi-sensory stimulation, group CST, and pet therapy, did not have corresponding economic evaluations that had assessed cost-effectiveness or cost-utility. In contrast, the systematic review of economic evaluations identified evidence of cost-effectiveness, measured in QALYs, for multi-component interventions (n=11) and training and education programmes for caregivers (n=4). Despite this, the number of economic evaluations for caregiver training was limited, highlighting a need for further research to determine their cost-effectiveness with greater certainty.

To better understand the implications of these findings, the clinically effective therapies were grouped based on the availability and strength of supporting economic evidence. The first group included therapies with either strong or limited evidence of cost-effectiveness. These were interventions for which economic evaluations had been conducted, even if the evidence base was small or methodologically constrained. This group consisted of maintenance CST, dementia care management, occupational therapy, and training and education programmes for staff in care or nursing home settings.

The second group comprised therapies that demonstrated clear clinical benefit but lacked sufficient economic evidence. In most cases, economic evaluations were either absent or too limited to draw meaningful conclusions. This group consisted of sensory therapies (such as art, music, and massage), group-based activities (including music, exercise, storytelling, and cooking), multi-component interventions, pet therapy, and training for family caregivers. The absence of economic data for these interventions

presents a gap in the evidence base and underscores the importance of research to evaluate their cost-effectiveness, particularly given their demonstrated clinical value.

4.6 Discussion

The findings of this review underscore the growing body of evidence supporting the clinical effectiveness of NPTs for PLwD. Interventions such as MT, exercise, and pet therapy have demonstrated positive outcomes across multiple domains, including reductions in BPSD, improvements in mood and engagement, and maintenance of cognitive function. These outcomes are particularly relevant given the limitations and side effects associated with pharmacological treatments, and therefore highlight the value of NPTs as safer, person-centred alternatives.

Despite the clinical benefits that have been demonstrated across multiple studies, there is a gap between evidence of effectiveness and the extent to which these interventions are economically evaluated and implemented in practice. Many therapies with strong clinical outcomes lack robust cost-effectiveness data, particularly model-based evaluations that can simulate long-term outcomes. As health systems continue to shift towards value-based models of care, it becomes increasingly important to integrate clinical and economic evaluations to ensure that therapies demonstrating effectiveness are also viable for long-term, sustainable implementation.

NPTs are generally well-accepted by PLwD and their caregivers, largely due to their non-invasive nature and alignment with person-centred care principles. Many PLwD perceive interventions such as music, exercise, and pet therapy as enjoyable and meaningful, and this perception contributes to their uptake in both residential and community settings. Their adaptability to individual preferences enhances engagement and supports a more personalised approach to care. However, practical challenges such as staff capacity, training requirements, and the need for consistent delivery can affect implementation and scalability.

Overall, the perceived benefits support the use of NPTs in dementia care. However, to realise their potential fully within health and social care systems, further research is required, particularly on cost-effectiveness through the use of robust, long-term evaluation methods. It will be essential to strengthen the economic evidence base in

order to inform policy decisions and ensure that clinically effective interventions are affordable, feasible, and deliverable across a wide range of care settings.

4.6.1 Limitations

A potential limitation of this review was the risk of publication bias, as the search was based primarily on published studies. Additionally, economic evaluations were excluded from this review, as their primary aim was to assess clinical outcomes. However, it is acknowledged that some of the included systematic or other types of reviews may have incorporated economic data. These data were not extracted or analysed within the scope of this review, which may limit the comprehensiveness of the findings in relation to the broader evidence base.

4.7 Conclusion

A review of published reviews on the clinical effectiveness of NPTs for PLwD was conducted. Several NPTs were shown to be clinically effective for PLwD, such as MT, exercise, and pet therapy across a range of outcomes. Reported benefits included reductions in BPSD such as apathy and agitation, improved engagement, decreased symptoms of depression, and either a delay in cognitive decline or maintenance of cognitive function.

The findings of this review highlight the potential of NPTs to deliver meaningful clinical benefits for PLwD and to support person-centred approaches to care. However, the lack of economic evaluations, particularly model-based analyses, presents a barrier to informed decision-making and large-scale implementation. As healthcare systems face increasing pressure to allocate resources efficiently, there is an urgent need for high-quality studies that evaluate both the clinical and cost-effectiveness of these interventions. Addressing this gap is critical to the advancement of evidence-based, equitable, and sustainable dementia care. This thesis aims to address this need by examining the economic value of specific NPTs, with a particular focus on outcomes for PLwD.

4.8 Chapter summary

The clinical effectiveness review that is described in this chapter identified several therapies that demonstrated clear clinical benefits for PLwD. Alongside the findings from the systematic review of economic evaluations (Chapter 3), these results informed the development of a list of therapies that showed either strong clinical effectiveness or highlighted a need for further cost-effectiveness research. This combined list formed the basis for the design of an online survey, aimed at identifying research priorities among people with lived experience of dementia.

Chapter 5 outlines how this survey was designed. It begins with a description of the role of PPI in the refinement of the online survey. This is followed by a discussion of survey methodology and a presentation of the results.

Chapter 5 Involvement of PLwD, caregivers and professionals to inform the selection of NPTs for economic modelling

5.1 Introduction

This chapter is set out in two parts. In the first part, the involvement of a group of patient and public involvement (PPI) contributors in the refinement of a survey to determine the research preferences of people with lived experience of dementia is discussed. The term *people with lived experience of dementia* is used here to refer to individuals who are living with a dementia diagnosis, as well as their family members or caregivers who are directly affected by the condition. This section outlines the methods used to engage PPI group members, describes their roles and contributions, and provides an overview of the meetings held with the group.

The second part of the chapter presents the methodology and findings of the online survey, which was used subsequently to identify the research priorities for the modelling component of the thesis, as detailed in subsequent chapters.

5.2 PART A: Survey development using PPI

5.2.1 Patient and public involvement

PPI promotes the principles of the phrase ‘Nothing about us without us’, which has been used for many years by disabled people’s organisations as part of a global initiative to ensure that people with disabilities are involved in consultation processes about new strategies and policies that affect them. The slogan was adopted by the Alzheimer’s Society in 2018 and applied to dementia research (Alzheimer’s Society, 2018). The aim was to end the exclusion of people with disabilities and to increase advocacy and involvement by the public and affected people in dementia research.

The term PPI is applied to the process of involving people with lived experience of an issue in all aspects of the research process, so that they contribute as more than research participants (Arumugam *et al.,* 2023). Funders increasingly require researchers to use PPI to ensure research integrity and reduce wastage, which can

occur because of irrelevant research questions and the conduct of unnecessary or inappropriate research studies. Biggane *et al.* (2019) summarised this issue. Evidence shows that PPI can improve healthcare decision-making and ensure that the healthcare system is people-focused (Pizzo *et al.,* 2015). Gove *et al.* (2018) published a paper in collaboration with the European research network Early Detection and Timely Intervention in Dementia and the European Working Group of People with Dementia, which summarised Alzheimer Europe's position on active involvement of PLwD in PPI initiatives. It emphasised that people with lived experience can provide valuable insights to improve relevance and impact. It provided recommendations for achieving meaningful PPI involvement, which included adaptation of communication methods, ensuring the use of accessible formats for meetings, provision of training if necessary and involvement of PLwD from the early stages of a project. The guidelines were used in the design of the PPI involvement for this thesis and are discussed more in section 5.2. The Alzheimer Europe approach to PPI was selected for its strong commitment to ethical inclusion, empowerment, and co-production with people who have lived experience of dementia. Alzheimer Europe promotes meaningful engagement that goes beyond tokenism and advocates for involvement in priority setting, research design, data interpretation, and dissemination (Alzheimer Europe, 2021).

The involvement of people with lived experience, in research of a related issue, is an essential component of health research nationally and internationally. It can improve the quality, relevance and impact of the research and improve its transparency (Brett *et al.*, 2017). It involves a collaborative, co-working/design process in which members have collaborative relationships (Walter *et al.*, 2024). Tasks undertaken by public contributors in PPI activities can include participation in steering groups, developing and advising on research materials, undertaking interviews, analysing data and engaging in the dissemination of findings. Throughout this thesis, the term 'public contributor' is used to describe members of the public who are actively engaged in PPI activities.

It is widely acknowledged that a gold-standard model of PPI activity starts with involvement as early as possible in research processes and contributes to the generation of research ideas and priority setting (Dews *et al.,* 2023). It is recommended that discussion with the PPI group around tasks, expectations and

support that is offered is an important part of undertaking PPI with PLwD (Gove *et al.,* 2018). PPI has been used successfully in health economics in terms of setting priorities, determining research questions and identifying approaches to the collection of outcomes, as summarised by Al-Janabi *et al.* (2021).

Gove *et al.* (2018) recommended that expenses for PPI group members should be covered. The NIHR provides guidance regarding payment of PPI contributors and states that it is good practice for organisations to cover any expenses and to offer payment (NIHR, 2024a). Current NIHR guidelines on payment for PPI activities have recently increased the payment recommendation to £25 for involvement in a task that involves little preparation and takes approximately one hour (NIHR, 2024b). It is recommended that acknowledgement of the contribution of PPI involvement should be fair, open and appropriately acknowledged (Gove *et al.*, 2018).

As PPI becomes more central to health research, there is a growing focus on the incorporation of wider outcomes and societal perspectives into economic models (Banner *et al.*, 2019). This shift shows a move toward more holistic, person-centred approaches to how healthcare interventions are valued, and recognition that efficiency must be balanced with equity, ethical considerations, and real-world impact. In this thesis, a group of people with lived experience informed the development of the survey that aimed to determine the research preferences of survey participants. The approach to PPI adopted in this thesis was informed by insights from published literature on meaningful engagement in dementia research.

5.2.1 Involvement of people with lived experience in the survey development

People with lived experience of dementia and MCI formed a PPI group that would inform and refine a survey to determine the research preferences of participants. As the PPI activities were advisory in nature and group members did not participate in the survey itself, these activities were considered outside the scope of formal research. Therefore, ethical approval was not required for their involvement.

The aim was to involve a group of people with lived experience of dementia in the development of a survey that would be used to set the priorities for the research and

to help inform the choice of NPTs for economic evaluation. The group was involved in the decision-making processes and throughout the survey.

5.2.2 Formation of the PPI group

An advertisement was placed on the Dementia Engagement and Empowerment Project (DEEP) website asking for people to volunteer to be involved in the PPI group (see Appendix 3.1). DEEP is a UK support network of people with lived experience of dementia/MCI, and many become involved in research and campaigns to raise awareness of dementia (DEEP, no date). The advertisement was approved by the team at DEEP and was displayed on its website as an opportunity to become involved in the project. A self-selection process was used; people who responded to the advertisement were sent further information and then invited to an initial online meeting to discuss the project and the public contributor role. A brief, plain-language summary of the survey and anticipated tasks was sent to those who expressed an interest in being in the PPI group (see Appendix 3.2). It was estimated that PPI members would each participate for about four-to-six hours, but in discussion with the PPI contributors, it was agreed that this could be reviewed as necessary.

The NIHR ARC team was consulted to determine the appropriate payment for PPI activities, and £20/per hour was suggested, which was the recommendation at the time. Funding for PPI activities had not been factored into the original project. Funding was secured from the Institute for Lifecourse Development at the University of Greenwich to cover the cost of shopping vouchers as a proxy payment to PPI group members to thank them for their time and help on the project.

5.2.1 Demographics

The PPI group comprised four members: three PLwD and one spousal caregiver. The demographics of the group were males (n=2), females (n=2). The age range was 67-80 years of age. All were White British. A variety of different dementia diagnoses were present: AD (young-onset) (n=1), dementia (n=1), mixed dementia (n=1), no dementia (n=1).

The demographics of the contributors met the national standards for PPI, which state that a diverse range of participants and people new to research and PPI should be included (NIHR, 2019). All group members were Caucasian and lived in the Southeast

of England. People with different dementia diagnoses were represented within the group as explained in the preceding paragraph. Each group member was at a different stage of dementia. It became apparent from observation of interactions among group members during the meetings that the level of cognitive function also varied between individuals.

The level of previous research experience also varied among the group members. Two members had been very research active; they had volunteered as part of advisory groups and given talks at local universities and conferences nationally and internationally. The other two group members did not have experience of being in research project advisory groups. The group members brought a mixture of life skills and experiences to the project, which was very valuable. It was important to include a range of people in the PPI to meet the first UK standard for PPI: to provide inclusive opportunities for PPI. This was important to ensure that the project was reviewed by people who had different diagnoses and levels of cognition and who might face different cognitive challenges and therefore have differing perspectives. One group member needed a lot of support during meetings, while another provided a lot of support to the other group members both inside and outside meetings. By getting to know the members of the group it was possible to see that between them they had a mixture of past and present experiences and circumstances such as occupation, marital status and diagnosis, all of which helped to ensure a good representation of PLwD within the group.

5.2.2 Planning PPI activities

Group members were involved in the review and development of the survey. The initial plan for the project had not included a survey or PPI involvement. Consequently, group members did not become involved until after the initial survey design stages. However, as the project progressed, the PPI aspect was integrated and PPI group members advised on the research, and despite late inclusion, PPI greatly enhanced the project.

The UK Standards for Public Involvement in Research, published by the NIHR, were applied to shape the design of the PPI work and enabled reflection on the processes (NIHR, 2019). The six standards are: inclusive opportunities, working together, support and learning, governance, communication, and impact. The standards provide guidelines for achieving effective PPI and an appraisal tool that can be used to reflect

on which areas work well and where there is scope for improvement. The standards are designed to be used by PPI group members and researchers.

5.2.3 Roles and responsibilities

The project was supported by the NIHR ARC, which is committed to involving members of the public in research and to the co-production of research. A local PPI coordinator from ARC was consulted to advise on suitable activities for the PPI group. This coordinator offered insight and experience on how this had worked well previously within an NHS research setting. They offered expert advice on the recruitment of PLwD, rates of payment to PPI group members, and suitable tasks for involvement. Initial tasks agreed upon for the group involved a review of survey materials to ensure suitability for participants.

Participation as PPI contributors was designed to be meaningful and impactful for participants and researchers rather than tokenistic and should include opportunities for learning and training (NIHR, 2019). To support this, the project adopted the principles of Arnstein's Ladder of Citizen Participation (Arnstein, 1969). This conceptualises eight levels of citizen involvement, ranging from non-participation to full citizen control. The group was encouraged to take a lead in the planning and format of the meetings reflecting higher engagement on the ladder. The opportunity for support and learning opportunities for the PPI contributors was discussed with the group, with a plan to involve them later in the project with dissemination tasks, including the writing of lay summaries and participation in conference.

5.2.4 PPI meetings

The author led the PPI group and was the main point of contact for the group members. Potential barriers to involvement were identified, which included accessibility of meetings, payment for time spent on the project and information sharing. Choice and flexibility were incorporated wherever possible to limit these barriers. Possible locations and formats of meetings were explored with the group members. Despite the close geographical proximity of the group members and the researcher, the contributors declined to meet in person and stated a preference for online meetings, which they found easier. Members may also have been reluctant to meet in person because the COVID-19 pandemic had only recently subsided and some members may

have been concerned about the risk of infection. As a result, a joint decision was made to hold all meetings via the Zoom online platform. Each session lasted one hour and included a short break midway to support engagement and comfort.

Accessibility of meetings and communications was important to ensure that they were inclusive for all group members. The members set the pace of the meetings. Documents were made available ahead of meetings, and what would comprise adequate thinking time was discussed, and this was provided. The option of sharing documents on screen during meetings was discussed but members declined this as they had found such sharing hard to follow when working on previous research projects. Instead, they preferred email communications so that they could browse information in their own time. It was recognised that members of the group had individual needs, and it was important that the group was inclusive. It was important that members were asked for input on how PPI interactions could be made accessible and effective in order to ensure equal access (Walter *et al.*, 2024).

The first meeting was spent getting to know the group members. Roles, responsibilities, and expectations about what the group could be expected to influence were discussed. There was no expectation that people would share personal details or experiences. However, people spoke openly and volunteered their personal stories and experiences of dementia. Sharing of personal stories has been shown to be a primary motivator for taking part in PPI (Park, Grill and Ameli, 2023).

The group members had already formed good relationships with each other prior to joining the project. They already knew each other through their meetings at DEEP and were happy to chat. Group members offered personal information such as their ages, diagnoses, and personal information about their dementia journeys. They verbally consented to the sharing of their demographic information in this project. Members discussed any previous experience of working on research studies and whether they had experience of using dementia therapies. Everyone who attended this initial meeting subsequently agreed to become a public contributor. Group members were informed that they were free to leave the group at any time, in line with recommendations (Gove *et al.*, 2018).

After the first meeting, members were emailed a link to the draft of the online survey, which they could test and review. The survey had been approved by the University

Research Ethics Committee (UREC; approval reference: UREC (no reference number assigned)) and was then sent to the PPI group for refinement and feedback. This step was important to understand whether people with lived experience of dementia found the survey accessible and to gather their feedback. A date was set for the next meeting at which group members would give their feedback on the survey.

Next, the group set up its own online meeting, without the researcher, to discuss the members' reviews of the survey. They then held a second meeting with the researcher to give their feedback as a group. The group members had tested the online survey by completing it via a separate survey link; these survey responses were later deleted. It is common for PPI contributors to review and test surveys in this way before distribution (Gove *et al.*, 2018; Price *et al.*, 2018). Meeting notes were documented, capturing discussions and decisions made during meetings.

5.2.5 Engagement and reimbursement

A newsletter was designed and emailed to the group members to share progress and findings (Appendix 3.3). The newsletter detailed a link to the published systematic review paper (contained in Chapter 3) and gave details of the results of the survey and plans for the next phase of the project.

PPI contributors spent in the region of three hours each on the project and were offered £ 60 worth of shopping vouchers each for their involvement. The vouchers were sent to group members to thank them for their time after completion of the survey reviews and were gratefully accepted. Participants were asked if they had incurred any expenses because of taking part, as these could be reimbursed, but as meetings had been conducted online, no members requested a claim for additional expenses.

5.2.6 Reporting and transparency

Research shows that in many research papers, PPI work is not well reported or is lacking in detail (Brett *et al.*, 2017). The lack of adequate reporting on PPI activities hinders future learning and can lead to research wastage (Biggane, Olsen and Williamson, 2019). Research waste can occur because of inefficient use of resources through poor study design, inadequate reporting, lack of transparency, or failure to publish findings (Biggane, Olsen and Williamson, 2019). These issues may all prevent future researchers from learning from past efforts, and this leads to duplication of work,

missed opportunities for improvement, and wasted time, money, and effort. There is a need to strengthen the PPI evidence base through the use of appraisal and reporting strategies to inform the understanding of the research community on effective working practices and potential costs and benefits of PPI activities (NIHR ARC North-West Coast, 2020). Several tools can be used for the reporting and evaluation of PPI activity in research, which include:

- The Public Involvement Impact Assessment Framework (Popay and Collins, 2014).
- Guidance for Reporting Involvement of Patients and the Public (GRIPP2) (Staniszewska *et al.*, 2017).
- The Public Involvement in Research Impact Toolkit (Marie Curie Research Centre, 2023).

The GRIPP tool was developed for the reporting of PPI involvement in health and social care research to improve PPI activities by sharing best practice with researchers in a clear, transparent way (Staniszewska *et al.*, 2011). The updated, GRIPP2 short version of the form was used to evaluate and report PPI in this project (Table 5.1). This follows recommendations that the short form be used to evaluate PPI in research in which PPI is not the primary focus (Staniszewska *et al.*, 2017). All points in the tool have been addressed and discussed in this chapter.

Table 5.1 GRIPP2 – Short form

Section and topic	Item
1. Aim	Report the aim of PPI in the study
2. Methods	Provide a clear description of the methods used for PPI in the study
3. Study Results	Outcomes – Report the results of PPI in the study, including both positive and negative outcomes
4. Discussion and conclusions	Outcomes – Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects
5. Reflections/ critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience

5.2.7 Impact of PPI on survey

The PPI group gave valuable feedback, which was used to refine the survey. This process is described in section 5.2.9. Feedback was then provided to the group about the impact that their ideas and contributions had provided on the survey design and the project. This took place both verbally and in written emails. Individuals were specifically thanked for their individual feedback and reference made to how their ideas had been implemented to amend and improve the survey.

5.2.8 Challenges encountered

The aim was always to involve the group more fully in the project as it went on, delegating power by having them assume responsibility for project tasks. It was challenging to retain group members and to keep their enthusiasm over the three-plus years of the project, and these issues contributed to a lack of work on the project after the survey review by the group. This may also have reflected possible decreases in cognition or increases in symptoms for some group members.

After the initial review of the survey, the group became less engaged. Delegation of further tasks would have involved the provision of economic training for PPI contributors. Considering the nature of the project and the demographics of the PPI contributors, this was not done, but the provision of training would be a consideration in future research projects.

On reflection, the provision of the shopping vouchers to group members after they had reviewed the survey may have seemed to members to signify the end of their involvement in the project. It proved more difficult to re-engage the group after this point. Engagement would be an important consideration in future PPI co-production projects. Previous research has shown that involvement and engagement of PPI contributors are essential components of success in economic evaluations (Al-Janabi *et al.*, 2021).

Initially, the aim was to ask opinions only of PLwD, with the spousal caregiver providing a supportive role to assist their spouse as required. However, as the project progressed, they became more involved with the project and offered extremely useful feedback on the draft survey based on their lived experience of dementia. They also received shopping vouchers to thank them for their time spent on the project. The

invaluable contribution of the PPI contributors has further been acknowledged verbally, in a recent poster presentation and at conferences with the agreement of the group members. Although PPI contributors have not yet presented at conferences, this remains a possibility for future dissemination activities.

5.2.9 Discussion

The survey was significantly improved by the involvement of the PPI group. Other studies have similarly shown that the involvement of a PPI group can improve trial design and the quality of study documents for participants (Crocker *et al.*, 2018). Although the PPI group was not involved from the start of the project, it still provided a valuable impact. A study by Walter *et al.* (2024) stated among its recommendations that it was never too late in a project to start PPI involvement.

The PPI contributors played a vital role in shaping and enhancing the project survey by offering insights grounded in lived experience. Their involvement significantly strengthened the research, despite some acknowledged limitations.

5.3 Part B: Survey methods and results

A survey was developed to determine the intervention preferences of people with lived experience of dementia. This was then used to inform the priorities for the modelling component of the thesis. Involvement of people with lived experience in dementia in research and understanding their perspective may not only help to improve the acceptability and design of interventions, it may also demonstrate the potential acceptability of interventions to participants in the interventions, which is critical for the success of such therapies and may improve adherence and outcomes (Kaltenthaler *et al.*, 2008; Qiu *et al.*, 2019).

5.4 Aim

The aim of the survey was to determine which types of interventions participants most wanted to see further research on. Survey participants were PLwD, caregivers, and people working in dementia services. The survey development was informed by a PPI group whose members had lived experience of dementia (see section 5.3).

5.5 Methods

5.5.1 Sampling frame and recruitment

Participants were recruited for the survey through voluntary sampling. There were several reasons why this method was chosen for this project.

- It is quicker, easier, and more economical than other methods (Rodriguez-Gomez *et al.*, 2015).
- It enabled the recruitment of individuals from different geographical areas to reduce geographical bias.
- Its use ensured that responses were not dominated by participants from one local area or group. Several interest groups, such as art and music clubs, invited the researcher to attend meetings to speak to potential respondents about the project; these were declined as this could have biased the results favourably towards these specific therapies, especially bearing in mind the small numbers of people that were required for the survey.
- Its use enabled participants to take as much time as they needed to answer questions in their own time, across multiple sessions if necessary. This takes their various cognitive needs/caring responsibilities into account.

However, as the sample is non-probabilistic, it may not be representative of the general population and external validity may be low.

5.5.1.1 Inclusion/exclusion criteria

Three groups of participants were included in the survey:

1. PLwD;
2. family caregivers; and
3. people working in dementia (paid caregivers or people working for dementia organisations).

These groups were chosen to ensure inclusion of people with a range of lived experiences of dementia and the views of professional caregivers and people from dementia support organisations. Caregivers could have past or present caring responsibilities. Inclusion/exclusion criteria are stated in Table 5.2.

Table 5.2 Inclusion/exclusion criteria of the three participant groups

People living with dementia	Family caregivers	People working in dementia
Aged over 18 years	Aged over 18 years	Aged over 18 years
Living with dementia or MCI (formal diagnosis not needed)	Family caregiver of a person living with dementia (current or past)	Professional caregiver or working with PLwD in support capacity (excluding clinicians and NHS health professionals)
Any dementia severity	N/A	N/A

To maximise diversity, no dementia-specific criteria were applied to the PLwD participants. To take part, individuals needed to self-identify as a person living with dementia, but did not need to have a formal dementia diagnosis. Participants had to be aged 18 years or over. The survey for people working in the field of dementia was aimed at paid caregivers or people working for dementia support organisations or similar. The survey was open to participants living anywhere in the world.

5.5.1.2 Informed consent

The participant information sheet and consent form were produced as one document. They formed part of the survey and explained the aims of the survey. Those for PLwD and caregivers are shown in Appendix 2.1, for people working in dementia are shown in Appendix 2.2. A separate consent form was initially considered but rejected to avoid overburdening participants and to ensure anonymity. Consent to take part in the survey was implied by participation after the participants had reviewed the consent eligibility statements. Six eligibility statements were included at the beginning of the survey:

- I am aged 18 years old or older
- I have read the above information about this project
- I have had an opportunity to ask questions and discuss this project
- I have received satisfactory answers to all my questions
- I have received enough information about this project
- I agree to take part in this project

If potential participants did not agree to all statements, they were prompted to review their answers. If they continued to disagree, they were directed to the end of the survey, where they were thanked for their time and interest.

The General Data Protection Regulation (2018) provides guidelines for anonymising personal or identifying data (UK Government, 2018). However, this survey was completed anonymously. There is no requirement for participants to be able to withdraw their data from anonymous surveys. Participants were informed that they would be unable to withdraw from the information about the survey, and again at the end of the survey, before they submitted their final answers. They were informed that they could stop the survey at any time by closing the internet browser if they did not wish to continue. The decision not to allow withdrawal was taken after consideration of the participant population; it was felt that asking PLwD to create unique identifiers to withdraw their data might be a confusing additional step. It was decided that, if it were clear from responses that participants had not completed the full survey, it would be assumed that consent had been withdrawn, and responses would be deleted.

5.5.1.3 Recruitment

Survey participation was voluntary and anonymous, with no identifiable data collected. Only the minimum amount of data required for the project was requested from participants. Participants were directed to cast a vote by selecting the therapies that they felt were important to them. No incentive was offered for taking part. Participants were asked to choose which NPTs they wanted to see more economic research on by selecting from a list. By asking people to state which therapies they most wanted to see research on, the survey also aimed to determine the acceptability of different therapies.

Recruitment targets for survey participants were pre-determined at 20 PLwD, 20 family caregivers and 10 people working in dementia services. As the purpose of the survey was to inform the priorities for the project, it was deemed appropriate to sample a small number of participants' opinions. The opinions of PLwD and family caregivers were prioritised for this project, and this is why recruitment targets were higher for these categories.

Four non-NHS organisations acted as gatekeepers, raising awareness of the survey to staff and PLwD without the researcher having to make direct initial contact. The

organisations involved were DEEP, Alzheimer Europe, Dementia Support and Know Dementia. These were selected because they were organisations that had established contact with the NIHR and it's Living Well with Dementia theme. As recruitment was not carried out through NHS organisations, specific NHS ethical approval was not required. Links were established with local members of these organisations , and they provided valuable advice throughout the project. By having these organisations involved in recruitment, the diversity of the potential participant pool was widened.

Social media was used to distribute the survey advert. The survey link was not publicised due to the increasing problem in research of online surveys being completed by internet bots, despite the built-in protection that is offered by survey platforms (Griffin *et al.*, 2022); this is more of a problem with surveys that offer an incentive for completion. Alzheimer Europe is a non-profit organisation that represents many national AD organisations. They work to improve the lives of PLwD by developing national dementia strategies, raising awareness, supporting PLwD and connecting Alzheimer's associations across Europe (Alzheimer Europe, 2021). Alzheimer Europe posted a notification of the survey on its Twitter page and interested participants could email the primary researcher for more information. The survey post was also reposted many times to increase the reach of the project and the potential participant pool.

Know Dementia is a Sussex-based dementia charity that offers advice and support to families, care partners and PLwD. It took a different approach and included a paper copy of the survey advert with its quarterly newsletter. Staff from Know Dementia distributed these and signposted PLwD and their caregivers to the survey. The staff were also able to take part in the survey as people working in dementia. By combining these two recruitment strategies, one using a paper copy of the leaflet and one using X (formerly Twitter), it was possible for the researcher to reach a wide population of PLwD, caregivers and people working in dementia.

The completion rate was monitored and reviewed weekly. The recruitment of PLwD and family caregivers was slow after four months. Therefore, it was decided to use an additional recruitment method to reach a wider number of potential participants. Join Dementia Research (JDR) is a database of people who have registered their details on the database to state that they are interested in taking part in dementia research

and are willing to be contacted with any suitable studies. If PLwD did not wish to be contacted directly about research opportunities, they were able to nominate a friend or relative as a primary contact.

The survey opportunity for caregivers and PLwD was opened on JDR, and individuals could see an explanation of the survey and email the project team if they were interested in taking part. The inclusion/exclusion criteria were stated, and the survey was only visible to people who met these. Specific postcode areas were chosen for inclusion, which enabled management of the number of responses. Postcode areas were chosen to represent a geographical spread across the UK. To boost the recruitment of PLwD, the geographical scope of the survey was wide.

Records of potential participants who met the inclusion criteria were manually screened on JDR. People were then contacted by their preferred method of contact to see if they were interested in taking part. Interested participants were emailed the link to the relevant survey. Efforts were made to ensure that potential participants from different ethnic groups were able to take part in the surveys. JDR was used to include postcodes purposely where there were large ethnic minority populations. During screening, attempts were made to engage participants from ethnicities other than White British in order to increase the ethnic diversity of responses. Direct emails were sent to English-speaking contacts of potential participants and offers were made to translate the survey if this was appropriate.

Attempts were made to enable PLwD who had moderate or severe symptoms to have their views represented in the survey. For instances in which a person with dementia had nominated a friend/relative as a primary contact and was living in a care home, suggestions were made regarding how the friend/relative could facilitate survey completion. It was suggested that the friend/relative could take a tablet or laptop into the home when they next visited to help the participant complete the survey if appropriate. Another suggestion was that staff at the care home could help to arrange a telephone call with an interested potential participant so that they could complete the survey over the telephone with help from the researcher. An additional question was incorporated into the survey that asked whether participants were completing the survey on behalf of a person with dementia, so that the views of PLwD could be recorded even if they were unable to complete the survey themselves.

Recruitment took place over nine months between November 2022 and July 2023 and was closed when the recruitment targets were reached. Recruitment of people working in dementia services was completed in March 2023 and recruitment of caregivers and PLwD was completed in July 2023.

5.5.2 Survey design and development

An online survey was designed using the internet-based survey platform Qualtrics. Online surveys have been used successfully in previous research with PLwD (Darlington *et al.,* 2021; Mayrhofer *et al.,* 2021; Tam *et al.,* 2021). Online surveys are commonly used in research and are a convenient way to collect data. They are inexpensive to produce, and quick, easy, and convenient for participants to complete. Online surveys also allow participants to take part anonymously and are a useful way to reach groups of people who are hard to access because they have difficulty travelling to the site of an in-person survey or finding time to do so.

A multi-stage process of development, refinement, and testing was used to develop the online survey. The performance of the included items was tested and modified based on feedback from the PPI group of people with lived experience of dementia.

First, the results of the systematic review and the review of effectiveness were combined, and from this combination, a list of potential dementia therapies for further cost-effectiveness research was formulated for use in the survey. The survey was drafted by the researcher and then improved through consultation with the PPI group as described in section 5.2 Part A. Feedback from the PPI group was used to improve the survey format and design. The main feedback from the PPG group on the first draft of the survey was that it was lengthy, and the amount of text might overwhelm PLwD. As a result, a modified survey version was designed for PLwD and family caregivers. This version was specifically tailored to their needs. Other changes made because of feedback were to the layout and appearance, to improve readability and ease of understanding. The survey was then sent to the UREB for approval of the amendments. The group members then completed a draft of the amended survey. Their feedback at this point was that the survey was much improved and was ready to distribute. Their responses to the survey were deleted and were not included in the data analysis.

Based on the input of group members, an option to complete the survey via a telephone call or online meeting was introduced. This option was added to offer additional support from the researcher if this was necessary, by explaining the survey and assisting with its completion if necessary. This allowed participants who might face challenges with completing an online survey, due to cognitive or other difficulties, to participate. One group member emphasised the importance of offering this option. They highlighted that it would be unfair to expect participants to rely on caregivers or family members for assistance if they needed help completing the survey, and they should be empowered to take part without caregiver support if they wished.

The final survey design for PLwD and caregivers is shown in Appendix 2.3. The final survey for people working in dementia services is shown in Appendix 2.4. The surveys listed a choice of NPTs, and participants indicated which they would like to see further research on based upon their previous experience/knowledge. The surveys captured basic demographic information for PLwD and caregivers only. The online survey format enabled the reach of the survey to extend outside the UK.

Consideration was given to the use of appropriate language during the design of the survey. The Dementia Knowledge Centre at the Alzheimer's Society was consulted about appropriate language to use. They advised that the preferred terms to use when referring to people with dementia and caregivers were ‘people with dementia’ and ‘family caregivers’. The term ‘family caregiver’ has been used throughout to refer to all informal caregivers, including unrelated caregivers, e.g., neighbours or friends. Advice was also taken from the Positive Language Guide on the Alzheimer's Society website. Careful attention was paid to the wording of the survey, which was written using lay terms to aid comprehension. The addition of qualitative questions to the survey was considered but discounted as qualitative responses were not necessary to answer the project’s research questions.

5.5.2.1 Therapies included in survey

The list of NPTs was identified from the systematic literature review and the review of effectiveness, as detailed in Chapter 3 and Chapter 4. The categories of therapies included in the survey were:

- multi-modal sessions: memory training, peer support, positive thinking, and education;
- dementia care management;
- exercise;
- combined therapies: art, music/singing;
- maintenance CST: puzzles, games, discussions of events;
- group activities: cooking and storytelling;
- occupational therapy;
- pet therapy;
- sensory therapies: massage, art, music;
- training and education programmes for family caregivers; and
- training for staff in care homes and nursing homes.

Short explanations about therapies were included in the survey where necessary. At the end of the survey, participants were signposted to the contact details of dementia organisations that could provide support and information.

5.5.3 Data analysis

Survey data were analysed by exporting results from Qualtrics into Microsoft Excel. The data were then cleaned to remove any responses that did not meet the inclusion criteria and surveys with incomplete responses. The data were analysed in Excel as this was most appropriate for the size of the dataset. Descriptive statistics were used to summarise the characteristics of the dataset. The small sample size meant that in-depth analysis was not feasible. The results of the voting were analysed by calculating and then ranking response frequencies for each therapy.

5.5.4 Ethical considerations

The UREB approved the ethics application for the project, including the online surveys, before participant recruitment commenced (REF: UREC, see Appendix 1.1). This project was supported by the NIHR ARC Kent, Surrey and Sussex network. PLwD are classed as a potentially vulnerable population who may face cognitive challenges, and therefore, inclusion of them in the survey population required careful consideration of ethical implications. To address the issues of potential vulnerability, the survey was highlighted to potential participants by means of dementia support organisations that

acted as gatekeepers, rather than initial contact being made directly by the researcher. Gatekeepers can play a significant role in research by facilitating researchers' access to potentially vulnerable, socially excluded, or hard-to-reach groups of people (Emmel *et al.*, 2007). In cases in which participants requested help to complete the survey over the telephone, the participants' capacity was assessed by the researcher, using provisions of the Mental Capacity Act 2005 (Mental Capacity Act, 2005). The researcher checked for capacity by ensuring that the potential participants understood the project and the consequences of taking part or refusing. Their ability to retain, weigh up, and use the information being given was checked through sensitive questioning. Finally, a check was made to clarify their decision about taking part and the researcher proceeded with the questionnaire only if the participant provided consent. The principles of the Mental Capacity Act (2005) advise that a person should be assumed to have the capacity to decide for themselves unless proved otherwise. Supervisors were available to discuss any safeguarding concerns during the survey process; however, no concerns were raised.

5.5.4.1 Ethical amendments

The UREB approved an application for a minor amendment in February 2023 (REF: UREB/, Appendix 1.2). The purpose of this was to refine the survey for PLwD and caregivers following feedback from the PPI group. This enabled the amendment of existing survey questions and the survey design along with the addition of demographic questions. An option to allow the survey to be carried out by telephone as well as online was added. Self-reported disease severity of PLwD was included as an additional question. This was a multiple-choice question, which enabled them to select their perceived stages of dementia from mild to severe. Other additional demographic questions enabled collection of age, gender, and ethnicity data for PLwD and family caregivers. These additional demographic questions were aimed to provide greater potential for data analysis and understanding of the therapy preferences of distinct groups of individuals. All demographic questions were optional and could be skipped if the participant did not wish to answer. One person had completed the caregiver survey and three PLwD had completed their survey at this point, so some demographic data were missing. All demographic questions were optional and could be skipped if the participant did not wish to answer, and this addition did not significantly affect the results. An additional question for caregivers asked if they were

completing the survey on behalf of someone else, and if so, whether the responses reflected the views of themselves or the person with dementia. The amendments were implemented after data collection had started. Another non-substantial amendment was submitted in March 2023 to add JDR as a source of recruitment for caregivers and PLwD (Appendix 1.3). This was due to recruitment being slower than anticipated.

The final survey format for family caregivers and PLwD contained 18 questions, which were broken down into shorter questions to aid readability and comprehension. The survey for people working in dementia consisted of four questions. Surveys contained a mix of binary yes/no, open-ended and multiple response questions.

5.6 Results

A total of 55 eligible survey responses were received. The responders comprised 11 people working in dementia, 22 caregivers and 22 PLwD. Five survey responses had to be excluded from the data analysis: four were excluded as participants had not answered whether they were a caregiver or a person with dementia, and one caregiver response was deleted due to incomplete data. The caregiver had only completed the demographic questions and did not vote for any therapies.

Four PLwD requested help from the researcher to complete the survey by telephone. Completing the survey in this way had additional challenges. Flexibility was needed as the task often took longer than expected due to participants wanting to chat and sometimes becoming sidetracked. Sufficient time was also needed to explain the survey and ensure comprehension. To exclude the possibility of the researcher influencing results in these cases, it was ensured that the questions were read out as written so that no undue influence was directed at the participant. The average time taken to complete the survey in this way was 60 minutes. The time anticipated for completion of the survey online was 20-30 minutes.

In the JDR database, PLwD were able to nominate someone other than themselves to be their contact point for any research opportunities. The researcher contacted six such alternative contacts who said that the person with dementia was now in a care or nursing home. These contacts declined to take up the suggestions explained earlier regarding how they could make the survey available in the care home. Due to this lack

of engagement, it was assumed that all PLwD participants were probably living at home and not in care homes.

5.6.1 Participant demographics

Demographic information was collected for both PLwD and caregivers. This information was not collected for professionals working in dementia. Demographic data for two PLwD and one caregiver were missing due to the late addition of these questions following survey amendment, but these participants have been included in all other analyses.

5.6.1.1 Demographics of PLwD

Demographic information for PLwD is shown in Table 5.3 and information for caregivers in Table 5.4. The responses of two PLwD have been excluded from the demographic analysis due to their not having been shown these questions, which were added after the amendment.

Table 5.3 Demographics of PLwD

Variable	Value
Gender	Male (n=11), female (n=9)
Age	Range: 60-83 years, average: 75 years
Ethnicity	English/Welsh/Scottish/Northern Irish/British (n=8), White British/White English (n=8), White (n=2), Swedish (n=1), Not stated (n=1)
Disease severity	Mild (n=17), Moderate (n=3)

There was an almost equal split of genders in the responses, so the responses were not biased towards a particular gender. There was an underrepresentation of ethnic minority groups in the research. The vast majority of PLwD participants were of White English ethnicity. Most respondents identified as having mild dementia, and no participant identified as having severe dementia.

5.6.1.2 Demographics of family caregivers

The demographics of caregivers are detailed in Table 5.4. The responses of one caregiver were excluded from this analysis due to the addition of these questions after their completion of the survey.

Table 5.4 Demographics of family caregivers

Variable	Value
Gender	Male (n=5), female (n=16)
Age	Range: 70-79 years, Average: 67 years
Ethnicity	English/Welsh/Scottish/Northern Irish/British (n=18), White (n=2), British Asian (n=1)
Caregiving responsibilities	Current (n=9), Past (n=13)

Most respondent caregivers were female Caucasians. Ethnicity was not represented well by caregivers in the survey. There was an almost equal split between caregivers with current and past caring responsibilities.

5.6.2 Therapy voting results by participant category

The therapy voting results for all participants are shown in Table 5.5.

Table 5.5 Summary of therapy voting results for all participants

Therapy	PLwD (%)	Family caregivers (%)	People working in dementia (%)
Art or music/singing (combined)	91%	100%	45%
Cooking and storytelling	27%	36%	18%
Occupational therapy	14%	82%	9%
Massage	18%	36%	18%
Exercise	55%	77%	0%
Multi-modal activity, which involves memory training, peer support, positive thinking, and education	73%	91%	18%
Pet therapy	55%	68%	27%
CST	77%	91%	18%
Training & education programmes for family caregivers	32%	36%	27%
Training for staff in care homes and nursing homes	9%	9%	9%
Dementia care management	73%	86%	36%

The results show that music/singing and art were rated highest by all three groups of participants: PLwD (91%), family caregivers (100%) and people working in dementia (45%). Massage and occupational therapy received a small number of votes from PLwD and people working in dementia, but it was highly rated by family caregivers (82%). Exercise was the only therapy that received zero votes, this was from people working in dementia. Training and education programmes for family caregivers did not

rate especially highly as a priority for family caregivers (36%); however, it was rated higher by people working in dementia (27%). The results found that training for care/nursing home staff was not a priority.

5.6.2.1 Gender and age

Two PLwD and one family caregiver did not state their genders and therefore, they were not included in this analysis. Results of the analysis for PLwD responses by gender and age are shown in Table 5.6.

Table 5.6 Voting results for PLwD by gender and age

Therapy	**Gender**		**Age**	
	Male (n=11)	Female (n=9)	Aged 70 or under (n=5)	Aged over 70 (n=17)
Art or music/singing (combined)	91%	89%	80%	94%
Cooking and storytelling	45%	11%	20%	29%
Occupational therapy	18%	11%	20%	12%
Massage	27%	11%	20%	18%
Exercise	73%	44%	40%	59%
Multi-modal activity, which involves memory training, peer support, positive thinking, and education	82%	67%	60%	76%
Pet therapy	55%	56%	100%	41%
CST	82%	67%	80%	76%
Training & education programmes for family caregivers	27%	22%	60%	24%
Training for staff in care homes and nursing homes	0%	22%	0%	12%
Dementia care management	73%	67%	80%	71%

There were similar numbers of male and female respondents. Differences were observed in the voting patterns between genders. Singing/music and art received the highest number of votes across both men and women (91%, 89% respectively). CST, exercise, massage, multi-modal therapies, cooking, and storytelling were all more popular with males than with females. Pet therapy was equally popular with females (56%) and males (55%). When looking at the carer training programmes, males were most interested in training for family caregivers (27%) than females (22%). There were no votes for nursing/care home training by males, however, females were more interested in this type of training (22%). PLwD aged under 70 years of age showed a strong preference for pet therapy (100%) compared to PLwD aged over 70 years

(41%). Training and education programmes for family caregivers were markedly more popular with younger PLwD than those who were older.

For family caregivers, voting results by gender and age are shown below (Table 5.7).

Table 5.7 Voting results for family caregivers by gender and age

Therapy	Gender		Age		Gender/age			
	Male (n=5)	Female (n=16)	Aged 70 or under (n=14)	Aged over 70 (n=8)	Female aged 70 or under (n=13)	Female aged over 70 (n=3)	Male aged 70 or under (n=1)	Male aged over 70 (n=4)
Art or music/singing (combined)	100%	94%	93%	100%	92%	100%	100%	100%
Cooking and storytelling	40%	38%	33%	43%	38%	33%	0%	50%
Occupational therapy	80%	81%	73%	100%	77%	100%	0%	100%
Massage	20%	44%	33%	43%	38%	67%	0%	25%
Exercise	80%	75%	73%	86%	69%	100%	100%	75%
Multi-modal activity, which involves memory training, peer support, positive thinking, and education	100%	94%	87%	100%	92%	100%	100%	100%
Pet therapy	80%	69%	67%	71%	77%	33%	0%	100%
CST	100%	94%	87%	100%	92%	100%	100%	100%
Training & education programmes for family caregivers	60%	25%	33%	43%	31%	0%	0%	75%
Training for staff in care homes and nursing homes	0%	13%	13%	0%	15%	0%	0%	0%
Dementia care management	100%	88%	80%	100%	85%	100%	100%	100%

There were more female caregiver respondents than male. Whilst voting percentages by male/female family caregivers were similar, there were some significant differences between the voting for some categories of therapy. The high results for art, music and singing were reflected across both genders. More males voted for family caregiver training (60%) than did females (25%). Females voted for dementia training for staff in care/nursing homes (13%) whilst this category received zero votes from males. Multi-modal therapies were extremely popular and received high numbers of votes from participants of both genders. There was a consensus in the voting by men, all of whom voted for art, music/singing, multi-modal activities, CST and dementia care management. There was a noticeable difference between genders in the votes for training for family caregivers; men were most likely to vote for this training (male 60%, female 25%).

Caregivers aged over 70 years were most likely to vote for art, music/singing, occupational therapy, CST and multi-modal activities.

5.6.2.2 Disease severity

Table 5.8 shows voting results for PLwD according to disease severity. Disease severity was not available for two respondents due to the late addition of demographic questions following the survey amendment.

Table 5.8 Voting results for PLwD by disease severity

Therapy	Mild (n=17)	Moderate (n=3)
Art or music/singing (combined)	100%	88%
Cooking and storytelling	0%	35%
Occupational therapy	33%	12%
Massage	67%	12%
Exercise	67%	59%
Multi-modal activity, which involves memory training, peer support, positive thinking, and education	67%	76%
Pet therapy	67%	53%
CST	100%	71%
Training & education programmes for family caregivers	0%	29%
Training for staff in care homes and nursing homes	0%	12%
Dementia care management	100%	65%

5.6.2.3 Ethnicity

It was not possible to assess the impact of ethnicity on voting results due to the poor diversity of ethnicity within the PLwD and family caregiver groups of participants.

5.7 Discussion

PPI was used to check and improve a survey to determine priorities for further research. The survey results indicated that participants placed significant value on MT and caregiver training, expressing a desire to see further research in these areas.

Using a PPI group to inform the project was a valuable learning experience for both the PLwD and the researcher. The experience of involving people with lived experience in the PPI group identified some barriers to taking part, which had been replicated in previous research findings. Issues of decline in cognitive function and

accessibility of communication have been identified as barriers to the conduct of research (Waite, Poland and Charlesworth, 2019).

Feedback from group members was that they had really enjoyed being involved in the PPI group for the project. This is in line with findings of other research on PPI on dementia, in which participants mentioned their motivations for taking part as being able to make a difference and to keep active (Waite, Poland and Charlesworth, 2019). Previous research has mentioned that attitudes and expectations of gatekeepers can be a barrier to co-production (Waite, Poland and Charlesworth, 2019). However, by using the DEEP website to recruit and by gaining prior approval from the DEEP website coordinator to advertise the PPI opportunity, this was avoided in this project.

Although the survey collected responses from only a small number of people, it provided a useful insight into the preferences of these groups of people. As well as guiding the research priority, the results of the survey provided useful insight into the acceptability of therapies. There were high numbers of votes for art and music/singing by family caregivers and PLwD. This popularity remained consistently high through analysis of age, disease severity and gender. Occupational therapy did not rate highly; this could be because participants considered that this therapy had received sufficient research and evidence, as it is already offered to PLwD, and, as discussed earlier, it is already recommended under NICE guidelines. The number of votes for pet therapy by PLwD was low among those aged over 70 years. This may have reflected worries about being able to look after a pet long-term due to the nature of the disease and having to plan for the pet's care if they go into a care home. Additionally, it is interesting to note that music therapy was rated highly in the survey, as this tends to be a social, group activity. An analysis by Chester *et al.* (2018) found that opportunities for support and social activities were most important to PLwD in the early stages of their diagnosis.

To address the issues of vulnerability, the survey was advertised by specialist dementia organisations. Participants recruited via JDR had joined the database to indicate that they were interested in taking part in research. These participants were screened for eligibility and contacted directly by their preferred means of contact if they met the inclusion criteria. Regarding cognitive challenges, the draft survey was reviewed by PLwD to make sure it was suitable for the target audience before it was sent out.

The predominance of female caregivers responding to the survey reflects the fact that informal caregiving is traditionally a female role (Joseph and Hallman, 1998). However, recent studies have shown that the number of male spousal caregivers is increasing (Pöysti *et al.*, 2012).

It is particularly important to make research accessible for PLwD and to enable them to take part independently as much as possible to empower them. This was achieved in this survey with the help and advice of the PPI group.

5.8 Limitations

It is acknowledged that it would have been desirable to have involved the PPI group at the project outset so that they could be involved in co-production during the design phase of the project. If the group had been involved at the start of the project, its members could have helped to develop the survey at its initial stages. This was not possible as the project was a pre-determined PhD project. The main framework for the project and funding were already in place and with its economic design, it was initially difficult to envisage a role for a public contributor. The original project design did not include people with lived experience. However, as the project evolved the concept of involving people with lived experience and adding a survey to inform the main research priority emerged.

All people in the PPI group were of White British ethnicity. It is not known whether this influenced survey design. Although attempts were made to ensure that the survey was accessible and appropriate for all ethnicities, it is acknowledged that this may not have been sufficient to encourage active participation from such groups. Efforts were made to recruit participants from ethnic backgrounds other than White British to the surveys. People from non-White British backgrounds were identified through JDR and contacted about the survey. Offers of translators and translated materials were made. Despite these efforts, the views of other ethnicities are not well represented in the survey. Findings may describe the research and therapy preferences of a White British ethnic population. This reflects the findings of other research, which highlights that ethnic minority groups are underrepresented in research trials (Cooper *et al.*, 2010). Further work in this area should attempt to have a range of ethnicities represented within survey participants and people in the PPI group.

Diagnosis of MCI was not represented within the PPI group; this would also be a consideration in future work. It is not known to what extent sexuality was represented, as these data were not collected, but steps to incorporate optional questions for this should also be incorporated in future studies.

It is accepted that the number of participants recruited for the survey was low and that results may not be representative of the wider population. However, the survey was intended to provide only a snapshot of opinions to inform the research priorities.

The online survey format meant that it was not possible to check participants' continued understanding of the research questions throughout the survey. It is possible that participants may have voted for the therapy that they would prefer themselves or their relative to take part in, as opposed to the therapy that they felt needed more research. Also, as the survey was anonymous it was not possible to determine whether anyone took part from outside the UK. Despite attempts to include the views of participants from countries other than the UK it is accepted that the survey may best reflect the views of people in the UK.

A potential bias was that the researchers were unable to ascertain whether responses were influenced by the opinions of an external supporter when completing the survey. However, attempts were made to reduce this bias with the addition of a question that asked supporters to indicate whether they were helping a person with dementia to complete the survey and to indicate whose views the responses reflected. Allowing support can enable researchers to capture the views of a larger percentage of PLwD who might otherwise be excluded (Darlington *et al.*, 2021).

During recruitment, several organisations and individuals offered researchers the chance to visit music groups for PLwD in order to recruit participants to the study from these groups. However, these offers were declined in order to avoid biasing the study towards music therapy by going specifically to music groups where participants may have been more inclined to vote for music.

Another possible approach to the survey would have been to consider the outcomes that participants prioritised, such as cognition, daily functioning, mood, social connection, or quality of life. Asking participants to identify the outcomes that they valued may have helped to clarify not just which therapies were preferred but also give insight into why these were important. This may have provided further insight into the

underlying priorities of PLwD and caregivers and informed how therapies are evaluated in practice. Whilst this survey did not include consideration of the outcomes, the findings still indicate clear preferences. Future research could build on this by exploring the value placed on outcomes more explicitly.

5.9 Conclusion

People with lived experience of dementia showed a preference for further research on interventions involving music, singing and art. Training and education programmes for family caregivers were a high priority for people working in dementia, but were rated less highly by caregivers.

5.10 Chapter summary

The results of the survey, which was developed using PPI involvement, informed the choice of therapies for the modelling phase of the project. Results showed that both PLwD and caregivers highly rated art, music and singing as therapies that they were keen to see further research on. People working in dementia voted for training and education programmes for family caregivers.

The results of the survey were used to inform the research priorities for the modelling phase of the project. The survey results were triangulated with the systematic review (Chapter 3) and review of effectiveness (Chapter 4), and this resulted in MT and caregiver training programmes for informal caregivers being selected for economic modelling. The involvement of the voices of people with lived experience in the project was invaluable and ensured that key issues were not overlooked. The modelling component aimed to generate new economic evidence on specific dementia therapies, specifically shaped by the priorities identified through engagement with people affected by dementia.

In the next chapter, an analysis is presented of an existing dataset involving PLwD who accessed mental health services within a single UK healthcare trust. This analysis explores patterns of service use and associated costs during the pre- to post-diagnosis period. In the study, the findings were used to inform the parameters for economic modelling, detailed in subsequent chapters.

Chapter 6 Estimating mental health service utilisation and costs pre-/post-diagnosis of dementia using routinely collected mental health data

6.1 Introduction

This chapter presents an analysis of an existing dataset of PLwD who had contact with mental health services within a single UK healthcare trust. This analysis explores patterns of service use and associated costs during the pre- to post-diagnosis period.

6.2 Background

Dementia is associated with high use of healthcare services and high costs of care (Chen *et al.*, 2014). Increased health service use over time reflects the underlying disease and its progression, which results in increased care needs. Previous studies have explored healthcare service use and associated costs for PLwD/MCI (Chen *et al.*, 2014; Browne *et al.*, 2017; Bassoli, Brugiavini and Carrino, 2024). PLwD/MCI have high rates of hospital admission and re-admission compared with people with normal cognitive function (Briggs *et al.*, 2016; Knapp *et al.*, 2016; Tropea *et al.*, 2017; Shepherd *et al.*, 2019). Additionally, PLwD have an increased rate of emergency hospital admissions (Phelan *et al.*, 2012; Sommerlad *et al.*, 2019). Once admitted to hospital, PLwD have longer stays (Annear *et al.*, 2016; Briggs *et al.*, 2016; Tropea *et al.*, 2017) compared with people without dementia. A study by Briggs (2016) found that PLwD had an increased risk of death or all-cause hospital re-admission within 12 months of a hospital stay (Briggs *et al.*, 2016). Hospital stays are associated with negative health outcomes, including falls, pressure ulcers, functional decline and an increased risk of mortality (Fogg *et al.*, 2018; Afonso-Argiles *et al.*, 2020). Patients with dementia who live alone have an increased likelihood of admission compared with patients who live with someone, such as an informal caregiver (Knapp *et al.*, 2016). This highlights the valuable role of informal caregiving, the costs and implications of which have been discussed in Section 2.3.2.

The number of comorbidities has been linked with increased numbers of hospital admissions and increased risk of mortality (Browne *et al.*, 2017). PLwD have a higher prevalence of comorbidities compared to patients without dementia (Kuo *et al.,* 2008;

Browne *et al.,* 2017; Fogg *et al.,* 2018). Comorbidities in PLwD frequently include mental health or neurological conditions, cardiovascular disease or diabetes (Kuo *et al.*, 2008). Chronic pain, depression, hearing loss and constipation are also frequently experienced by PLwD (Browne *et al.*, 2017). Risk of hospital admission is associated with polypharmacy, a history of falls and high caregiver burden (Afonso-Argiles *et al.*, 2020). This suggests that when caregivers feel unsupported, overwhelmed or stressed, the likelihood of avoidable hospitalisation for the person with dementia increases.

High use of secondary healthcare services and associated high costs due to dementia or MCI is a significant concern for healthcare providers. While some of this service use can be directly attributed to dementia-related complications (i.e., behavioural symptoms or cognitive decline) a large proportion may be due to other age-related conditions (i.e. cardiovascular disease, infections, and falls), which can be exacerbated by cognitive impairment and lead to more complex and lengthened hospital stays.

It has been suggested that increased use of healthcare services, admission to hospital and transfer to a care home can stem from crises in the community setting, which could potentially be avoided (Knapp *et al.*, 2016). Supporting patients with MCI or dementia in the community is often a less expensive option than hospital admission or transfer to a care home. Given that the number of PLwD is increasing and healthcare budgets in the UK are constrained, it is important to maintain a balance between community and institutional care (Alzheimer's Disease International, 2015). It is important that healthcare providers and decision-makers understand service use and costs of care before and after diagnosis of dementia when they plan services and budgets.

6.3 Aim

The work explained in this chapter aimed to describe and analyse data on mental health service use and costs pre-/post-diagnosis of dementia or MCI, based on a retrospective cohort study of patients with dementia or MCI who had been referred to mental health services within a UK NHS healthcare trust. The objective was to build

upon the current understanding of service utilisation and associated costs for PLwD and MCI.

To guide this analysis and provide comprehensive insights, the following research questions were explored.

i. What was mental health service use one year pre- and one year post-diagnosis?
ii. What were the average total costs of care and costs of specific services?
iii. What were the costs and service uses for different demographic subgroups in the cohort?
iv. Which patient characteristics were significantly associated with high cost?

6.4 Methods

6.4.1 Overview

In the work described in this chapter, existing secondary data on mental health service use from a cohort of UK patients who had been diagnosed with MCI or dementia were analysed to discover patterns of service use and associated costs. Patients were registered with South London and Maudsley NHS Foundation Trust (SLaM). Data from the trust's electronic clinical records system were linked to the specialist CRIS database of the Biomedical Research Centre. Secondary data were sourced from the CRIS database, which provides authorised researchers with regulated, secure access to anonymised data extracted from the SLaM electronic clinical records system. CRIS has overarching ethical approval from South Central − Oxford C Research Ethics Committee (approval number 23/SC/0257). Approval to use the CRIS de-identified data for research purposes was granted by SLaM and an honorary contract with SLaM was secured (Appendix 4.1). These contracts were extended to cover the analysis period (Appendix 4.2, 4.3).

SLaM provides specialist mental health and dementia care services across London and nationally. It covers a catchment area that comprises 1.3 million patients in south London across the boroughs of Croydon, Lambeth, Lewisham and Southwark (SLaM NHS Foundation Trust, 2024). The community of Southeast London is diverse, as shown in Table 6.1 (Office for National Statistics, 2022). It has a high burden of

physical and mental health challenges, deprivation, and socioeconomic and health inequalities (King's Health Partners, no date).

Table 6.1 Characteristics of boroughs in Southeast London.

Borough	Population	Ethnic diversity	Age 65+
Croydon	397,741	Very diverse	High
Lambeth	317,500	Very diverse	Lower than average
Lewisham	299,800	Very diverse	Moderate
Southwark	306,400	Very diverse	Lower than average

A requirement of using the CRIS database was that all data were required to remain secured within the NHS firewall during analysis. Data were accessed via a secure portal. The CRIS database is a retrospective database of routinely gathered de-identified data. This means it was not collected specifically for the purposes of this data analysis. It was used as a source of secondary data that could provide insights into historical patient service use, whilst it was ensured that individual identities remained anonymous. An opt-out system is in operation whereby patients can choose to exclude their data from the CRIS database. This protects patient autonomy whilst enabling the collection of valuable, anonymised data to inform mental health research and service improvement. A local contact/governor was assigned by SLaM with responsibility for oversight of the data analysis and database use. Specification requirements for the data extraction were planned with a data analyst from the Biomedical Research Centre. Expert advice and insight on mental health service use were obtained by consultation with a professor of old age psychiatry and clinicians from mental health services.

6.4.2 Inclusion/Exclusion criteria

Demographic data and mental health service utilisation data were analysed for the one-year periods before and after MCI/dementia diagnosis. Inclusion and exclusion criteria were applied to the CRIS data for these analyses (Table 3.1). Patients were included if they were aged 18 years or older with a primary diagnosis of MCI or dementia. The following dementia diagnosis codes from the International Classification of Disease (ICD-10) codes for mental and behavioural disorders (World Health Organization, 1993) were used to establish inclusion criteria for the study:

- F00 Dementia in AD
- F0.67 MCI
- F01 Vascular dementia
- F02 Dementia in other diseases classified elsewhere
- F03 Unspecified dementia

Table 6.2 Inclusion criteria

Inclusion criteria	Exclusion criteria
Aged 18 years or over	Less than one full year of data post-diagnosis
Primary diagnosis of MCI or dementia	Diagnosed after death
Diagnosed between 01/01/2010 and 31/12/2020	

ICD-10 codes beginning with “G” (Diseases of the Nervous System) were excluded from the analysis because the focus was on primary diagnoses only. No patients had a primary diagnosis coded under G30 (AD), and other G-codes represent neurological conditions not specific to dementia. Although G30 appeared as a secondary diagnosis for a small number of individuals (n = 11), only primary diagnoses were included to ensure that the analysis reflected the main reason for contact with mental health services and avoided confounding from non-dementia neurological disorders.

The ICD-10 codes captured patients with different forms of dementia and cognitive impairment, helping to create a well-defined study population. Only patients who had been diagnosed with dementia or MCI between 01/01/2010 and 31/12/2020 were included. However, if a person was diagnosed only after their death (i.e. on their death certificate) they were excluded. This exclusion ensured that only patients who were alive at the time of diagnosis were analysed. This allowed for more accurate analysis of service use and healthcare costs post-diagnosis. To ensure validity of the data and allow for analysis of sufficient post-diagnosis service use, only patients who had survived for at least one year after their diagnoses were included in the study. This enabled assessment of long-term health service utilisation and costs associated with dementia and MCI over the immediate periods before and after diagnosis. Care home residents were included.

6.4.3 Data analysis

Data were cleaned using Microsoft Excel and analysed using Stata version 15.1 (StataCorp, 2023). The data analysis was divided into two categories: pre-diagnosis and post-diagnosis, allowing for a comparison of service use and costs before and after diagnosis. Pre- and post-diagnosis time periods were calculated using the diagnosis date -/+ 12 months, respectively, to assess any significant changes in healthcare utilisation and associated costs following diagnosis. Each patient had a unique patient identifier to enable per-patient data analysis.

Descriptive analyses were conducted to summarise the background characteristics of the sample. Categorical variables were summarised as frequencies and percentages. Continuous variables were presented as means, medians, standard deviations and ranges. Service use was reported as frequencies, means, standard deviations and percentages and costs were reported as mean, median and standard deviations.

A structured approach to understanding service use patterns and related costs before and after diagnosis was taken. There were four key stages of data analysis, which are explained next.

Key stages of data analysis

1. **Comparison of numbers of contacts** – using t-tests and Shapiro-Wilk test of distribution for normality (dependent on the data type and distribution).
2. **Comparison of costs** – using t-tests, Shapiro-Wilk test of distribution for normality and linear regression models to test whether relationships between dependent variables and the outcome were significant.
3. **Sensitivity analyses** – tests of robustness of cost estimates and conclusions under different scenarios by varying the unit costs.

6.4.3.1 Time period

Service use and costs were analysed by time period. Pre-diagnosis service use data were collected from one year before the diagnosis date (including the day of diagnosis). Post-diagnosis service use data were collected for the year after diagnosis.

6.4.3.2 Type of service contact

- **Inpatient services**

    - Inpatient days (number of days in inpatient care)

- **Outpatient services**
    - In-person contacts (number of days with at least one in-person outpatient service)
    - Indirect contacts (number of contacts not in-person − these included phone, video, and web communications)
- **Memory clinic services**
    - In-person memory clinic contacts (number of in-person clinical contacts)
    - Indirect memory clinic contacts (number of indirect or remote clinical contacts)

Service use was analysed through exploration of the status of use, user or non-user, of a service during the period.

Data were categorised into two distinct groups: service users and the whole cohort.

- **Service users only** − individuals with at least one recorded episode of service use were categorised as service users. This group comprised patients with at least one recorded interaction with a service. This enabled analysis of the costs and usage associated with active service users.
- **Whole cohort** − included all individuals, regardless of whether they had used services, to provide a comprehensive understanding of service use and associated costs. This showed a wider view of service distribution and overall costs. This allowed the analysis to reflect the overall cost of providing the service across the cohort, even if it was not being used by every individual.

Through analysis of these two groups, it was possible to estimate not only the direct costs associated with service use but also the broader financial impact of making services available to the entire cohort, even though some individuals did not engage with the services that were provided. Using this approach, it was possible to provide a

more comprehensive overview of resource allocation and how the infrastructure for service delivery contributed to costs.

6.4.3.3 Numbers of contacts

Service use data for numbers of contacts with inpatient, outpatient and memory clinic services were extracted from the database to provide insight into the utilisations of healthcare resources. Each patient had a unique patient identifier, which enabled estimation of total service use and patterns of service use over the period. These patterns can inform resource allocation and cost-effectiveness evaluations and enable identification of potential gaps in care.

Data on clinical service contacts, including outpatient in-person, indirect (telephone/email), and all memory clinic contacts, were collected only for appointments that patients attended. Unattended appointments were not included in the original data extraction. Any contacts that occurred during hospital stays were excluded.

Inpatient, outpatient and memory clinic service use were chosen to facilitate understanding of the healthcare demands of each. These data insights are vital for service planning, improving patient care and determining the economic burden of dementia. This is especially important in the current climate, as the budgets of many healthcare organisations are considerably stretched.

6.4.3.4 Costs

The total economic impact of service use was assessed and compared for pre- and post-diagnosis periods. The aim was to highlight resource allocation and the distribution of costs. Costs for mental health service use were estimated using cost references taken from the *Unit Costs of Health and Social Care 2022 Manual* (Jones *et al.*, 2023) and the national schedule of NHS costs for the financial year 2021/22 (NHS England, 2023b). These sources provide comprehensive and updated data on the costs associated with health and social care services in the UK. This ensured that cost estimates reflected current pricing and relevant economic conditions and enabled the alignment of cost calculations with real-world service utilisation rates. By applying these unit costs to the extracted data on service use, the total costs for both pre- and post-diagnosis service utilisation were determined. These costings facilitated analysis

of the economic implications that are associated with the diagnosis and ongoing management of patients with MCI and dementia.

Costs were applied to calculate total service utilisation costs. They covered inpatient days, outpatient visits and use of memory clinic services. Both direct patient contacts (in-person appointments) and indirect contacts (telephone appointments) were costed. All costs referenced in this analysis are presented in 2024 UK pounds sterling. The costs used in the analysis are presented in Table 6.3.

Memory clinic appointments were assumed to last for 60 minutes with a clinical psychologist (Band 7). This rate was divided by four for the indirect memory clinic appointments, reflecting the assumption that indirect contacts take less time than in-person contacts. Through this method, a cost was calculated for a 15-minute period of indirect contact. These durations were informed by existing evidence (Cambridge University Hospitals, 2025).

The cost for in-person outpatient appointments was derived from a weighted average of all types of outpatient attendances to estimate a representative cost. Similar to the calculation of the cost of an indirect memory clinic appointment, the cost of an in-person outpatient appointment was divided by four for indirect outpatient contacts, to align with the shorter assumed duration of these contacts.

Table 6.3 Service use costs

	Cost per unit	**Per**	**Description**
Inpatient service costs			
Inpatient days	£341	Bed day	Average cost of a bed day (mental health services)
Outpatient service costs			
In-person contacts	£235	Outpatient contact	Average cost of outpatient appointment (weighted average number of all outpatient attendances)
Indirect contacts	£58.75	Telephone/email contacts	Telephone/email contacts Value as per in-person contacts above divided by 4. It is assumed that the indirect contacts have reduced costs
Memory clinic costs			
In-person memory clinic contacts	£66	60 minutes	Clinical psychologist (Band 7) cost/hr
Indirect memory clinic contacts	£16.50	15 minutes	The cost of a clinical psychologist (as stated above) was divided by four to reflect the shorter duration of indirect contacts. These were assumed to be follow-up appointments. The average estimated duration of an in-person

			follow-up appointment at the memory clinic is 30 minutes (Cambridge University Hospitals, 2025) it is assumed that an indirect contact takes less time than this

6.4.3.5 Subgroup analysis

Key demographic variables were obtained from the data: gender, age, ethnicity, living situation, primary diagnosis, MMSE scores and HoNOS scores. Use of this comprehensive dataset enabled in-depth analysis of the demographic, clinical, and service use factors that affect patients. These provided a comprehensive framework to explore how different characteristics may influence service use and costs associated with dementia care. To improve the understanding of this, univariable analysis was conducted on subgroups that were determined by the demographic and clinical data. This enabled the creation of an initial overview of how these demographic subgroups compared in their service use and provided a foundation for further statistical analysis and cost comparisons.

6.4.3.6 Gender

Gender was recorded as either male or female, as reported by the referring GP. One individual was excluded from the analysis due to missing gender data.

6.4.3.7 Age

Age group variables were constructed using the pre-existing variables for date of birth and date of diagnosis. A categorical variable was developed to represent age at diagnosis by calculating the difference between the date of birth and the date of diagnosis. This variable was also used to calculate age in the periods before and after diagnosis (-/+1 year). Patients were then categorised into three age groups to aid demographic analysis: 18-64 years (young to middle-aged adults), 65-84 years (older adults), and over 85 years (seniors). Age is commonly categorised in clinical research to classify patients into separate age groups to perform meaningful comparisons and analyses. Grouping patients by age at diagnosis is particularly relevant in dementia studies, as age is a key factor that influences the onset and progression of the disease (Ferrari *et al.*, 2018). Age categorisation is particularly useful in cases in which the relationship of age with the outcome is not linear, as it can help to identify patterns or differences that might be missed if age were treated as a continuous variable. If the

relationship were linear, use of age as a continuous variable would be more appropriate, as this use would retain more information and statistical power.

6.4.3.8 Primary diagnosis

The diagnostic codes that had been used for the primary diagnosis were recoded using ICD-10 codes to create two categories: dementia and MCI. Dementia was categorised using codes F00, F01, F02 and F03, which included various types of dementia as shown in section 6.4.2. MCI was categorised using code F06.7, which refers specifically to a diagnosis of MCI. The classification of primary diagnosis helped to ensure that the data analysis would effectively capture and compare the health service utilisation and costs for individuals with dementia and MCI. This was important as the two groups are likely to have different healthcare needs.

6.4.3.9 Ethnicity

Ethnicity data was originally recorded in the CRIS database using 20 categories. For this data analysis, they were recoded into seven broader categories to streamline the analysis and ensure better comparability across ethnic groups. The re-coded categories were:

- **White British**
- **White non-British** (included White Irish, White Gypsy or Irish traveller and Other White)
- **Black** (including Black/Black British, African, Caribbean and Other Black)
- **Asian** (including Asian and Asian British, Indian, Bangladeshi, Pakistani and Chinese)
- **Mixed Race** (combined individuals who identified with more than one ethnic group. Included White and Black Caribbean, White and Black African, White and Asian and Other Mixed Race)
- **'Other' ethnicity** (included Arab and patients who did not fall into the above categories)
- **Unknown** (for cases in which ethnicity data was missing or not stated)

It is acknowledged that the range of identities of patients who were grouped into the 'Other' category of ethnicity may have been broad and diverse. The re-coding approach aligned with previous approaches to the use of CRIS, which combined

ethnicity into categories using CRIS data (Sommerlad *et al.*, 2019). It reflected the need to simplify demographic analysis while ensuring that the most common ethnic groupings were adequately represented, and that the data remained manageable for statistical purposes. The combination of specific ethnic subcategories meant that it was possible to focus on broad trends while maintaining meaningful distinctions between the major ethnic groups.

6.4.3.10 Living situation

In the CRIS database, living situation data were originally recorded in 12 categories. These were simplified for this data analysis into three broader categories to facilitate comparison and analysis. The re-coded categories were:

- **Lives with someone** (included living with mother, father, parents, children only, foster carer, friends, other relatives, partner, partner and children, another person)
- **Lives alone**
- **Unknown** (for cases in which living situation was not known or missing from the data)

By combining the separate categories for living situation and simplifying the data, the analysis could be made to focus on significant distinctions and provide valuable insights into the role of social support structures in healthcare.

6.4.3.11 Outcome scales

The MMSE and HoNOS measures were used as key instruments for the assessment of cognitive and behavioural functioning in patients with dementia or MCI. These scores were important to understand how cognitive function affected service use and costs.

6.4.3.11.1 MMSE scores

MMSE is an outcome measure that is used to define dementia severity or to assess disease progression (Shigemori *et al.*, 2010). It is calculated from a 30-question assessment of cognitive function, which evaluates seven domains (Arevalo-Rodriguez *et al.*, 2021). Each question is allocated one point, so there is a minimum possible score of zero and a maximum possible score of 30. Lower scores indicate greater

dementia severity. MMSE scores were recorded as numerical values in the database; each patient could have multiple scores across different time points. The data were initially structured in a wide format, with one row per patient and separate columns for each MMSE measurement. To enable the analysis of repeated measures, the data were reshaped into a long format in Stata, resulting in multiple rows per patient, with each row corresponding to a different MMSE score.

Values were recoded to categorise patients into one of four groups of dementia severity based on their MMSE score: normal (score ≥27), mild (score 21-26), moderate (score 10-20), and severe (score ≤9). Categories of severity were determined by adapting the thresholds contained in the NICE guidelines (NICE, 2018b). Data were then extracted to provide results from the pre-diagnosis and follow-up, post-diagnosis scores for each person. There was a moderate number of scores in which more than one MMSE score had been recorded for a patient on the same day and these scores differed. In these cases, an average score was calculated and used in the analysis. The number of days between MMSE test dates ranged between one and 724 days.

The majority of MMSE scores were rated out of 30 items. However, some MMSE assessments were scored out of a denominator less than the standard 30 (n = 4,106); many scores were produced from tests that comprised fewer than 25 items (n = 1,593). In a similar cohort study, scores with a denominator of less than 25 were excluded and it was suggested that this reflected substantial missing data or an incorrectly administered test (Perera *et al.*, 2016). However, there are several possible reasons for a reduced denominator, including the patient's inability to complete the test due to severe cognitive/physical impairments, refusal to complete the test, poor vision or hearing, lack of literacy or the effects of a previous stroke (Raiha *et al.*, 2001). Given the demographic of the patients in this data analysis, it was deemed important to capture results that might reflect cognitive or other impairments. For this reason, scores with a reduced denominator were included in the analysis. This was to ensure that the data remained as inclusive as possible and captured valuable information on the cognitive function of patients who may not have been able to complete the full test. By including these scores, the analysis remained robust as it incorporated a broad spectrum of patients, including people with severe cognitive impairment. Published research has reported that incomplete assessments of cognitive function are common

and has stressed the importance of correct handling of missing data to show a comprehensive picture of cognitive health (Lees *et al.*, 2017).

Surrogate outcome measures such as MMSE can be mapped to more generic outcome measures, such as quality-of-life scores, to obtain health-related utility values that can be used in economic evaluations to calculate QALYs. This approach can be particularly useful in cases in which direct measurement of health utility is unavailable or impractical. The use of mapping tools allows for the translation of specific clinical outcomes, such as cognitive function, to broader measures of well-being, such as quality of life. It is then possible to estimate the economic impact of interventions for conditions such as dementia (Franklin and Hernández Alava, 2023). The mapped values can be used to generate QALYs, which combine both the quantity and quality of life into a single metric that is widely used in health economics to assess the cost-effectiveness of interventions (Kaplan *et al.,* 2003). Mapping enables the evaluation of cognitive, emotional, and functional aspects of interventions as well as of associated costs (Smith *et al.*, 2017).

MMSE scores were mapped to utility values to create a proxy QoL score, using a method previously applied by Brazier (2001) in work on disease progression in AD. Brazier (2001) first mapped outcome measures from trials of a drug therapy for AD to the health utilities index mark 3 to create a QoL measure. Brazier (2001) applied regression modelling to determine the relationship between MMSE scores and utility, concluding that a one-point reduction in MMSE was associated with a 0.03 reduction in utility (see Figure 6.1). Based on this, Brazier (2001) developed the following equation to estimate utility:

Utility = 0.0982 + (0.0298 x MMSE score) (Brazier, 2001)

Figure 6.1 Mapping equation for MMSE score

This mapping technique was applied to the dataset in this study to convert MMSE scores into utility values, which were then used to calculate QALYs. Pre-diagnosis and follow-up MMSE scores were each mapped to corresponding utility values using the

Brazier (2001) equation. Assuming a linear change in utility over time, an average utility value was calculated by taking the mean of the pre- and post-diagnosis utility scores. This average utility value was then multiplied by the actual mean time between assessments, expressed as a proportion of a year, to estimate the QALY value over that period. For individuals with fewer than two recorded MMSE scores, QALY calculation was not possible (n=5,808). The formula used was:

QALY = (Utility pre + Utility post) /2 X (Time in years)

Brazier's 2001 work is a preprint, has not undergone peer review and is not widely cited in formal peer-reviewed literature. However, the MMSE to utility mapping method that it proposes has been applied in other studies, including a NICE-commissioned HTA by Loveman *et al.* (2006). It offers a practical solution in cases in which direct utility measures are unavailable. The mapping equation has been cited in NICE guidelines (NICE, 2018a) and has been referenced in economic models that have been used to inform NICE technology appraisals, including those related to treatments for AD (NICE, 2018). As such, the method is recognised and has been used in key health economic evaluations, despite the original source remaining unpublished.

6.4.3.11.2 HoNOS scores

In the original CRIS database, scores were assessed using either HoNOS or HoNOS 65+ scales. HoNOS is commonly used in the general psychiatric population, whereas HoNOS 65+ has been specifically adapted for use with older adults. HoNOS and HoNOS 65+ scores were treated as comparable variables in this study as both tools were designed to measure mental health outcomes.

The earliest (pre-diagnosis) and the latest (post-diagnosis) HoNOS scores for each person were extracted from the database to reflect changes that may have occurred in mental health status over time. Adjusted scores were recoded to form three groups based on HoNOS score: 1-14 (mild symptoms), 15-24 (moderate symptoms) and ≥25 (severe symptoms). The creation of categories from HoNOS scores to represent the absence or presence of mental health problems aligns with methods used in previous dementia research (Knapp *et al.*, 2016; Perera *et al.*, 2016; Sommerlad *et al.*, 2019). HoNOS scores of zero, which indicate no mental health problems, were not included in this part of the analysis. The number of people with scores of zero was considered too small to add useful data for analysis (n=48).

The HoNOS scores in the original database had been adjusted to account for missing data in cases in which not all 12 items had been assessed. The weighting formula applied was a total possible score of 48 multiplied by 12, divided by the number of questions answered. By applying this formula, the score was weighted to estimate what the total score would have been if all 12 items had been completed. This adjustment ensured that the final scores for incomplete assessments were comparable with those that contained complete data. The adjustment helped to reduce potential bias introduced by the use of incomplete data. In some cases, two different scores had been assigned on the same date. These data were excluded as scores could not be reconciled to determine the most accurate result (n=527). The approach regarding the handling of missing or inconsistent data aligned with standard methodologies used in health research (Hoe *et al.*, 2009; Knapp *et al.*, 2016; Raglio *et al.*, 2017). Its use ensured that only consistent and reliable data were included in the analysis.

The data analysis involved the extraction of the earliest and latest MMSE and HoNOS scores for each patient. The earliest scores were coded as ‘pre-diagnosis’ and the latest scores were coded as ‘follow-up’ scores. This approach allowed for the evaluation of changes in cognitive function (MMSE scores) and mental health outcomes (HoNOS scores) over time. Through comparison of pre-diagnosis and follow-up scores for each outcome measure, the analysis could be used to identify trends in service use and potential shifts in the levels of care required.

6.4.4 Identification of predictors of total cost using multivariable regression analysis

Multivariable linear regression was conducted to explore which individual characteristics were independently associated with total cost. The aim was to identify potential predictors by examining the contribution of each variable while accounting for the others, rather than to comprehensively predict cost. Stata was used to fit the regression models. Categorical variables included gender, primary diagnosis, ethnicity and living situation. Continuous variables were age and MMSE and HoNOS scores. Results were reported with 95% CI and p-values of < 0.05 were considered statistically significant. The reporting of both p-values and 95% CIs provided complementary

information regarding statistical significance ($p<0.05$) and offered insight into the precision and direction of estimated effects.

6.5 Results

Basic statistical tests of frequency distributions were applied to assess the independence of variables. Values marked with 'N/A' indicate missing data or cases in which calculations could not be performed due to insufficient or undefined data (e.g., division by zero).

6.5.1 Cohort demographics

The cohort consisted of 16,081 people, key demographic characteristics are described (Table 6.4). Most of the cohort were female (61%) and aged 65 years or older at the time of diagnosis (94%). Most patients in the cohort had a diagnosis of dementia (82%), and the most common type of dementia was late-onset AD (32%).

More than two-thirds (67%) of the cohort identified as of White ethnicity. Almost three-quarters of the patients (71%) lived with someone.

It was noted that some individuals who were assessed using MMSE or HoNOS scores did not have follow-up assessments within one year of diagnosis. This may have impacted the completeness and reliability of the data.

Table 6.4 Cohort demographics

Demographic variable	Number of patients (%)
Gender	
Female	9,760 (61)
Male	6,321 (39)
Age	
18-64 years	1,105 (7)
65-84 years	9,909 (62)
≥85 years	5,067 (32)
Ethnicity	
White British	9,002 (56)
White non-British	1,696 (11)
Black	2,979 (19)
Mixed race	151 (1)
Asian	1,027 (6)
'Other' ethnicity	414 (3)
Unknown	812 (5)
Living situation	
Lived alone	4,661 (29)
Not living alone	6,162 (38)
Unknown	5,258 (33)
Primary diagnosis	
Dementia	13,229 (82)
MCI	2,852 (18)
MMSE score (pre-diagnosis) (n=12,968)	
Normal (≥27)	1,978 (15)
Mild (21-26)	4,630 (36)
Moderate (10-20)	5,426 (42)
Severe (≤9)	934 (7)
MMSE score (follow-up) (n=8,642)	
Normal (≥27)	1,436 (17)
Mild (21-26)	3,097 (36)
Moderate (10-20)	3,498 (40)
Severe (≤9)	611 (7)
HoNoS score (pre-diagnosis) (n=14,478)	
Mild (≤14)	11,758 (81)
Moderate (15-24)	2,553 (18)
Severe (≥25)	167 (1)
HoNoS score (follow-up) (n=7,919)	
Mild (≤14)	6,308 (80)
Moderate (15-24)	1,528 (19)
Severe (≥25)	83 (1)

Key: MCI - mild cognitive impairment, HoNOS - health of the nation outcome scores, MMSE - mini mental state examination

The means of the subgroup variables were then calculated to show an overview of the central tendencies within the cohort (Table 6.5).

Table 6.5 Means of subgroup variables

Demographic variable	Number of patients	Mean (SD)
Age	16,081	79 (9.51)
MMSE score (pre-diagnosis)	12,968	19.81 (6.32)
MMSE score (follow-up)	8,642	20 (6.35)
HoNOS score (pre-diagnosis)	14,478	9.75 (5.43)
HoNOS score (follow-up)	7,919	10.30 (5.26)
QoL score (pre-diagnosis)	12,968	0.69 (0.19)
QoL score (follow-up)	8,642	0.69 (0.19)
QALYs (overall)	8,642	0.37 (0.32)

Key: MCI - mild cognitive impairment, HoNOS - health of the nation outcome scores, MMSE - mini mental state examination, QoL - quality of life, QALYs - quality-adjusted life years

The average age of patients in the cohort was 79 years. Mean MMSE scores showed a decrease from pre- to post-diagnosis, indicating a decline in cognition. Similarly, HoNOS scores increased over the same period, suggesting a worsening of mental health and social functioning. Mean QoL scores also declined, indicating that patients reported having a better quality of life before their diagnosis than after. The average QALY was 0.37, calculated over the period between the two MMSE assessments. The interpretation of this shows that, on average, the patients in this cohort had a substantially reduced quality of life.

6.5.2 Univariable analysis of subgroup data

Univariable analysis was carried out to determine the distribution of type of diagnosis (MCI or dementia) with the variables of age (at diagnosis) and living situation (Table 6.6). Most patients in the cohort were aged 65 to 84 years with dementia (82%). PLwD were more likely to live with someone than to live alone (40% and 29% respectively).

The data showed that 29% of patients with MCI lived alone and 32% lived with someone. This suggests a relatively balanced distribution of living situations among patients with MCI. However, it was noted that the living situation was not well recorded

within the database, and there was a great deal of missing data. Patients under the age of 65 years were most likely to have MCI (40%).

Table 6.6 Univariable analysis of primary diagnosis within the subgroups: age group and living situation

Subgroups	Dementia (n, %)	MCI (n, %)
Age group		
18-64 years	662 (60)	443 (40)
65-84 years	8,082 (82)	1,827 (18)
≥85 years	4,485 (89)	582 (11)
Living situation		
Lives alone	3,834 (29)	827 (29)
Not living alone	5,240 (40)	922 (32)
Unknown	4,155 (31)	1,103 (39)

Key: MCI - mild cognitive impairment

6.5.3 Comparison of contacts

Mental health service use was analysed to compare patterns of use for service users, defined as patients who had at least one contact with any service type either before or after diagnosis). A summary of the frequency distribution is shown (Figure 6.2). Results showed that patients were more likely to use a mental-health service before their diagnosis (91%) than after (69%).

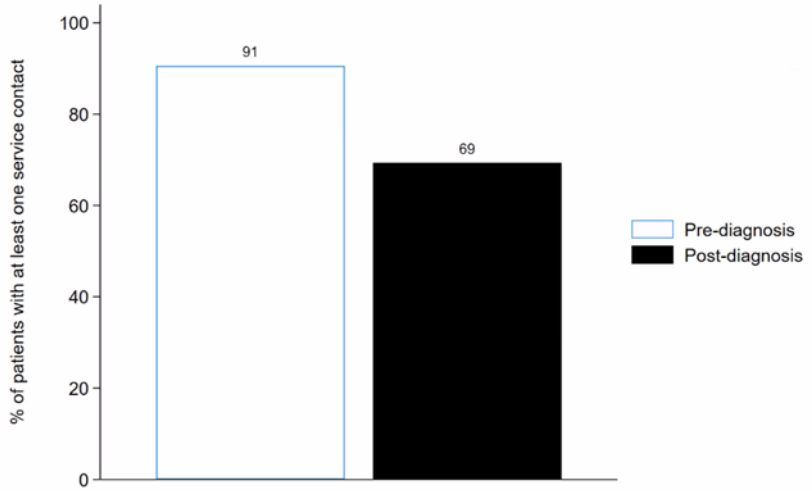


Figure 6.2 Proportion of service users pre-/post-diagnosis

6.5.4 Comparison of contacts and costs by period

A summary of service use and costs pre- and post-diagnosis and type of service is presented (Table 6.7). Results are shown for service users and the whole cohort.

Table 6.7 Summary of contacts and costs

	Pre-diagnosis				Post-diagnosis			
	Service users (n, %)	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**
Inpatient services								
Inpatient days	346 (2)	101.34 (118.22)	34,557 (40,312)	744 (7,747)	462 (3)	127.50 (111.89)	43,477 (38,156)	1,249 (9,720)
Outpatient services								
In-person contacts	14,446 (90)	3.25 (5.59)	764 (1,313)	686 (1,266)	10,980 (68)	5.44 (8.93)	1,278 (2,098)	872 (1,833)
Indirect contacts	159 (1)	1.28 (0.58)	75 (34)	1 (8)	348 (2)	3.58 (4.31)	210 (253)	5 (48)
Memory clinics								
In-person memory clinic contacts	8,876 (55)	1.83 (1.18)	120 (78)	67 (83)	6,212 (39)	1.98 (1.46)	131 (96)	51 (87)

Indirect memory clinic contacts	135 (1)	1.24 (0.51)	21 (8)	<0 (2)	176 (1)	2.18 (2.03)	36 (33)	<0 (5)

The key results as shown in Table 6.7 were:

- **all service −** whole cohort costs and the mean numbers of contacts for all service types were higher post-diagnosis than pre-diagnosis;
- **inpatient days −** inpatient care had the highest cost of all services, pre- and post-diagnosis. The frequency with which patients stayed as inpatients remained relatively constant from before to after diagnosis (2%; 3% respectively). Patients had more inpatient days after their diagnosis than they did before (101.34; 127.50, pre-/post-diagnosis, respectively);
- **outpatient contacts** – there was a significant reduction in the rate at which patients engaged with in-person outpatient services after diagnosis (68%), compared with before (90%). However, the mean number of outpatient contacts (both in-person contacts and indirect) increased from before diagnosis to after. This finding suggests that more patients used services post-diagnosis before their diagnosis; and
- **memory clinic contacts −** patients were more likely to use in-person memory clinic services pre-diagnosis (55%) than post-diagnosis (39%). After diagnosis, the rate of indirect memory clinic contacts remained relatively similar to that before diagnosis. The mean number of contacts in-person with memory clinic services was similar pre- and post-diagnosis (1.18; 1.46, respectively). Patients were more likely to use memory clinic services before diagnosis and there was little change in the average number of contacts between before and after diagnosis.

The following section presents the results of the analysis of contacts with services and associated costs pre- and post-diagnosis. Results were categorised by service type and by demographic subgroups. The subgroups that were analysed were gender, age group, primary diagnosis, ethnicity, living situation, MMSE category and HoNOS scores. All results are presented for patients who used the services (service users) and for the whole cohort. Observations on cost findings relate to the cost for the whole cohort unless otherwise stated.

6.5.1 Comparison of contacts and costs by subgroup

6.5.1.1 Gender

Service use and costs by gender are shown in Table 6.8. Inpatient days were the only service that showed a gender difference. The proportion of patients using inpatient services was almost twice as high for males pre- and post-diagnosis (2.94%; 3.78%) as for females (1.64%; 2.28%). Males had longer inpatient stays after diagnosis (132.22 days), on average, than did females (122.43 days).

Inpatient care costs for men pre- and post-diagnosis (£1,023; £1,705) were almost twice as high as those for women (£563; £954). Rates of use of indirect contacts were low overall, both pre- and post-diagnosis.

Table 6.8 Service use and costs by gender

	Female (n=9,760)				Male (n=6,321)			
Service	Service users (n, %)	Service user contacts (mean, SD)	Service user costs (mean, SD)	Whole cohort costs (mean, SD)	Service users (n, %)	Service user contacts (mean, SD)	Service user costs (mean, SD)	Whole cohort costs (mean, SD)
Inpatient days								
Pre-diagnosis	160 (1.64)	100.69 (121.62)	34,334 (41,473)	563 (6,858)	186 (2.94)	101.90 (115.53)	34,749 (39,396)	1,023 (8,940)
Post-diagnosis	223 (2.28)	122.43 (110.76)	41,750 (37,769)	954 (8,448)	239 (3.78)	132.22 (112.97)	45,088 (38,522)	1,705 (11,395)
In-person contacts								
Pre-diagnosis	8,780 (89.96)	3.10 (4.98)	729 (1,170)	655 (1,131)	5,666 (89.64)	3.48 (6.41)	819 (1,507)	734 (1,448)
Post-diagnosis	6,690 (68.55)	5.37 (9.17)	1,262 (2,155)	865 (1,878)	4,290 (67.87)	5.54 (8.54)	1,303 (2,007)	884 (1,762)
Indirect contacts								
Pre-diagnosis	96 (0.98)	1.30 (0.58)	76 (34)	1 (8)	63 (1)	1.25 (0.57)	74 (33)	1 (8)
Post-diagnosis	207 (2.12)	3.65 (4.63)	214 (272)	5 (50)	141 (2.23)	3.48 (3.82)	205 (224)	5 (45)
In-person memory clinic contacts								
Pre-diagnosis	5,422 (55.55)	1.80 (1.16)	119 (77)	66 (82)	3,454 (54.64)	1.87 (1.22)	123 (80)	67 (86)
Post-diagnosis	3,809 (39.03)	1.96 (1.43)	130 (94)	51 (86)	2,403 (38.02)	2.01 (1.52)	133 (100)	50 (89)
Indirect memory clinic contacts								
Pre-diagnosis	83 (0.85)	1.28 (0.55)	21 (9)	<0 (2)	52 (0.82)	1.19 (0.44)	20 (7)	<0 (2)
Post-diagnosis	109 (1.12)	2.16 (1.73)	36 (29)	<0 (5)	67 (1.06)	2.21 (2.45)	36 (40)	<0 (6)

6.5.1.2 Age

Results of the analysis of service use and costs by age group are shown in Table 6.9. A trend was observed in which the mean number of inpatient days increased with age pre-diagnosis but decreased with age post-diagnosis.

Patients aged under 65 years showed some of the highest whole cohort costs across all service types. They imposed the highest mean cost of inpatient care pre-/post-diagnosis (£1,224 pre-diagnosis; £2,070 post-diagnosis). Patients aged under 65 years were the highest cost in terms of in-person memory clinic contacts pre- and post-diagnosis (£88; £56, respectively).

Patients aged 85+ years showed the lowest costs of inpatient care pre- and post-diagnosis (£417; £746). They also imposed the lowest costs pre- and post-diagnosis for in-person contacts (£580; £750) and in-person memory clinic contacts (£54; £43).

Table 6.9 Service use and costs by age group

	Under 65 years (pre/post n=1,317; 1,020)				65-84 years (pre/post n=11,867; 10,283)				85+ years (pre/post n=5,557; 7,438)			
Service	Service users (n, %)	Service user contacts (mean, SD)	Service user costs (mean, SD)	Whole cohort costs (mean, SD)	Service users (n, %)	Service user contacts (mean, SD)	Service user costs (mean, SD)	Whole cohort costs (mean, SD)	Service users (n, %)	Service user contacts (mean, SD)	Service user costs (mean, SD)	Whole cohort costs (mean, SD)
Inpatient days												
Pre-diagnosis	53 (247)	85.51 (95.73)	29,159 (32,645)	1,224 (8,839)	247 (2.34)	102.45 (120.16)	34,935 (40,976)	818 (8,190)	46 (1.08)	113.63 (131)	38,748 (44,670)	417 (6,085)
Post-diagnosis	43 (4.36)	139.19 (119.92)	47,462 (40,893)	2,070 (12,859)	314 (3.40)	127.64 (109.92)	43,524 (37,141)	1,482 (10,446)	105 (1.79)	122.30 (117.91)	41,703 (40,208)	746 (7,693)
In-person contacts												
Pre-diagnosis	1,154 (91.37)	4.47 (8.58)	1,050 (2,017)	960 (1,950)	9,460 (89.69)	3.31 (5.58)	777 (1,311)	697 (1,264)	3,833 (89.74)	2.75 (4.24)	646 (996)	580 (963)
Post-diagnosis	605 (61.36)	6.38 (9.95)	1,500 (2,337)	920 (1,971)	6,471 (70.16)	5.73 (9.41)	1,348 (2,210)	946 (1,952)	3,905 (66.49)	4.80 (7.84)	1,127 (1,843)	750 (1,595)
Indirect contacts												
Pre-diagnosis	9 (0.71)	1.33 (0.50)	78 (29)	1 (7)	99 (0.94)	1.35 (0.64)	80 (38)	1 (8)	51 (1.19)	1.14 (0.40)	67 (24)	1 (8)
Post-diagnosis	15 (1.52)	3.33 (2.35)	196 (138)	3 (29)	218 (2.36)	3.53 (4.56)	207 (268)	5 (52)	115 (1.96)	3.71 (4.05)	218 (238)	4 (45)
In-person memory clinic contacts												
Pre-diagnosis	735 (58.19)	2.29 (1.95)	151 (129)	88 (123)	5,938 (56.30)	1.86 (1.13)	123 (75)	69 (83)	2,204 (51.60)	1.58 (0.90)	104 (59)	54 (67)
Post-diagnosis	351 (35.60)	2.37 (2.20)	156 (145)	56 (114)	3,777 (40.95)	2.03 (1.46)	134 (96)	55 (90)	2,085 (35.50)	1.83 (1.29)	121 (85)	43 (77)
Indirect memory clinic contacts												
Pre-diagnosis	8 (0.63)	1.38 (0.52)	23 (9)	<0 (2)	86 (0.82)	1.28 (0.55)	21 (9)	<0 (2)	41 (0.96)	1.15 (0.42)	19 (7)	<0 (2)
Post-diagnosis	6 (0.61)	1.67 (0.82)	28 (13)	<0 (2)	115 (1.25)	2.03 (1.92)	34 (32)	<0 (5)	55 (2.53)	2.53 (2.30)	42 (38)	<0 (5)

6.5.1.3 Primary diagnosis

Service use and costs were analysed according to primary diagnosis categories of dementia and MCI (Table 6.10). Rates of inpatient service use increased from before diagnosis to after for patients with MCI (0.67%; 0.98%) and dementia (2.47%; 3.28%). Patients with MCI had higher rates of in-person memory clinic use both pre- and post-diagnosis (66.06%; 40.39%) than did patients with dementia (52.86%; 38.25%).

The pre-diagnosis whole cohort costs of inpatient care for individuals with dementia (£870) were almost 85% higher than for individuals with MCI (£155). Patients with dementia were more likely to have in-person contacts both pre- and post-diagnosis (90.12%; 70.95%) than were patients with MCI (88.50%; 55.89%). The pre-diagnosis cost of in-person contacts for patients with dementia (£798) was higher than for people with MCI (£602). In-person memory clinic costs were higher pre-diagnosis than post-diagnosis for patients with MCI (£79; £50) and people with dementia (£64; £51).

Table 6.10 Service use and costs by primary diagnosis

	Dementia (n=15,633)				**MCI (n=3,108)**			
Service	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**
Inpatient days								
Pre-diagnosis	327 (2.47)	103.26 (119.96)	35,211 (40,908)	870 (8,434)	19 (0.67)	68.37 (77.46)	23,314 (26,413)	155 (2,829)
Post-diagnosis	434 (3.28)	128.42 (113.43)	43,790 (38,680)	1,437 (10,479)	28 (0.98)	113.25 (84.85)	38,618 (28,934)	379 (4,736)
In-person contacts								
Pre-diagnosis	11,923 (90.12)	3.40 (5.88)	720 (1,334)	798 (1,383)	2,524 (88.50)	2.56 (3.82)	532 (866)	602 (897)
Post-diagnosis	9,387 (70.95)	5.65 (9.14)	1,327 (2,148)	941 (1,907)	1,594 (55.89)	4.20 (7.44)	988 (1,748)	552 (1.396)
Indirect contacts								
Pre-diagnosis	130 (0.98)	1.30 (0.57)	76 (33)	1 (8)	29 (1.02)	1.21 (0.62)	71 (36)	1 (8)
Post-diagnosis	280 (2.21)	3.77 (4.58)	222 (269)	5 (50)	68 (2.38)	2.79 (2.87)	164 (169)	4 (36)
In-person memory clinic contacts								
Pre-diagnosis	6,993 (52.86)	1.83 (1.16)	121 (77)	64 (82)	1,884 (66.06)	1.82 (1.27)	120 (84)	79 (89)
Post-diagnosis	5,061 (38.25)	2 (1.46)	132 (97)	51 (88)	1,152 (40.39)	1.87 (1.45)	124 (95)	50 (86)
Indirect memory clinic contacts								
Pre-diagnosis	108 (0.82)	1.25 (0.48)	21 (8)	<0 (2)	27 (0.95)	1.22 (0.64)	20 (11)	<0 (2)
Post-diagnosis	126 (0.95)	2.27 (2.14)	37 (35)	<0 (5)	50 (1.75)	1.94 (1.72)	32 (28)	1 (6)

6.5.1.4 Ethnicity

Service use costs were analysed according to ethnicity subgroup (Table 6.11). Ethnicity data were unknown for approximately 5% of the cohort. This group was not interpreted in the subgroup analysis due to the small sample size. However, figures for this group have been shown for transparency and completeness of the data. Ethnicity was shown to impact service use. Patients who identified as White non-British and Asian had fewer inpatient days post-diagnosis, whereas for patients from all other categories of ethnicity, the number of inpatient days increased after diagnosis.

Patients who were of White non-British ethnicity had the highest cost of all ethnicities for inpatient care pre-diagnosis (£1,194); this cost was over twice as high as that for patients from White British (£595), mixed (£763) and Asian (£645) ethnicities and almost seven times higher than the cost of inpatient care for patients who identified as of ‘other’ ethnicity (£287). In contrast, they imposed the lowest costs for in-person contacts pre-diagnosis (£70). This group also had the lowest costs for post-diagnosis, in-person memory clinic contacts (£48). Patients of Black ethnicity had the highest rate of inpatient service use post-diagnosis (3.69%). They also had the highest inpatient costs post-diagnosis (£1,788) of all ethnicities.

Patients who identified as of 'other' ethnicity showed the lowest mean costs of all ethnicities, pre-diagnosis, for inpatient care (£253) and in-person contacts (£616). Individuals from ethnic groups categorised as 'other' were the least likely to access inpatient care; they showed a rate of access of just 1.21% for pre- and post-diagnosis.

Patients of Asian ethnicity, post-diagnosis, showed the lowest costs for inpatient care (£479) and for in-person contacts (£610). Patients identifying as Asian showed the highest costs for in-person memory clinic contacts pre-diagnosis (£83).

Table 6.11 Service use and costs by ethnicity

	White British (n=9,003)				White non-British (n=1,696)				Black (n=2,979)				Mixed (n=151)			
Service	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**
Inpatient days																
Pre-diagnosis	189 (2.10)	83.19 (105.31)	28,366 (35,912)	595 (6,593)	45 (2.65)	131.96 (138.69)	44,997 (47,292)	1,194 (10,506)	79 (2.65)	132.82 (132.53)	45,293 (45,193)	1,201 (10,319)	4 (2.65)	84.5 (84.92)	28,814 (28,957)	763 (6,191)
Post-diagnosis	259 (2.88)	123.1 (106.90)	41,976 (36,453)	1,208 (9,345)	61 (3.6)	124 (119.06)	42,390 (40,600)	1,525 (10,986)	110 (3.69)	141.96 (117.54)	48,410 (40,082)	1,788 (11,923)	4 (2.65)	155.75 (143.60)	53,111 (48,969)	1,407 (11,008)
In-person contacts																
Pre-diagnosis	8,061 (89.54)	3.33 (5.75)	782 (1,351)	700 (1,301)	1,509 (88.97)	3.38 (5.58)	794 (1,311)	70 (1,261)	2,700 (90.63)	3.23 (5.27)	758 (1,239)	687 (1,200)	133 (88.08)	3.51 (6.27)	825 (1,473)	727 (1,407)
Post-diagnosis	6,229 (69.19)	5.64 (8.8)	1,325 (2,068)	917 (1,825)	1,176 (69.34)	5.57 (7.54)	1,310 (1,772)	908 (1,594)	2,111 (70.86)	5.76 (11.19)	1,353 (2,630)	959 (2,297)	101 (66.89)	5.84 (11.06)	1,373 (2,600)	918 (2,220)
Indirect contacts																
Pre-diagnosis	92 (1.02)	1.27 (0.58)	75 (34)	1 (8)	11 (0.65)	1.55 (0.69)	91 (40)	1 (8)	25 (0.84)	1.28 (0.68)	75 (40)	1 (8)	2 (1.32)	1.5 (0.71)	88 (42)	1 (11)
Post-diagnosis	176 (1.95)	3.38 (3.88)	199 (228)	4 (42)	30 (1.77)	2.7 (2.14)	159 (125)	3 (27)	65 (2.18)	4 (4.52)	235 (266)	5 (52)	3 (1.99)	6.33 (4.93)	372 (290)	7 (62)
In-person memory clinic contacts																
Pre-diagnosis	4,871 (54.10)	1.82 (1.18)	120 (78)	65 (83)	864 (50.94)	1.8 (1.22)	119 (81)	61 (83)	1,730 (58.07)	1.81 (1.15)	119 (76)	69 (83)	86 (56.95)	1.86 (1.32)	123 (87)	70 (90)
Post-diagnosis	3,436 (38.17)	2.03 (1.49)	134 (99)	51 (89)	607 (35.79)	2.04 (1.49)	134 (98)	48 (87)	1,279 (42.93)	1.91 (1.43)	126 (94)	54 (88)	59 (39.07)	2.15 (1.83)	142 (121)	56 (102)
Indirect memory clinic contacts																
Pre-diagnosis	80 (0.89)	1.23 (0.53)	20 (9)	0 (2)	10 (0.59)	1.6 (0.70)	26 (12)	0 (2)	21 (0.70)	1.19 (0.4)	20 (7)	0 (2)	2 (1.32)	1.5 (0.71)	25 (12)	0 (3)
Post-diagnosis	89 (0.99)	2.24 (2.08)	37 (34)	0	12 (0.71)	1.92	32 (20)	0 (3)	33 (1.11)	2.15 (1.72)	36 (28)	0 (5)	2 (1.32)	3.5 (0.71)	58 (12)	1 (7)

Continued

	Asian (n=1,027)				'Other' (n=414)				Unknown (n=812)			
Service	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**
Inpatient days												
Pre-diagnosis	17 (1.66)	114.35 (125.40)	38,994 (42,763)	645 (7,300)	5 (1.21)	69.8 (74.90)	23,802 (25,541)	287 (3,619)	7 (0.86)	40 (31.99)	13,640 (10,908)	118 (1,572)
Post-diagnosis	14 (1.36)	103 (127.32)	35,123 (43,416)	479 (6,363)	5 (1.21)	153.8 (93.57)	52,446	633 (6,539)	9 (1.11)	109.89 (118.77)	37,472 (40,500)	415 (5,620)
In-person contacts												
Pre-diagnosis	954 (92.89)	3.29 (6.56)	774 (1,541)	719 (1,499)	375 (90.58)	2.84 (5.26)	668 (1,235)	605 (1,192)	715 (88.05)	2.32 (2.74)	545 (644)	480 (630)
Post-diagnosis	703 (68.45)	3.79 (4.77)	891 (1,122)	610 (1,016)	274 (66.18)	4.33 (6.81)	1,017 (1,600)	673 (1,388)	387 (47.66)	3.72 (6.67)	874 (1,567)	416 (1,166)
Indirect contacts												
Pre-diagnosis	11 (1.07)	1.18 (0.4)	69 (24)	1 (8)	1 (0.24)	1 (<0)	59 (<0)	0 (3)	17 (2.09)	1.24 (0.44)	73 (26)	2 (11)
Post-diagnosis	27 (2.63)	3.78 (5.37)	222 (316)	6 (62)	6 (1.45)	3.67 (5.13)	215 (301)	3 (42)	41 (5.05)	4.07 (5.86)	239 (344)	12 (93)
In-person memory clinic contacts												
Pre-diagnosis	664 (64.65)	1.95 (1.36)	129 (90)	83 (95)	247 (59.66)	2.02 (1.07)	133 (71)	79 (85)	415 (51.11)	1.67 (0.94)	111 (62)	56 (71)
Post-diagnosis	442 (43.04)	1.94 (1.51)	128 (100)	55 (91)	171 (41.30)	1.99 (1.18)	131 (78)	54 (82)	219 (26.97)	1.47 (0.85)	97 (56)	26 (52)
Indirect memory clinic contacts												
Pre-diagnosis	8 (0.78)	1.12 (0.35)	19 (6)	0 (2)	1 (0.24)	1 (<0)	16 (<0)	0 (1)	13 (1.6)	1.23 (0.44)	20 (7)	0 (3)
Post-diagnosis	19 (1.85)	1.95 (2.2)	32 (36)	1 (6)	3 (0.72)	1.67 (1.15)	28 (19)	0 (3)	18 (2.22)	2.28 (2.78)	38 (46)	1 (9)

6.5.1.5 Living situation

Patients' living situations were not well recorded in the database. Approximately 33% of the cohort (n=5,258) was labelled as having 'unknown' living status. Data for the unknown category are shown but not included in the subgroup analysis.

Living situation was shown to affect service use and costs (Table 6.12). Patients who lived with someone were more likely to access in-person memory clinic services pre- and post-diagnosis (56.13%; 40.23%) than were patients who lived alone (47.2%; 36.44%). Patients living alone had higher rates of inpatient bed-days (2.6%; 3.3%) pre- and post-diagnosis than did patients living with someone (2.01%; 2.76%). Patients who lived alone had shorter periods of inpatient days before diagnosis (88.53 days) and longer after diagnosis (124.15 days) compared with patients who lived with someone (100.99; 115.25 days).

Patients living alone had higher mean costs of inpatient days (£784; £1,398) and of in-person contacts (£779; £981) pre-/post-diagnosis than did patients who shared their home. However, patients who lived by themselves had lower costs for in-person memory clinic contacts (£65; £47) pre-/post-diagnosis than did patients living with someone (£72; £55). These patients were more likely to access in-person memory clinic services pre- and post-diagnosis (56.13%; 40.23%) than were patients who lived alone (47.2%; 36.44%).

Table 6.12 Service use and costs by living situation

	Lives alone (n=4,662)				Lives with someone (n=6,162)				Unknown (n=5,258)			
Service	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**
Inpatient days												
Pre-diagnosis	121 (2.6)	88.53 (116.43)	30,188 (39,701)	784 (7,977)	124 (2.01)	100.99 (108.5)	34,438 (37,340)	693 (7,157)	101 (1.92)	117.12 (129.42)	39,938 (44,132)	767 (8,192)
Post-diagnosis	154 (3.3)	124.15 (110.05)	42,335 (37,527)	1,398 (10,173)	170 (2.76)	115.25 (105.44)	39,299 (35,954)	1,084 (8,769)	138 (2.87)	146.33 (119.73)	49,897 (40,828)	1,310 (10,348)
In-person contacts												
Pre-diagnosis	4,266 (91.51)	3.62 (6.02)	851 (1,415)	779 (1,374)	5,664 (91.92)	3.25 (5.44)	765 (1,280)	703 (1,244)	4,517 (85.91)	2.9 (5.31)	681 (1,247)	585 (1,180)
Post-diagnosis	3,254 (69.8)	5.98 (9.77)	1,406 (2,297)	981 (2,024)	4,436 (71.99)	5.51 (8.37)	1,295 (1,967)	932 (1,768)	3,291 (62.59)	4.8 (8.74)	1,128 (2,054)	706 (1,714)
Indirect contacts												
Pre-diagnosis	20 (0.43)	1.4 (0.75)	82 (44)	0 (6)	29 (0.47)	1.21 (0.41)	71 (24)	0 (5)	110 (2.09)	1.28 (0.58)	75 (34)	2 (12)
Post-diagnosis	63 (1.35)	4 (4.2)	235 (247)	3 (39)	95 (1.54)	3.01 (4.68)	177 (275)	3 (40)	190 (3.61)	3.73 (4.15)	219 (244)	8 (62)
In-person memory clinic contacts												
Pre-diagnosis	2,470 (47.2)	1.85 (1.19)	122 (79)	65 (83)	3,459 (56.13)	1.93 (1.24)	128 (82)	72 (88)	2,948 (56.07)	1.68 (1.1)	111 (72)	62 (77)
Post-diagnosis	1,699 (36.44)	1.96 (1.41)	129 (93)	47 (84)	2,479 (40.23)	2.08 (1.55)	137 (103)	55 (94)	2,035 (38.7)	1.88 (1.38)	124 (91)	48 (83)
Indirect memory clinic contacts												
Pre-diagnosis	14 (0.3)	1.29 (0.47)	21 (8)	0 (1)	27 (0.44)	1.22 (0.42)	20 (7)	0 (1)	94 (1.79)	1.24 (0.54)	21 (9)	0 (3)
Post-diagnosis	23 (0.49)	2.78 (2.24)	46 (37)	0 (4)	42 (0.68)	28 (32)	28 (32)	0 (3)	111 (2.11)	37 (33)	37 (33)	1 (7)

6.5.1.6 MMSE category

The results of the subgroup analysis by MMSE severity are shown in Table 6.13. The rate of use of inpatient services increased after diagnosis compared with before for all categories of cognition except 'normal', which decreased (2.12%; 1.74%). Rates of in-person contacts were similar for all categories of cognition and decreased after diagnosis compared with before. The rate of in-person contacts was similar for all categories pre-diagnosis. However, after diagnosis this pattern of service use changed and the rate of in-person contacts for patients with moderate (80.90%) or severe impairment (80.69%) was higher than for patients with normal impairment (76.18%) or MCI (77.85%).

Patients with severe cognitive impairment had the lowest rates of in-person memory clinic use (50.75%; 34.21%) and showed the lowest costs (£61; £49). Prior to diagnosis, patients with mild severity dementia had the lowest costs for inpatient days (£510). Inpatient costs were highest for patients with severe dementia (pre- £1,581; post- £2,366). Patients with normal cognition had the highest in-person contact costs pre-diagnosis (£767), but the lowest costs for inpatient days post-diagnosis (£517). Patients with moderate severity dementia had the lowest mean costs for in-person contacts, pre-diagnosis (£688). The rate of in-person memory clinic visits decreased after diagnosis for all categories. Post-diagnosis cost of in-person memory clinic contacts decreased as the MMSE score category increased.

Post-diagnosis, the mean cost of inpatient care and in-person contacts increased with the level of cognitive impairment. However, the costs of in-person memory clinic contacts declined with increasing cognitive impairment, both pre- and post-diagnosis.

Table 6.13 Service use and costs by MMSE score

	Normal (MMSE score ≥ 27)				Mild (MMSE score 21-26)				Moderate (MMSE score 10-20)				Severe (MMSE score ≤ 9)			
Service	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**
Inpatient days																
Pre-diagnosis	42 (2.12)	86.88 (104.50)	29,626 (35,635)	629 (6,677)	85 (1.84)	81.52 (96.70)	27,798 (35,635)	510 (5,801)	111 (2.05)	77.19 (93.78)	26,322 (31977)	538 (5,884)	36 (3.85)	120.31 (126.09)	41,024 (42,996)	1,581 (11,480)
Post-diagnosis	25 (1.74)	87.08 (105.83)	29,694 (36,087)	517 (6,072)	86 (2.78)	111.23 (90.92)	37,930 (31,003)	1,053 (8,077)	160 (4.57)	121.85 (100.24)	41,551 (34,182)	1,901 (11,336)	39 (6.38)	108.72 (98.66)	37,073 (33,642)	2,366 (12,360)
In-person contacts																
Pre-diagnosis	1,849 (93.48)	3.49 (7.18)	820 (1,687)	767 (1,643)	4,302 (92.92)	3.26 (5.73)	766 (1,347)	711 (1,314)	4,956 (91.34)	3.21 (5.29)	753 (1,242)	688 (1,206)	863 (92.40)	3.20 (4.45)	752 (1,046)	694 (1,025)
Post-diagnosis	1,094 (76.18)	4.51 (7.29)	1,060 (1,713)	808 (1,562)	2,411 (77.85)	5.58 (10.08)	1,311 (2,370)	1,020 (2,160)	2,830 (80.90)	6.69 (10.39)	1,572 (2,441)	1,271 (2,281)	493 (80.69)	7.56 (10.13)	1,776 (2,281)	1,433 (2,251)
Indirect contacts																
Pre-diagnosis	15 (0.76)	1.13 (0.35)	67 (21)	1 (6)	19 (0.41)	1.11 (0.32)	65 (19)	0 (4)	32 (0.59)	1.25 (0.51)	73 (30)	0 (6)	4 (0.43)	1.50 (0.58)	88 (34)	0 (6)
Post-diagnosis	29 (2.02)	2.93 (3.08)	172 (181)	5 (41)	49 (1.58)	3.37 (3.19)	198 (187)	2 (27)	67 (1.92)	4.01 (4.76)	236 (280)	4 (52)	13 (2.13)	3.00 (2.35)	176 (138)	5 (60)
In-person memory clinic contacts																
Pre-diagnosis	1,461 (73.86)	1.93 (1.20)	128 (79)	94 (88)	3,039 (65.64)	1.86 (1.15)	123 (76)	81 (85)	2,985 (55.01)	1.75 (1.11)	115 (73)	63 (79)	474 (50.75)	1.81 (1.2)	119 (79)	61 (82)
Post-diagnosis	846 (58.91)	2.09 (1.54)	138 (102)	81 (103)	1,627 (52.53)	2.19 (1.59)	144 (105)	76 (105)	1,444 (41.28)	2 (1.36)	132 (90)	55 (87)	209 (34.21)	2.17 (1.77)	143 (117)	49 (96)
Indirect memory clinic contacts																
Pre-diagnosis	11 (0.56)	1.09 (0.30)	18 (5)	0 (1)	16 (0.35)	1.06 (0.25)	18 (4)	0 (1)	27 (0.50)	1.26 (0.53)	21 (9)	0 (2)	4 (0.43)	1.50 (0.58)	25 (10)	0 (2)
Post-diagnosis	19 (1.32)	2.42 (2.73)	40 (45)	1 (7)	24 (0.77)	2.29 (2.2)	38 (36)	0 (5)	18 (0.51)	1.50 (1.04)	25 (17)	0 (2)	5 (0.82)	2.80 (1.64)	46 (27)	0 (5)

6.5.1.7 HoNOS score

Analysis of service use and costs according to HoNOS score is shown (Table 6.14). Patients with fewer than two HoNOS scores recorded for comparison were excluded (n=8,009).

The rate of inpatient care and associated costs increased after diagnosis across all categories of HoNOS scores. Cost of inpatient care and in-person contacts increased after diagnosis compared with before and as HoNOS score category increased. The lowest mean in-person contact costs pre-/post-diagnosis were in the mild category (£643; £741). The highest mean inpatient care costs were reported in the severe category (£5,357; £6,123) and the lowest in the mild category (£488; £703). The highest mean costs of in-person contacts pre-/post-diagnosis were in the severe category (£1,335; £4,100). The cost of in-person contacts increased most in this group after diagnosis compared with before. Patients with a mild HoNOS score had the highest rate of use of in-person memory clinic contacts (63.80%; 40.84%). This group also had the highest costs for in-person memory clinic contacts pre-/post-diagnosis (£77; £62). Cost of in-person memory services decreased as the HoNOS score increased. The lowest mean costs for in-person memory clinics were shown in the severe category (£20; £10). Use of indirect memory clinic services was negligible in the severe HoNOS category

Table 6.14 Service use and costs by HoNOS score

	Mild (HoNOS score 1-14)				Moderate (HoNOS score 15-24)				Severe (HoNOS score 25+)			
Service	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**	**Service users (n, %)**	**Service user contacts (mean, SD)**	**Service user costs (mean, SD)**	**Whole cohort costs (mean, SD)**
Inpatient days												
Pre-diagnosis	153 (1.3)	104.08 (117.77)	35,493 (40,159)	462 (6,085)	161 (6.31)	98.89 (120.20)	33,721 (40,988)	2,127 (13,136)	26 (15.57)	111.04 (122.14)	37,864 (41,648)	5,895 (21,233)
Post-diagnosis	252 (3.99)	104.38 (94.97)	35,595 (32,386)	1,422 (9,505)	177 (11.58)	162.60 (124.35)	55,448 (42,403)	6,423 (22,855)	19 (22.89)	155.37 (126.40)	52,981 (43,101)	12,128 (30,155)
In-person contacts												
Pre-diagnosis	10,745 (91.38)	2.95 (5.05)	694 (1,187)	634 (1,152)	2,353 (92.17)	4.85 (7.94)	1,140 (1,867)	1,050 (1,818)	153 (91.62)	6.20 (8.50)	1,458 (1,999)	1,335 (1,955)
Post-diagnosis	5,187 (82.23)	6.32 (9.26)	1,484 (2,177)	1,221 (2,054)	1,335 (87.37)	11 (14.01)	2,586 (3,291)	2,259 (3,194)	78 (93.98)	18.56 (19.83)	4,363 (4,659)	4,100 (4,634)
Indirect contacts												
Pre-diagnosis	10,745 (91.38)	2.95 (5.05)	694 (1,187)	634 (1,152)	2,353 (92.17)	4.85 (7.94)	1,140 (1,867)	1,050 (1,818)	153 (91.62)	6.2 (8.5)	1,458 (1,999)	1,335 (1,955)
Post-diagnosis	135 (2.14)	4.37 (4.97)	257 (292)	5 (57)	42 (2.75)	5.07 (5.31)	298 (312)	8 (71)	4 (4.82)	8.25 (9.5)	485 (558)	23 (149)
In-person memory clinic contacts												
Pre-diagnosis	7,502 (63.80)	1.83 (1.13)	121 (74)	77 (83)	652 (25.54)	1.69 (1.02)	112 (67)	29 (59)	25 (14.97)	2.04 (2.44)	135 (161)	20 (78)
Post-diagnosis	2,576 (40.84)	2.29 (1.62)	151 (107)	62 (101)	217 (14.20)	2.17 (1.73)	143 (114)	20 (66)	6 (7.23)	2 (2)	132 (132)	10 (47)
Indirect memory clinic contacts												
Pre-diagnosis	123 (1.05)	1.24 (0.5)	20 (8)	0 (2)	9 (0.35)	1.44 (0.73)	24 (12)	0 (2)	0 (0)	N/A	N/A	0 (0)
Post-diagnosis	40 (0.63)	2.4 (2.61)	40 (43)	0(5)	1 (0.07)	1 (.)	16 (.)	0 (0)	1 (1.20)	1 (N/A)	16 (N/A)	0 (2)

6.5.2 Comparison of total costs

Total costs pre-/post-diagnosis were calculated. A mean total service use cost for each patient pre- and post-diagnosis was calculated by adding together the cost-of-service use for each individual patient using their unique identifiers. This involved the addition of costs of service use across all five categories of service use: inpatient days, in-person outpatient contacts, indirect outpatient contacts, in-person memory clinic contacts and indirect memory clinic contacts. Total costs per person were calculated by adding together the mean whole cohort costs for each service (Table 6.15).

Table 6.15 Total costs per person

	Total costs per person, mean (SD)
Pre-diagnosis	1,497 (8,049)
Post-diagnosis	2,177 (10,240)

Total costs were compared for patients pre- and post-diagnosis. Results showed that post-diagnosis, total costs for service users increased greatly compared with pre-diagnosis (Figure 6.3). The significance of this difference is assessed in Section 6.5.3.1 (paired t-test). The large standard deviations reflect high variability in costs, likely driven by a small number of individuals with exceptionally high service use. The large standard deviations reflect high variability, likely due to a small number of individuals with exceptionally high costs.

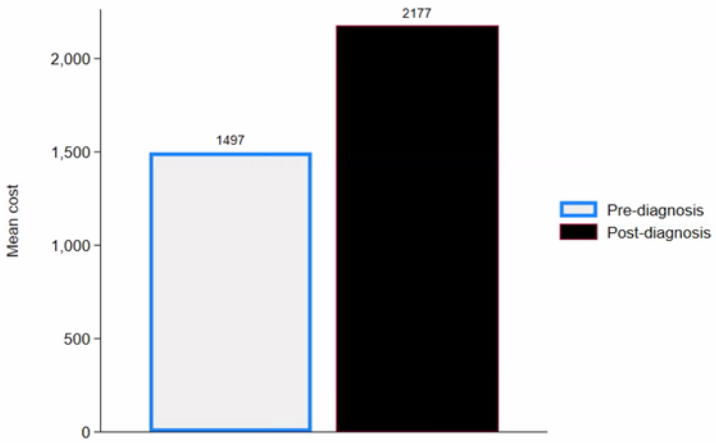


Figure 6.3 Total mean costs for service users pre- and post-diagnosis

The total costs were analysed by subgroup to see whether there were any patterns of difference between subgroups. Results are presented for patients using the services and for the whole cohort. The results of the analysis of total costs for the whole cohort are reported by subgroup (Table 6.16). A histogram was calculated for each subgroup, showing the mean cost of total service use for service users. Results for each subgroup are presented and discussed.

Table 6.16 Summary of total costs by subgroup

	Pre-diagnosis					Post-diagnosis				
	Service user costs only			Whole cohort costs		Service user costs only			Whole cohort costs	
	Service users (n, %)	Service user costs (mean, SD)	Service user costs (median)	Whole cohort costs (mean, SD)	Whole cohort costs (median)	Service users (n, %)	Service user costs (mean, SD)	Service user costs (median)	Whole cohort costs (mean, SD)	Whole cohort costs (median)
Gender										
Female	8,847 (90.65)	1,418 (7,406)	470	1,285 (7,063)	470	6,786 (69.53)	2,696 (10,705)	602	1,874 (9,012)	301
Male	5,714 (90.40)	2,019 (9,825)	602	1,825 (9,360)	470	4,360 (68.98)	3,834 (14,138)	602	2,644 (11,875)	301
Age group										
Under 65	1,160 (91.84)	2,474 (9,988)	602	2,272 (9,595)	602	611 (61.97)	4,920 (167,54)	903	3,049 (13,400)	301
65-84	9,535 (90.40)	1,753 (8,907)	602	1,585 (8,484)	470	6,574 (71.29)	3,490 (12,936)	705	2,488 (11,036)	301
85+	3,866 (90.52)	1,162 (6,517)	470	1,052 (6,209)	301	3,961 (67.44)	2,287 (9,735)	602	1,543 (8,066)	301
Primary diagnosis										
Dementia	12,020 (90.86)	1,821 (9,156)	602	1,655 (8,743)	470	9,525 (72)	3,380 (12,835)	705	2,434 (10,996)	352
MCI	2,541 (89.10)	862 (3,351)	470	768 (3,174)	301	1,621 (56.84)	1,734 (7,005)	602	986 (5,350)	301
Ethnicity										
White British	8,121 (90.21)	1,510 (7,325)	536	1,362 (6,972)	470	6,310 (70.10)	3,110 (11,685)	705	2,180 (9,886)	301
White non-British	1,525 (89.92)	2,182 (11,263)	602	1,962 (10,700)	470	1,194 (70.40)	3,528 (13,362)	705	2,484 (11,325)	301
Black	2,721 (91.34)	2,144 (10,966)	602	1,958 (10,498)	470	2,143 (71.94)	3,901 (14,653)	602	2,806 (12,550)	301
Mixed	135 (89.40)	1,747 (6,915)	602	1,562 (6,558)	470	103 (68.21)	3,502 (13,519)	705	2,389 (11,268)	301
Asian	961 (93.57)	1,548 (8,098)	602	1,448 (7,843)	470	717 (69.81)	1,648 (8,015)	602	1,150 (6,738)	301
'Other' ethnicity	376 (90.82)	1,070 (4,601)	602	972 (4,396)	602	275 (66.43)	2,054 (8,382)	602	1,364 (6,896)	301
Unknown	722 (88.92)	738 (1,845)	414	656 (1,755)	301	404 (49.75)	1,751 (8,606)	470	871 (6,130)	0
Living situation										
Lives alone	4,279 (91.80)	1773 (8,655)	602	1,628 (8,308)	470	3,281 (70.39)	3,453 (12,621)	705	2,431 (10,705)	301

Lives with someone	5,691 (92.36)	1,590 (7,808)	602	1,468 (7,515)	470	4,479 (72.69)	2,854 (10,859)	705	2,075 (9,345)	470
Unknown	4,591 (87.31)	1,622 (8,963)	470	1,416 (8,411)	301	3,386 (64.40)	3,218 (13,326)	602	2,072 (10,803)	301
MMSE category										
Normal	1,853 (93.68)	1,591 (7,681)	602	1,491 (7,444)	602	1,099 (76.53)	1,842 (7,552)	602	1,410 (6,652)	301
Mild	4,312 (93.13)	1,399 (6,378)	602	1,303 (6,166)	536	2,424 (78.27)	2,751 (10,012)	705	2,153 (8,930)	602
Moderate	4,974 (91.67)	1,408 (6,508)	602	1,290 (6,244)	470	2,847 (81.39)	3,970 (13,281)	903	3,231 (12,081)	602
Severe	868 (92.93)	2,514 (12,087)	470	2,337 (11,669)	470	501 (82)	4,698 (14,281)	1,175	3,853 (13,055)	837
HoNOS score										
Mild	10,816 (92.10)	1,275 (6,677)	602	1,174 (6,416)	470	5,229 (82.89)	3,269 (11,040)	903	2,710 (10,127)	680
Moderate	2,381 (93.26)	3,438 (13,897)	602	3,206 (13,449)	470	1,358 (88.87)	9,801 (24,587)	1,880	8,710 (23,382)	1,410
Severe	156 (93.41)	7,762 (22,108)	903	7,251 (21,450)	705	79 (95.18)	17,084 (31,191)	4,465	16,261 (30,642)	3,953

6.5.2.1.1 Gender

The proportions of males (90.40%; 68.98%) and females (90.65%; 69.53%) who used services were similar pre- and post-diagnosis. The proportion of patients with at least one contact dropped significantly after diagnosis for all genders.

Total service use costs for the whole cohort pre-/post-diagnosis by gender are shown (Figure 6.4). Costs increased post-diagnosis compared with pre-diagnosis for males and females. Males had higher costs of total service use (£1,825; £2,644) than females (£1,285; £1,874) pre- and post-diagnosis.

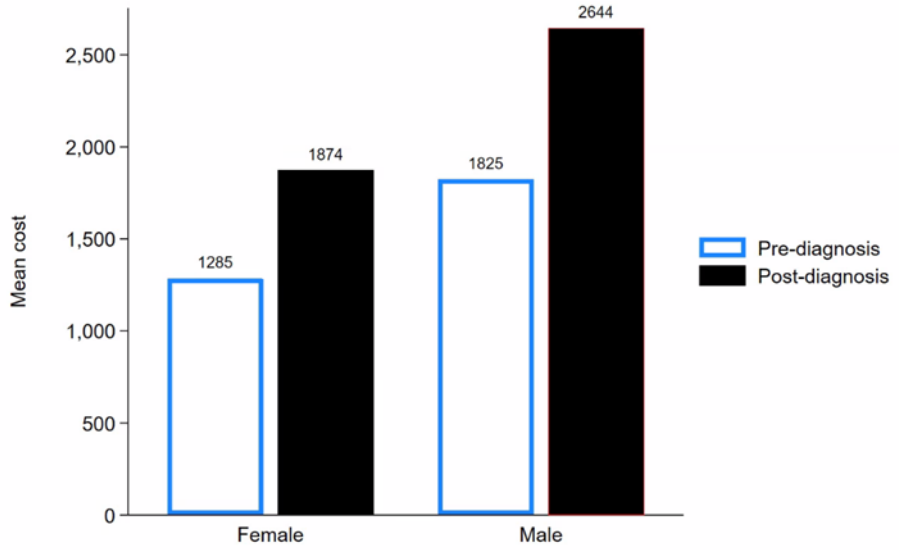


Figure 6.4 Mean total costs for the whole cohort by gender

6.5.2.1.2 Age

The proportion of service users in each age group was similar and decreased after diagnosis compared with before.

Total costs pre-/post-diagnosis for the whole cohort were analysed by age group category (Figure 6.5 and Figure 6.6). The results showed that costs decreased with age, both pre- and post-diagnosis. Patients aged under 65 years had the highest mean total costs pre- and post-diagnosis (£2,272; £3,049).

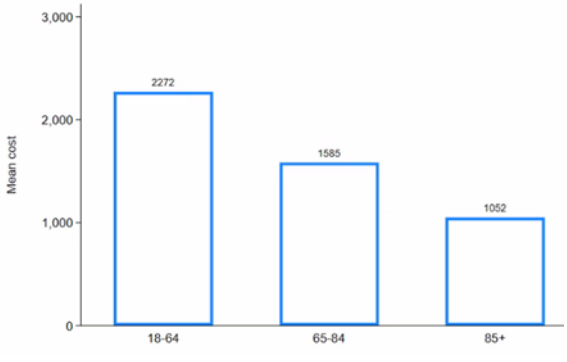


Figure 6.5 Mean total costs for the whole cohort pre-diagnosis by age

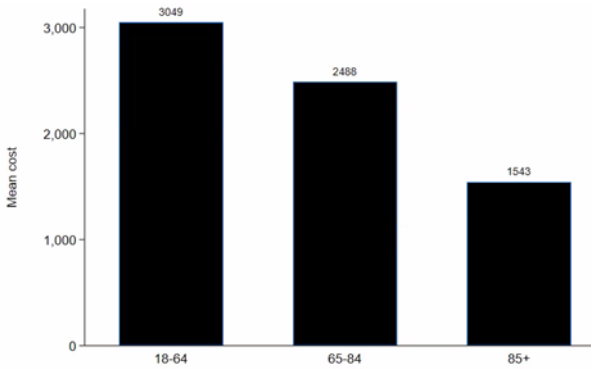


Figure 6.6 Mean total costs for the whole cohort post-diagnosis by age

6.5.2.1.3 Primary diagnosis

Results showed that similar proportions of patients with dementia (90.86%) and MCI (89.10%) used services pre-diagnosis. Differences in service use were shown post-diagnosis, when patients with MCI used services less than did patients with dementia. Patients with dementia used services more intensively than patients with MCI pre- and post-diagnosis, as demonstrated by differences in the mean number of contacts.

Total service costs for the whole cohort pre-/post-diagnosis by primary diagnosis were analysed (Figure 6.7). The costs for patients with dementia, pre- and post-diagnosis, were almost twice as high (£1,655; £2,434) as those for patients with MCI (£768; £986). Costs increased post-diagnosis for patients with MCI and dementia.

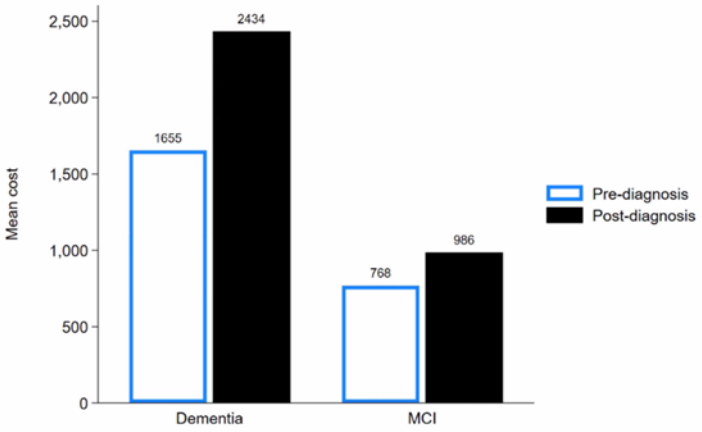


Figure 6.7 Mean total costs for the whole cohort by primary diagnosis

6.5.2.1.4 Ethnicity

Total service costs pre-/post-diagnosis by ethnicity are presented (Figure 6.8). No major difference was observed in the likelihood of service use among different ethnic groups. Patients with White non-British ethnicity had the highest costs pre-diagnosis, but this trend shifted after diagnosis, with the Black ethnicity group experiencing the highest post-diagnosis costs. Specifically, Black patients incurred £2,806 in costs post-diagnosis, while Asian patients had the lowest costs at £1,150 during the same period.

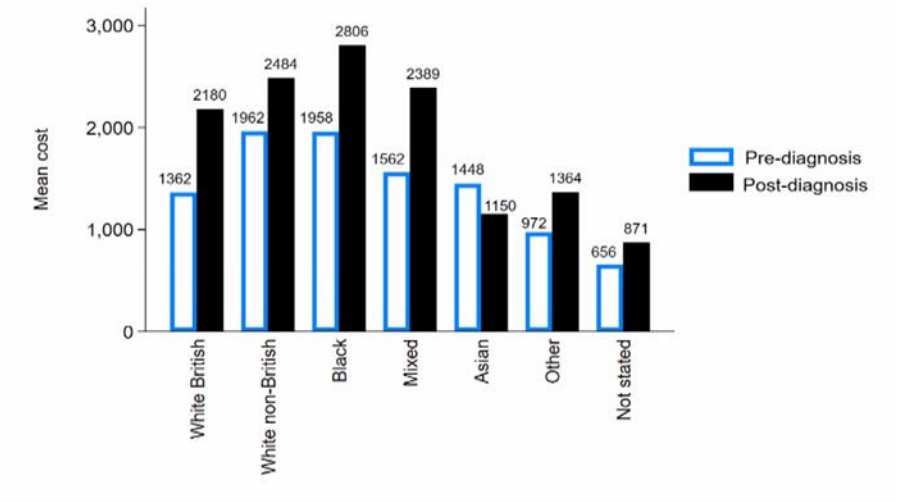


Figure 6.8 Mean total costs for the whole cohort by ethnicity

6.5.2.2 Living situation

The rate of service use was similar for patients living alone (91.80%; 70.39%) and patients living with someone (92.36%; 72.69%), both pre- and post-diagnosis.

Total service costs pre-/post-diagnosis by living situation are presented (Figure 6.9). Costs post-diagnosis increased for all categories. Patients who lived alone had the highest total mean costs pre-/post-diagnosis (£1,628; £2,431); those for patients not living alone are shown (£1,468; £2,075). It is acknowledged that these results may be skewed by the large proportion of missing data (unknown = 33%).

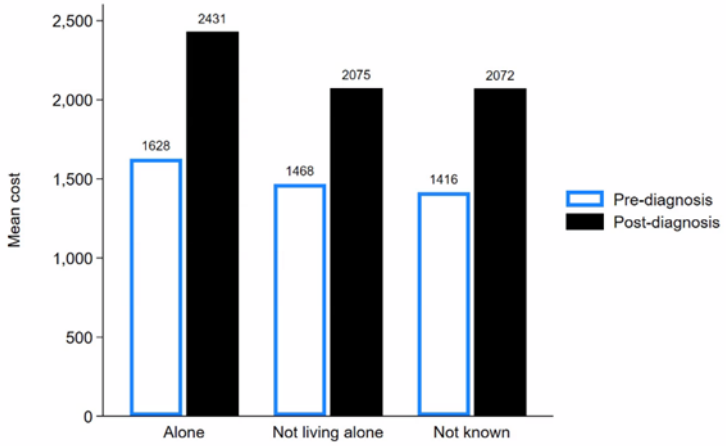


Figure 6.9 Mean total costs for the whole cohort by living situation

6.5.2.3 MMSE score

Dementia severity as categorised by MMSE score did not affect the proportions of patients who used services, which were similar for all categories of severity both pre- and post-diagnosis.

Total service costs pre-/post-diagnosis by dementia severity as categorised by MMSE score are presented (Figure 6.10 and Figure 6.11). Post-diagnosis costs increased with dementia severity. Costs post-diagnosis increased for all categories except for patients with normal cognition, which showed a slight decrease in costs post-diagnosis. As might be expected, patients with severe dementia had the highest costs of all groups, both pre- and post-diagnosis. Patients with severe dementia had the highest mean total costs pre-/post-diagnosis (£2,337; £3,853). Post-diagnosis costs were slightly lower than pre-diagnosis costs for patients in the mild category. Patients with moderate dementia (£1,290) had the lowest costs pre-diagnosis. However, after diagnosis, patients with normal cognition had the lowest costs (£1,410).

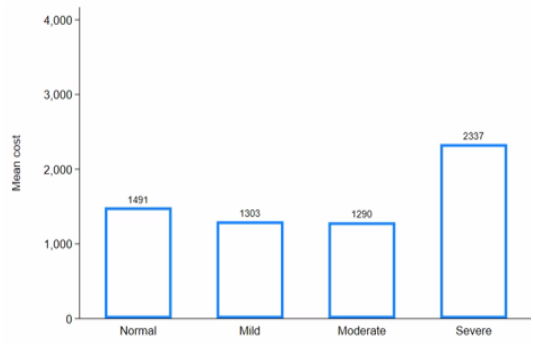


Figure 6.10 Mean total costs pre-diagnosis for the whole cohort by MMSE score

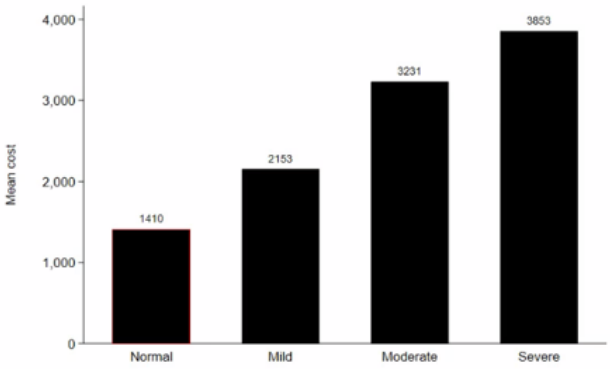


Figure 6.11 Mean total costs post-diagnosis for the whole cohort by MMSE score

6.5.2.4 HoNOS score

HoNOS score did not affect the rate of service use pre-diagnosis. However, post-diagnosis, a greater proportion of patients with HoNOS scores of 25+ were using services. Post-diagnosis costs were significantly higher than pre-diagnosis. Although HoNOS score did not affect the rate of service use, patients with HoNOS scores of 25 or higher incurred the highest costs pre- and post-diagnosis among groups in the

subgroup analysis. Patients with HoNOS scores of 25 or higher had the highest average costs per person (£7,762; £17,084) pre- and post-diagnosis.

Total service costs pre-/post-diagnosis by HoNOS score category are presented (Figure 6.12 and Figure 6.13). Higher HoNOS scores indicate poorer mental health and costs increased as HoNOS scores increased. Post-diagnosis costs increased for all categories of dementia severity. Patients with the highest HoNOS scores had the highest costs (pre-diagnosis £7,251; post-diagnosis £10,556). The lowest costs were shown for patients with fewer mental health outcomes (pre-diagnosis £1,174; post-diagnosis £16,261).

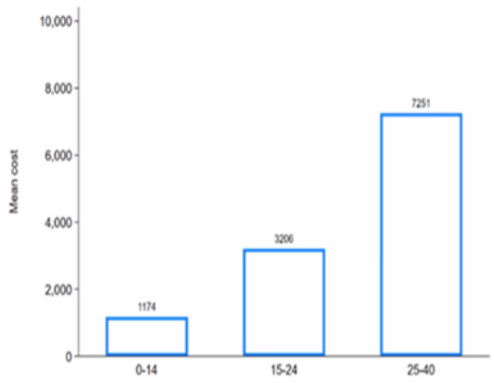


Figure 6.12 Mean total costs pre-diagnosis for the whole cohort by HoNOS category

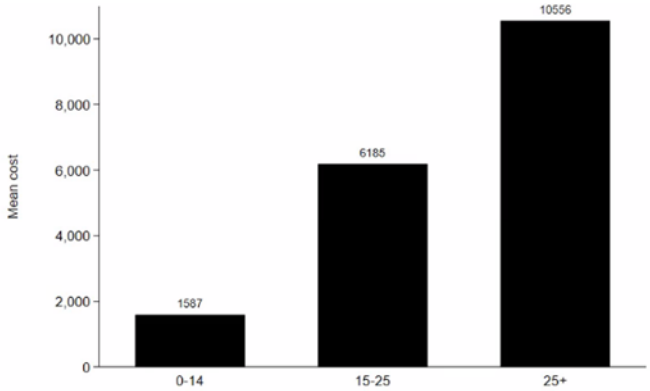


Figure 6.13 Mean total costs post-diagnosis for the whole cohort by HoNOS category

6.5.3 Inferential statistics

6.5.3.1 T-tests of total costs

Total costs data were observed for normality and skewness using histograms and the Shapiro-Wilk test. The results indicated that the data were not normally distributed, with a large proportion of individuals incurring low costs, while a smaller number showed high costs. A Wilcoxon matched pairs signed rank test (Wilcoxon, 1945) was run to compare the distributions of mean total costs pre- and post-diagnosis. The test revealed a significant difference between the distributions ($p<0.05$). Given the non-normal distribution of the data and the large sample size, t-tests were deemed reliable for further data analysis despite these characteristics. The threshold for significance was set at $p<0.05$.

A paired t-test was run to determine whether there was a statistically significant mean difference between total costs, pre- and post-diagnosis, for service users and the whole cohort (Table 6.17). Results showed a statistically significant difference between costs pre- and post-diagnosis ($p<0.05$). Mean costs for the whole cohort were higher pre-diagnosis, which suggests that there was a reduction in costs after diagnosis. The high t-value supports this finding (9.4944). However, for service users, costs significantly increased after diagnosis compared with before (0.69 before; 0.91 after). This suggests that overall costs significantly decreased for the whole cohort after diagnosis, but increased for service users, which may reflect more intensive service use by patients who used the services.

Table 6.17 Paired t-test results – total costs by time period

	Whole cohort				
	Mean (£)	**SD (£)**	**df**	**t**	**p**
Pre-diagnosis	2,177	10,240			
Post-diagnosis	1,497	8,049	16,080	9.4944	p< 0.001

Two-sample t-tests with equal variances were then run on the subgroups of gender and primary diagnosis to determine whether there was a statistically significant mean difference in total costs.

Results of the analysis by gender are shown in Table 6.18. The results showed that the observed difference in total service use costs between men and women across the whole cohort was significant both pre- and post-diagnosis ($p<0.05$). Males incurred costs that were significantly higher than those incurred by females, both pre- and post-diagnosis. For service users, the observed difference in costs was not significant between genders.

Table 6.18 Two-sample t-test results – total costs by gender

	Female		**Male**				
	Mean (£)	**SD (£)**	**Mean (£)**	**SD (£)**	**df**	**t**	**p**
Pre-diagnosis							
Service users	0.91	0.29	0.90	0.29	16,079	0.5259	0.5990
Whole cohort	1,285	7,063	1,825	9,360	16,079	-4.1159	p< 0.001
Post- diagnosis							
Service users	0.70	0.46	0.69	0.46	16,079	0.7416	0.4583

Whole cohort	1,874	9,012	2,644	11,875	16,079	-4.6602	p< 0.001

The results of the analysis of total costs pre-/post-diagnosis by primary diagnosis are shown in Table 6.19. Results showed that for the whole cohort and for service users there was a significant association between primary diagnosis and costs. Patients with dementia had costs that were significantly higher than patients with MCI.

Table 6.19 Two-sample t-test results – total costs by primary diagnosis

	Dementia		**MCI**				
	Mean (£)	**SD (£)**	**Mean (£)**	**SD (£)**	**df**	**t**	**p**
Pre-diagnosis							
Service users	0.91	0.29	0.89	0.31	16,079	2.9239	0.0035
Whole cohort	1,655	8,743	768	3,174	16,079	5.3410	p< 0.001
Post-diagnosis							
Service users	0.72	0.45	0.57	0.50	16,079	16.0516	p< 0.001
Whole cohort	2,434	10,996	986	5,350	16,079	6.8597	p< 0.001

6.5.4 ANOVA

Analysis of variance (ANOVA) tests were carried out to test for significant differences in whole cohort total costs between subgroups. The effects of age, ethnicity, living situation and MMSE and HoNOS scores and their interaction on total costs were examined.

One-way ANOVA tests were conducted on all subgroups with variables with three or more categories: age, ethnicity, living situation and MMSE and HoNOS scores. Results appear in order of significance. All one-way ANOVA tests showed a significant difference in costs within subgroups, except living situation (Table 6.20).

The results showed a significant effect of HoNOS scores on total costs, both pre-diagnosis ($f=99.54$, $p<0.05$) and post-diagnosis ($f=144.44$, $p<0.05$). This showed that costs were significantly influenced by severity of mental health symptoms. Significant associations were shown between MMSE scores and costs pre- and post-diagnosis ($f=6.54$, $p<0.05$; $f=15.58$, $p<0.05$). This suggests that the level of cognitive function influenced costs.

Table 6.20 Results of one-way ANOVA tests on total costs and subgroups

	Pre-diagnosis			Post-diagnosis		
	df	**f**	**p**	**df**	**f**	**p**
HoNOS score	2	99.54	p< 0.001	2	144.44	p< 0.001
Age group	2	13.04	p< 0.001	2	19.13	p< 0.001
Ethnicity	6	4.78	0.0001	6	6.51	p< 0.001
MMSE score	3	6.54	0.0002	3	15.58	p< 0.001
Living situation	2	0.92	0.3990	2	2.01	0.1335

6.5.5 Regression

The results of the univariable linear regression are shown in Table 6.21.The regression coefficients (Coef.) indicate how much the total service costs changed with a one-unit increase in the independent variable. The 95% CIs provide a range within which the true coefficient likely falls.

The results showed that primary diagnosis was a significant predictor of total costs pre-diagnosis; these costs were lower for MCI (-£877) than for dementia. Living situation was also a significant predictor of total costs; living with someone predicted lower costs (-£159) than living alone. Patients with MCI and patients who lived with someone continued to show negative association with costs post-diagnosis.

Ethnicity showed a significant association with total costs pre-/post-diagnosis. Patients categorised as ‘other’ ethnicity and unknown categories of ethnicity had lower total costs than patients from White non-British, Black, Mixed and Asian ethnicities, who showed a positive association with costs.

There was a significant negative association between total costs and age; as age increased, costs decreased (-£39; -£56 pre/post-diagnosis respectively).

The main difference results for MMSE and HoNOS scores predicted by the regression model showed a significant association between scores and total costs. There was a negative association between MMSE and total costs. Costs were lower for patients with higher MMSE scores (indicating more severe dementia) at -£27 pre-diagnosis and -£1 post-diagnosis. There was a positive association between HoNOS score and total costs. With higher HoNOS scores (indicating worsening health and social functioning), costs increased to +£194 pre-diagnosis and +£188 post-diagnosis. QoL scores mapped from MMSE scores showed a significant negative association with

costs. With higher QoL scores, indicating a better quality of life, there were lower total costs pre- and post-diagnosis.

Table 6.21 Univariable regression: effects on total service costs pre-/post-diagnosis

	Univariable regression			
	Pre-diagnosis		Post-diagnosis	
Independent variable	**Coef.**	**95% CI**	**Coef.**	**95% CI**
Gender (male)	540	285 to 794	770	446 to 1,094
Age	-39	-52 to -25	-56	-73 to -40
Primary diagnosis (MCI)	-887	-1,212 to -561	-1,448	-1,862 to -1,034
Ethnicity				
White non-British	600	183 to 1,018	304	-226 to 835
Black	596	263 to 930	626	203 to 1,050
Mixed	200	-1,094 to 1,493	209	-1,436 to 1,854
Asian	87	433 to 606	-1,029	-1,690 to -369
'Other' ethnicity	-390	-1,182 to 402	-815	-1,823 to 192
Unknown	-706	-1,283 to -128	-1,309	-2,043 to -574
Living situation				
Lived with someone	-159	-466 to 147	-356	-745 to 34
Unknown	-211	-529 to 106	-358	-762 to 46
MMSE score	-27	-46 to 9	-1	-2 to -1
MMSE score (severe category excluded)	-533	-852 to -214	-497	-933 to -60
HoNOS score	194	168 to 219	-4	-4 to -3
QoL score (from MMSE)	-920	-1,555 to -287	-4,642	-4,794 to -3,490

The overall results of multivariable regression across total costs pre-/post-diagnosis are shown in Table 6.22. These results show that all variables were statistically significant predictors of total costs pre-/post-diagnosis ($p<0.001$), due partly to the large sample size.

Pre-diagnosis, total costs increased with gender and ethnicity: males (+£493), White non-British ethnicity (+£451), Black ethnicity (+£88), mixed ethnicity (+£269). Costs decreased with each additional year of age pre-diagnosis (-£61) and post-diagnosis (-£56). The reduction in costs with age was slightly greater post-diagnosis. Total costs pre-diagnosis increased as HoNOS score increased (+£188). Post-diagnosis results showed that gender and ethnicity affected costs. Higher costs were predicted for males (+£1,493) and Black ethnicity (+£481). Living with someone was associated with lower costs (-£1,317). Gender consistently affected costs in both periods, with a

larger effect post-diagnosis. Primary diagnosis led to significantly lower costs in both periods, with a stronger effect post-diagnosis.

Each additional point of MMSE score was associated with a £27 decrease in total service costs, per person, pre-diagnosis, and a decrease of £1 post-diagnosis. People with lower MMSE scores, indicating more severe dementia, would have higher total costs.

The multivariable regression for MMSE score was also run excluding MMSE scores representing severe dementia (with a score of 9 or below). Without including people with severe dementia, results showed a £533 decrease in total costs pre-diagnosis and a decrease of £497 post-diagnosis. Patients with worsening cognitive function continued to have high costs, even when the patients with the most severe conditions were removed from the analysis.

Table 6.22 Multivariable regression: effects on total service costs pre-/post-diagnosis

	Multivariable regression			
	Pre-diagnosis		**Post-diagnosis**	
Independent variable	**Coef.**	**95% CI**	**Coef.**	**95% CI**
Gender (male)	493	234 to 752	1,493	753 to 2,233
Age	-61	-77 to -45	-179	-225 to -133
Primary diagnosis (MCI)	-707	-1,061 to -352	-1,108	-2,154 to -63
Ethnicity				
White non-British	451	33 to 870	-645	-1,788 to 498
Black	88	-2,478 to 423	481	-462 to 1,423
Mixed	269	-1,077 to 1,614	-1,010	-4,766 to 2,747
Asian	-78	-603 to 446	-1,740	-3,292 to -188
'Other' ethnicity	-313	-1,126 to 499	-1,761	-4,426 to -905
Unknown	-582	-1,246 to 83	-1,342	-4,006 to 1,322
Living situation				
Lived with someone	-361	-702 to -19	-1,317	-2,131 to -503
Unknown	-165	-488 to 158	651	-346 to 1,647
MMSE score	25	3 to 47	-40	-102 to 22
HoNOS score	188	163 to 214	517	444 to 591
Constant	4,116	2,641 to 5,590	14,347	10,098 to 18,596

Model diagnostics: Model fit was modest (Pre-diagnosis: $R^2 = 0.027$, adjusted $R^2 = 0.026$; Post-diagnosis: $R^2 = 0.065$, adjusted $R^2 = 0.063$) which is expected given the heterogeneity of healthcare cost data. Assumptions of linearity, independence, and homoscedasticity were broadly met. Multicollinearity was minimal (Mean VIF = 1.15 pre-diagnosis, 1.12 post-diagnosis; all VIF < 5)

Multiple regression was repeated with the severe category of MMSE excluded. Results are shown in Table 6.23.

Table 6.23 Multivariable regression: effects on total service costs pre-/post-diagnosis with severe MMSE excluded

	Multivariable regression			
	Pre-diagnosis		**Post-diagnosis**	
Independent variable	**Coef.**	**95% CI**	**Coef.**	**95% CI**
Gender (male)	382	-1262 to 2026	2950	-164 to 6065
Age	-74	-174 to 26	-151	-341 to 40
Primary diagnosis (MCI)	-1441	-6140 to 3257	-4086	12283 to 4111
Ethnicity				
White non-British	5006	2568 to 7443	3816	-857 to 8488
Black	1067	-930 to 3064	1051	-2485 to 4588
Mixed	-638	-8075 to 6799	-1471	-16884 to 13941
Asian	-552	-3559 to 2456	-2271	-9414 to 4872
'Other' ethnicity	-997	-5675 to 3680	-32	-13743 to 13678
Unknown	-791	-5354 to 3324	881	-13070 to 14832
Living situation				
Lives with someone	-1535	-3511 to 442	-307	-3809 to 3195
Unknown	-791	-2966 to 1383	-593	-4853 to 3667
MMSE score (with severe category excluded)	-519	-853 to -185	-741	-1377 to -106
HoNOS score	128	-12 to 268	349	35 to 662
Constant	10113	1367 to 18858	16432	45 to 32818

Model diagnostics: Model fit was modest (Pre-diagnosis: $R^2 = 0.042$, adjusted $R^2 = 0.028$; Post-diagnosis: $R^2 = 0.056$, adjusted $R^2 = 0.025$), which is expected given the variability of healthcare cost data. Assumptions of linearity, independence, and homoscedasticity were broadly met. Residuals showed positive skew, consistent with healthcare cost data, as indicated by the normal probability plot. Multicollinearity was minimal (Mean VIF = 1.14 pre-diagnosis, 1.11 post-diagnosis; all VIF < 5)

6.5.6 Sensitivity analysis

One-way sensitivity analysis was used to test the robustness of cost estimates and conclusions under different scenarios by varying the unit costs. This helped to explore the potential impact of changes to service costs. Sensitivity analysis ensures the stability of the findings even if costs are higher or lower than initially estimated in the base case analysis. The values used in the sensitivity analysis are detailed (Table 6.24).

Table 6.24 Sensitivity analysis values

	Cost per unit (used in base case)	Per	Cost per unit (sensitivity analysis +25%)	Cost per unit (sensitivity analysis +50%)
Inpatient service costs				
Inpatient days	£341	Bed day	£426	£512
Outpatient service costs				
In-person contacts	£235	Outpatient contact	£294	£353
Indirect contacts	£58.75	Outpatient contact	£74	£88
Memory clinic service costs				
In-person contacts	£66	Hour	£83	£99
Indirect contacts	£16.50	Hour	£21	£25

A summary of the results of the first sensitivity analysis, in which service use costs were increased by 25%, is shown in Table 6.25. The sensitivity analyses confirmed that the pre-diagnosis cost estimates were sensitive to changes in unit costs. The large percentage increases for service users in the post-diagnosis phase showed that they were disproportionately affected by the cost increase. The whole cohort analysis showed this to a lesser extent, as the impact of cost changes was averaged over patients who did not use the services, and so changes were less noticeable. The observed differences were magnified by increasing the costs by 50% (Table 6.26).

Table 6.25 Summary of impact on total mean cost of increasing service use costs by 25%

	Pre-diagnosis costs +25%						Post-diagnosis costs +25%					
	Service user costs only			Whole cohort costs			Service user costs only			Whole cohort costs		
Service cost varied	**Mean (SD) cost for service users only (per person)**	**Median cost for service users only (per person)**	**Total % difference in mean cost from base case**	**Mean (SD) cost for whole cohort (per person)**	**Median cost for whole cohort (per person)**	**Total % difference in mean cost from base case**	**Mean (SD) cost for service users only (per person)**	**Median cost for service users only (per person)**	**Total % difference in mean cost from base case**	**Mean (SD) cost for whole cohort (per person)**	**Median cost for whole cohort (per person)**	**Total % difference in mean cost from base case**
Inpatient days	1,858 (10,452)	536	-95%	1,683 (9,961)	470	126%	3,590 (15,041)	602	2716%	2,488 (12,631)	301	99%
In-person contacts	1,844 (8,551)	654	141%	1,670 (8,155)	588	143%	3,457 (12,366)	720	63448%	2,396 (10,418)	360	175%
Indirect contacts	1,654 (8,443)	536	2105%	1,497 (8,048)	470	149600%	3,142 (12,176)	602	87665%	2,178 (10,240)	301	43460%
In-person memory clinic contacts	1,672 (8,441)	553	1293%	1,514 (8,047)	470	2160%	3,159 (12,172)	636	159445%	2,190 (10,238)	318	4194%
Indirect memory clinic contacts	1,654 (8,443)	536	7776%	1,497 (8,048)	470	N/A	3,141 (12,175)	602	143983%	2,177 (10,239)	301	N/A

Table 6.26 Summary of impact on total mean cost of increasing service use costs by 50%

	Pre-diagnosis costs +50%						Post-diagnosis costs +50%					
	Service user costs only			Whole cohort costs			Service user costs only			Whole cohort costs		
	Mean (SD) cost for service users only (per person)	Median cost for service users only (per person)	Total % difference in mean cost from base case	Mean (SD) cost for whole cohort (per person)	Median cost for whole cohort (per person)	Total % difference in mean cost from base case	Mean (SD) cost for service users only (per person)	Median cost for service users only (per person)	Total % difference in mean cost from base case	Mean (SD) cost for whole cohort (per person)	Median cost for whole cohort (per person)	Total % difference in mean cost from base case
Inpatient days	2,065 (12,491)	536	-94%	1,870 (11,901)	470	151%	4,044 (17,952)	602	3072%	2,803 (15,062)	301	124%
In-person contacts	2,034 (8,671)	772	166%	1,841 (8,272)	706	168%	3,772 (12,575)	838	69238%	2,615 (10,613)	419	200%
Indirect contacts	1,654 (8,443)	536	2105%	1,498 (8,048)	470	149700%	3,144 (12,176)	602	87721%	2,179 (10,240)	301	43480%
In-person memory clinic contacts	1,690 (8,440)	569	1308%	1,531 (8,046)	470	2185%	3,177 (12,170)	668	160355%	2,202 (10,237)	334	4218%
Indirect memory clinic contacts	1,654 (8,443)	536	7776%	1,497 (8,048)	470	N/A	3,141 (12,175)	602	143983%	2,177 (10,239)	301	N/A

6.6 Discussion

The analysis of the data from a UK cohort of patients with dementia/MCI who used mental health services at an NHS Trust in London, UK, found that more patients used mental health services pre-diagnosis than post-diagnosis. However, services were used more intensively post-diagnosis, and this resulted in a higher cost of care per patient post-diagnosis. Patients with dementia had higher total costs than patients with MCI, both before and after diagnosis. Those of male gender who lived alone, were of increased age, who identified as White non-British or 'other' ethnicity, and who had lower MMSE scores, higher HoNOS scores, and primary diagnoses of dementia were all significantly associated with higher service use costs.

Inpatient care was the most expensive service, with costs increasing significantly after diagnosis compared with before. Patients with dementia used inpatient services more intensively after diagnosis and had more hospital days, which significantly contributed to higher costs. These results align with previous research findings, which have shown that patients with dementia are more likely to be hospitalised (Weber, Pirraglia and Kunik, 2011; Shepherd *et al.*, 2019), re-admitted to hospital (Tropea *et al.*, 2017) and have longer hospital stays (Power *et al.*, 2017; Tropea *et al.*, 2017) compared with patients with MCI or normal cognition.

The findings of this analysis show that in this cohort, only 3% of patients were admitted to hospital. Findings from other studies show much higher rates of admission, with approximately half of all patients being admitted in the period after diagnosis (Mueller *et al.*, 2018; Sommerlad *et al.*, 2019). The lower number of admission rates in the analysis performed for this thesis could be due to the impact of the pandemic, which saw a reduction in the number of non-emergency admissions due to the pressures it caused on NHS services (Health Foundation, 2020).

In the study performed for this thesis, the inpatient cost for patients who lived alone was higher than that for patients who lived with someone. Living alone has been previously reported as a predictor of hospital admission and higher costs (Knapp *et al.*, 2016) and extended hospital stays (Agosti *et al.*, 2018). Social isolation and lack of support may affect rates of use of mental health services. Individuals who live by themselves may lack the consistent, in-home caregiving support that can delay or

prevent hospital admission. Family caregivers or spouses typically provide crucial support at home to individuals with dementia, helping to manage daily care needs and reduce the likelihood of hospital admissions. During the pandemic many social care and support services closed, meaning that many PLwD and caregivers struggled to find support (Giebel *et al.*, 2021b). This lack of support may have most affected patients who lived alone and may be responsible for the increase in inpatient admissions. Social support plays a significant role in how soon after treatment a patient is discharged from hospital to the community; patients who do not live alone can be discharged more readily as they have someone at home to help them (Provencher *et al.*, 2020). The data analysis showed that after diagnosis, patients living alone had more contacts with all types of services than did patients who lived with someone.

Gender was shown to significantly affect service use and associated costs. Men had higher inpatient costs and service use. Previous research has highlighted how gender affects healthcare access (Ladwig *et al.*, 2000). Gender-related social roles and caregiving responsibilities may impact healthcare needs and service use among different groups (Albizu-Garcia *et al.*, 2001; Brodaty and Donkin, 2009). Previous studies, however, have found that women were more likely to use healthcare services than men due to differences in health-seeking behaviour and the types of conditions they experienced (Ladwig *et al.*, 2000). The reason for this may be that women with a history of previous mental health service use are more likely to access mental health services than are patients who have not used these services before (Albizu-Garcia *et al.*, 2001).

Memory clinic services were mostly accessed before diagnosis rather than after. This finding was expected, as patients with suspected MCI/dementia are commonly referred to mental health services for assessment at a memory clinic pre-diagnosis. The decrease in memory clinic use post-diagnosis may be due to the tendency in the UK for patients to be managed in the community by their GP after diagnosis (Weber, Pirraglia and Kunik, 2011; Koychev *et al.*, 2024). During the COVID-19 pandemic, there was a reduction in rates of diagnosis of dementia and patients struggled to access GP appointments and memory clinic services (Hazan *et al.*, 2023). As this data analysis covered care during the pandemic period, this may partly account for fewer patients accessing memory clinic services post-diagnosis, as many secondary care

services had not returned to pre-pandemic levels. This is in agreement with previous research, which observed higher costs of care for patients with dementia compared with non-dementia (Briggs *et al.*, 2016).

After a dementia diagnosis, patients generally used in-person services less frequently than they did before their diagnosis. This decline may be linked to reduced service availability during the COVID-19 pandemic. While fewer patients had in-person appointments post-diagnosis, those who did had more frequent interactions than pre-diagnosis, resulting in higher costs for service users.

Ethnic cost differences were observed. These suggest significant disparities in healthcare utilisation and associated costs. Patients who identified as White and non-British were least likely to seek help from memory clinic services before their diagnosis. This could stem from cultural factors such as language barriers and misconceptions about the disease, which may cause delays in seeking dementia diagnosis and subsequent care (Mukadam, Basit and Livingston, 2011; Nielsen *et al.*, 2011). Patients of Asian and 'other' ethnicities had the lowest rates of inpatient admissions of all ethnicities. This may be due to a cultural tendency for patients from these ethnic minority groups to look after older family members (Mukadam, Basit and Livingston, 2011). Variations in inpatient service use across ethnic groups could also be linked to factors such as inequalities in access to healthcare services and inadequacies in the healthcare system, such as a lack of cultural awareness and diversity (Kenning *et al.*, 2017). Additionally, disparities in socioeconomic factors, including income, housing, and community support, might contribute to these differences.

Dementia severity was shown to impact costs, which increased as dementia severity increased. These findings have been confirmed in previous research, which has indicated that per-person post-diagnosis costs increase with the severity of dementia (Leniz *et al.*, 2021; Wimo *et al.*, 2023). The increasing costs with severity emphasise the financial strain that the disease places on healthcare systems. Published figures show that the average cost of care per person with mild dementia in the UK is £28,700; with moderate dementia, £42,900; and with severe dementia, £80,500 (Carnall Farrar, 2024). Similarly, the global annual cost per person in 2019 increased with the severity of the dementia, with estimates of US$15,899 for mild dementia, US$26,859 for moderate dementia and US$36,180 for severe dementia (Wimo *et al.*, 2023).

Age was shown to be significantly associated with total costs. Inpatient costs were highest for patients aged under 64 years and decreased as age increased. This finding is likely related to the fact that the analysis only includes NHS costs. As PLwD age and move into later-stage symptoms, their care needs may shift away from NHS diagnostic and treatment services and more toward social care and family support, which are not captured in this dataset. Therefore, the observed reduction in NHS costs with increasing age does not necessarily indicate lower overall care needs, but rather a shift in the type and source of care provided, with a greater proportion being met outside the NHS. Despite the higher cost of inpatient care that was found for the younger age group, published research suggests that older age is associated with increased numbers of hospital admissions (Shepherd *et al.*, 2019), longer hospital stays and higher costs (Prince *et al.*, 2016). The high costs shown in the findings of the data analysis in this chapter may be due to admission for other co-morbid mental health conditions and may not relate exclusively to MCI or dementia.

Quality of life was a key consideration in the data analysis, with patients demonstrating reduced QALYs compared with people who do not have dementia. This finding aligns with previous research that has also reported diminished quality of life among PLwD (Banerjee, 2015).

6.7 Limitations

Strengths of this data analysis include the large sample size and range of data available. However, it is acknowledged that the data was from a UK population during the COVID-19 pandemic and as such, results may not be generalisable to PLwD outside the UK or the pandemic period. As discussed, the pandemic had an impact on health service utilisation. This was due to numerous factors such as differences in healthcare systems, social care models, population demographics, and available services. The NHS and its community care frameworks are distinct and influence healthcare delivery and associated outcomes. Additionally, the cultural context, support structures, and socioeconomic factors in the UK can differ significantly from those in other countries.

Patients in the database may not be representative of all PLwD who use mental health services in the UK. London has a diverse population, which includes significant ethnic variation and socioeconomic disparities. These factors can greatly influence access to and use of mental health services. Areas with elevated levels of deprivation, common in parts of London, can lead to particular healthcare challenges and outcomes that may not be generalisable to other regions of the UK.

Service use may not have been accurately or comprehensively recorded in the database. This may have led to underreporting or underestimation. Inaccurate data may be due to factors such as incomplete data entry, misclassification of service types, or limitations in how services are tracked across different systems of healthcare records. Therefore, it is accepted that figures reported here may be underestimates. Patients may also have been lost to follow-up, untraced or unreported.

The original database included only a binary classification of gender as male or female. While categorising gender in this binary way is common in many clinical settings, it may not fully capture the complexity of gender identity in clinical research (Lindqvist, Sendén and Renström, 2021). As the male gender was found to be associated with increased service use and cost, it would be interesting to have been able to view more comprehensive gender data. This would have helped to reflect the full spectrum of patients' identities and ensure that the findings were more inclusive and representative. Use of a binary gender classification may have led to these differences being overlooked and a failure to address potential variations in healthcare needs and treatment experiences among different gender identities. This limitation should be considered during the interpretation of any gender-related findings, as it may affect the generalisability and inclusivity of the results.

Care home data were not well recorded in the database. Therefore, they were not included in the data analysis. This is because the analysis is an NHS costs analysis from a database used to reflect mental health service provision. Most care home services are not provided through the NHS but are funded through local authorities or self-funded arrangements, so cost of care home services cannot be attributed to the NHS. This could limit the findings in relation to incomplete data for PLwD or MCI living in care homes and may have led to underrepresentation of individuals in long-term care settings.

There was missing data for some variables. Significant missing information can limit the accuracy and generalisability of findings related to the care and outcomes of individuals with dementia or MCI. This gap in data can affect a researcher's ability to understand the true impact of living arrangements on healthcare utilisation and caregiving dynamics. Improvement in the collection and completeness of such data in future research would offer more insights into what influences the need for long-term care and healthcare resource allocation.

The overall recorded use of indirect contacts (outpatient and memory clinics) was low (≤2%). This may be due to underreporting or a sign that these types of interactions occur infrequently.

A limitation of this study was that the mapping of MMSE scores to utility values was based on a preprint (Brazier, 2001), which has not been peer-reviewed. Although the method has been applied in previous research, its validity may be considered less robust than that of more established mapping algorithms. This should be considered when interpreting the resulting QALY estimates.

6.8 Conclusion

Data for analysis were obtained from a cohort of patients receiving care from a large mental health provider in the UK. This observational data enabled an examination of service use and outcomes. This provided insights into patterns of care and associated costs over specific periods pre- and post- diagnosis. Service use and costs pre-/post-diagnosis were compared across the cohort and analysed within subgroups. The analysis window for all the sampled patients spanned two years, divided into two one-year periods (before and after diagnosis) to facilitate comparisons between these timepoints.

Overall, mental health service use and associated costs were higher in the year after a formal diagnosis than before it. This pattern indicates that mental health services were used more frequently after diagnosis compared with before. This reflects a shift in the type or intensity of healthcare service utilisation following diagnosis as dementia progresses. This insight is crucial for healthcare commissioners as they plan the allocation of resources to services. They must ensure that resources are allocated efficiently and that care services are sufficiently supported. Efficient use of resources

can help to address short- and longer-term care needs and improve care and ongoing treatment (Chen *et al.*, 2014).

Age was observed to be a significant predictor of higher dementia-related costs, with younger individuals incurring higher costs than older individuals. This may be due to differences in service use patterns or care needs for younger PLwD. While the growing number of older adults living with chronic conditions such as dementia continues to place pressure on the healthcare system, these findings highlight the importance of recognising and addressing the distinct needs of younger PLwD. Ensuring that healthcare services are well-planned and efficiently managed is critical for the sustainable use of limited NHS resources. Effective planning should prioritise resource allocation that reflects the diverse and evolving needs across age groups, supporting both immediate and long-term care demands.

The findings of this data analysis also underline the importance of addressing ethnic inequalities in dementia care and ensuring that resources are allocated appropriately to manage the needs of all groups effectively.

The incremental rise in healthcare costs with dementia severity is largely attributed to the need for advanced medical, behavioural, and support interventions that are necessary to manage severe dementia symptoms effectively. As individuals age, the progression of dementia and related complications often requires more intensive and specialised care, which carries increased healthcare costs. In the later stages of dementia, many patients require specialised care in order to manage cognitive and behavioural challenges. Transfer to a care home typically occurs when a person's condition becomes too advanced for them to be safely managed at home, either due to the complexity of their care needs or a lack of family support.

Many people with dementia incur higher costs of mental health service use, which include lengthened hospital stays, due to a lack of community support services. This situation results in higher inpatient costs. Better dementia treatment and care in the community could reduce admission rates.

6.9 Chapter summary

In this chapter, patterns of mental health service use and associated costs of PLwD have been explored at a UK healthcare trust. The results show that PLwD often have higher costs and longer hospital stays after diagnosis than they have before diagnosis.

In the next chapter, an economic model to evaluate the cost-effectiveness of MT is presented. The selection of the NPT for the modelling evaluation was informed by the online survey, which was described in Chapter 5.

Chapter 7 Decision-analytic modelling of a music therapy intervention versus usual care for people with dementia who live in the community in the UK

7.1 Introduction

This chapter presents an economic evaluation of music therapy (MT) for improving the cognitive function of PLwD in a community setting in the UK. The model evaluates MT compared with usual care. Costs and outcomes are compared, and results are presented alongside a discussion of the findings of the model and implications. The choice of MT as the therapy evaluated in the model was informed by the results of the survey described in Chapter 5, which determined the research preferences of people with lived experience of dementia. Survey participants highlighted the importance of MT and expressed a clear preference for further research in this area.

7.2 Background

Music has been used throughout history to improve people's health. It is known to have therapeutic benefits that include reductions in stress levels and improved mental health (Mofredj *et al.*, 2016). There have been many reported benefits of music for PLwD. It positively affects language skills and can facilitate the recall of songs that were familiar many years before (McDermott *et al.*, 2013). It also addresses psychosocial needs by encouraging social interaction, reducing anxiety, and improving quality of life (Ting *et al.*, 2024). It can also slow the decline of cognitive function (Shimizu *et al.*, 2018). The ability of people to recall song lyrics despite other memory impairments highlights the multifaceted benefits of music, making it a valuable tool in dementia care. People are often able to recall song lyrics even when other types of memory are impaired. This can be attributed to several factors such as emotional resonance, repetition and rhythm, language processing, associative memory, visual and auditory integration, brain plasticity, and cultural and social factors (Liu, 2025).

MT is a structured intervention that uses musical experiences and the relationships that develop through them to support and promote health (Carr, Odell-Miller and

Priebe, 2013). Music is classed as MT if it is provided by a trained music therapist and if an interpersonal therapeutic relationship is established between the recipient and the therapist through the music (MacDonald, Kreutz and Mitchell, 2012). MT commonly involves a combination of melody, rhythm and harmony, which are cognitively processed by the brain to produce a therapeutic effect (Sihvonen *et al.*, 2017). MT was first reported to have been used as a complementary medical therapy in 1914, when it was introduced in clinical settings to enhance the psychological and emotional well-being of hospitalised patients (Mofredj *et al.*, 2016). Music can influence a person's physical and mental state; for instance, it can calm a patient before or during a medical procedure. However, such provision of music is not considered MT as it lacks the development of an interpersonal therapeutic relationship through the music (MacDonald, Kreutz and Mitchell, 2012).

In many studies of MT, its clinical effectiveness has been assessed. Studies have also shown that MT can be effective in addressing BPSD, such as depression, agitation and aggression, which are common in PLwD (van der Steen *et al.*, 2025). Additionally, MT has been associated with improvements in social interaction and communication skills. Engagement in music activities can encourage a sense of connection and reduce feelings of isolation among PLwD. MT has also been shown to improve relationships between caregivers and PLwD (Stedje *et al.*, 2023). These researchers reported benefits including enhanced closeness, intimacy and communication between the person with dementia and their spouse. Indeed, music-based activities such as singing groups are a popular and enjoyable activity for both caregivers and PLwD (Camic, Williams and Meeten, 2013; Dowson *et al.*, 2023).

It has been shown that MT can help to slow the decline in cognitive function by activating the neural networks related to cognitive function (Shimizu *et al.*, 2018). It engages auditory processing and activates frontal brain systems, thereby improving recognition, information processing and memory through the melody and rhythm (Ting *et al.*, 2024). The cognitive and sensory engagement activities involved in MT can encourage neuroplasticity, the brain’s ability to adapt, reorganise and form new neural connections (Ceccato *et al.*, 2012). MT has also shown promise in the improvement of sleep for PLwD (Rapaport *et al.*, 2024).

However, despite evidence of clinical effectiveness, there is limited evidence of the cost-effectiveness of MT (Livingston, Kelly, *et al.*, 2014; Gaviola, Searles and Dilworth, 2022; Riedl *et al.*, 2025). Few studies have provided economic evidence, so there is not sufficient reliable evidence to enable policy- and decision-makers to introduce MT into routine practice.

Economic modelling is a tool for the generation of necessary economic evidence. It involves a comparison of the costs and benefits of one intervention with those of its alternatives. By estimating outcomes and costs through the integration of data from multiple published sources, it can provide crucial insights into potential cost-effectiveness. Policy- and decision-makers often rely on economic modelling, especially when trial-based data are unavailable, to assess cost-effectiveness before introducing new therapies into routine care. While models are sometimes seen as a second-best option, they can offer greater generalisability than clinical trials as they can incorporate a wider range of data sources and simulate long-term outcomes beyond the trial context.

Given the lack of robust economic evaluations of MT for PLwD the aim of this research was to develop a model-based economic evaluation of MT. In the survey of people with lived experience of dementia in Chapter 5, MT emerged as a prioritised intervention. The selection of MT for the economic model was directly informed by these survey findings, which captured the perspectives of people with lived experience of dementia, who included family caregivers and professionals working in dementia care alongside people with dementia.

7.3 Aim

The aim of this part of the PhD study was to assess the cost-effectiveness of active MT compared with usual care for improving cognitive function in PLwD in the UK community setting. A decision-tree approach was adopted for an economic model, which used secondary data in the analyses. Determination of the cost-effectiveness of this intervention would have practical relevance for policy and decision-makers. The model that was developed in this thesis was designed to contribute new evidence on the cost-effectiveness of MT to add to the available evidence.

This chapter:

- provides a background of MT and its relevance in dementia care;
- develops a healthcare economic decision-tree model by which the cost-effectiveness of MT could be evaluated;
- presents the methods used to structure and populate the model; and
- discusses the findings and implications for policy, practice and future research.

7.4 Overview of MT in dementia care

MT is an evidence-based, person-centred intervention that uses music experiences to address emotional, cognitive, and social needs. In the context of dementia care, MT has shown promise in improving quality of life, reducing agitation, and supporting communication in PLwD, particularly in community settings in which ongoing engagement is critical.

To explore the potential effectiveness of MT a literature search was conducted in the Medline database to identify relevant RCTs and systematic reviews. The search strategy included the terms dementia or alzheimers or mild cognitive impairment (in title) AND music therapy (in title) and was limited to studies published between 1st January 2020 and 10th February 2025. Studies were included if they evaluated MT for PLwD and reported outcomes relating to quality of life or health measures. Articles were excluded if they focused on end-of-life populations. The reference lists of the included studies were also screened to identify additional relevant publications. Characteristics from these studies were extracted and are presented in Table 7.1 (results from RCTs), and in Table 7.2 (results from systematic reviews and meta-analyses).

This section outlines the key components of MT as delivered to community-dwelling PLwD, including its primary outcomes, delivery settings, therapeutic approaches (active versus receptive) and the role of facilitators. Practical considerations such as frequency of MT sessions, their duration, equipment needs, costs, and the influence of dementia stage on intervention suitability are also discussed. These aspects must be understood in order to inform decision-analytic modelling and economic evaluation of MT as an NPT.

7.4.1 Primary outcomes

Studies have used a range of validated tools to measure different outcomes in order to assess the effectiveness of MT in improving dementia situations. These outcomes typically include impacts on cognition, BPSD and quality of life. The tools include the MMSE, which is used to assess cognitive function through its standardised evaluation of memory, attention, language, and orientation (Han *et al.*, 2017; Giovagnoli *et al.*, 2018; Gomez-Gallego *et al.*, 2021; Cheour *et al.*, 2023); the Neuropsychiatric Inventory (NPI), which is widely used in dementia research to assess BPSD such as agitation and anxiety (Raglio *et al.*, 2015; Han *et al.*, 2017; Gomez-Gallego *et al.*, 2021); and the quality of life in AD scale (QoL-AD) (Han *et al.*, 2017; Prick *et al.*, 2024), which is designed to capture the subjective well-being of PLwD.

Some studies have also measured caregiver outcomes through the use of tools such as the Zarit Burden Interview (ZBI) (Prick *et al.*, 2024) and the hospital anxiety and depression scale (HADS) (Jimenez-Palomares *et al.*, 2024). This measurement recognises that MT can indirectly impact caregiver well-being. Together, these measures provide a broad picture of the cognitive, emotional, and social benefits that MT interventions can offer. However, the choice of outcome measures for use in MT studies is limited by the lack of such standardised, validated measures that are tailored to MT for dementia, and this lack hampers the ability to assess long-term benefits (McDermott *et al.*, 2013).

7.4.2 Therapeutic approaches

An MT session may include a variety of activities that are tailored to the needs of participants. This may involve elements of relaxation, cognitive stimulation, emotional expression, or social engagement. Additionally, it might involve playing instruments, singing, listening to music, rhythm, movement or dance, and sharing of ideas through discussion and reflection (Fusar-Poli *et al.*, 2018; Tsoi *et al.*, 2018). Understanding the musical preferences of participants and familiarity of the participants with the music are significant factors for success and acceptability of the sessions (Sung *et al.*, 2006; Tsoi *et al.*, 2018). Three main types of MT are commonly recognised: reminiscence, receptive and active (Gomez-Gallego *et al.*, 2021; Jordan, Lawlor and Loughrey, 2022). These are described next, along with examples of RCTs of each method.

7.4.2.1 Reminiscence MT

Reminiscence MT is intended to evoke memories by using familiar music (Jordan, Lawlor and Loughrey, 2022). A small-scale, exploratory study of group reminiscence MT took place with five PLwD in a care facility in Ireland (Kelly and Ahessy, 2021). In this study, a dementia care mapping tool was used to assess the quality of the intervention from the perspective of the PLwD, by observing the mood and engagement of participants during the sessions. The sessions lasted 45 minutes on average and were delivered once a week over a five-week period. Findings from the study indicated that group reminiscence MT was effective in enhancing quality of life and well-being by promoting positive mood, engagement and social interaction.

7.4.2.2 Receptive MT

Receptive MT involves participants actively listening to pre-recorded or live music rather than creating or performing the music themselves (Tsoi *et al.*, 2018). The music is selected by a music therapist based on the individuals' needs and preferences. A small-scale RCT of receptive MT was performed among 80 people in China who had MCI and depression (Xue *et al.*, 2023). The study showed significant improvements in cognitive function and reductions in levels of depression. Cognitive function was assessed through use of the Montreal Cognitive Assessment (MoCA), which is a widely used screening tool designed to detect cognitive impairments, particularly in individuals with MCI. The frequency of sessions was four times a week for eight weeks.

7.4.2.3 Active MT

Active MT encourages participants to contribute by singing, expressing their emotions or making their own musical sounds and rhythms by using musical instruments (Gomez-Gallego *et al.*, 2021). Active MT sessions often include movement in the form of dance or free movement to the music, such as tapping or stomping (Moreno-Morales *et al.*, 2020; Gomez-Gallego *et al.*, 2021; Aleixo *et al.*, 2022). Active MT can enhance movement through the use of rhythmic cues, which can help with the rehabilitation of the brain and nervous system. For example, in an RCT, Gomez-Gallego *et al.* (2021) assessed the effects of active versus receptive MT on cognition. Ninety people with moderate AD who lived in six nursing homes in a region of Spain took part. Their cognition was assessed using MMSE scores. Participants were randomly assigned to one of three groups: an active MT group that incorporated active

dance and rhythm movements to the music and encouraged the participants to engage actively; a receptive MT group whose members simply listened to music in a group; and a control group of participants who watched animal videos that did not contain any music (Gomez-Gallego *et al.*, 2021). The results showed that those who received the active MT showed improved cognitive function, reductions in behavioural symptoms and improved functional state compared with the control group (Gomez-Gallego *et al.*, 2021). It should be noted that all participants were already in receipt of CST and pharmacological therapies as part of their usual care.

In another RCT, Lyu (2018) also explored the effects of active MT on cognition, as well as its effect on BPSD and daily activities. It took place in China and involved 298 PLwD with varying degrees of AD severity (Lyu *et al.*, 2018). Cognitive function was assessed using MMSE scores. The researchers found that MT significantly improved verbal fluency and reduced psychiatric symptoms, including depression. Improvements in language skills were shown to last for three months after the MT had finished (Lyu *et al.*, 2018). Subgroup analysis indicated that MT enhanced memory and language abilities in mild AD and reduced psychiatric symptoms and caregiver distress in moderate to severe AD. There was no significant impact on the ADLs across any group. Active MT was concluded to be effective for enhancing cognition and mental well-being, and it was recommended as an alternative way to manage symptoms of AD.

In a study of PLWD in Italy, with mild dementia, Giovagnoli *et al.* (2018) investigated the effect of active MT plus pharmacotherapy (memantine) on cognitive function compared with memantine therapy alone. Forty-five PLwD attended MT sessions once a week for 25 minutes over 12 weeks (Giovagnoli *et al.*, 2018). Cognition was measured through application of the MMSE, neuropsychiatric symptoms using the NPI and language function using the severe impairment battery (SIB). The study concluded that active MT combined with pharmacotherapy contributed to reductions in neuropsychiatric symptoms in people living with moderate stage AD, but it did not enhance language function compared with pharmacotherapy alone.

To further understand the role of active MT, an RCT was conducted by Han *et al.* (2017). The researchers assessed the impact of a structured, multi-modal intervention that included MT. It took place in South Korea with 64 individuals with MCI or mild

dementia (Han *et al.*, 2017). A range of cognitive and physical therapeutic components were included: MT, art therapy, physical exercise, reminiscence therapy and social activities. The control group took part in non-specific social activities without the therapeutic components. Sessions of MT, each of which lasted for three hours, were conducted three times per week over eight weeks. People who received the intervention showed significant improvements in cognitive function, as measured by the MMSE (effect size=0.47, p=0.013) and the AD assessment scale-cognitive subscale (ADAS-Cog) (effect size=0.35, p=0.045). Additionally, behavioural symptoms and quality of life showed greater improvements in people who underwent the intervention compared with the control group. The study concluded that the intervention was more effective at improving cognition, behaviour, and quality of life for individuals with MCI or mild dementia than were the activities offered to the control group.

7.4.2.4 Active versus receptive MT

Studies have shown that active MT is more effective than receptive MT in the enhancement of cognitive function (Lyu *et al.,* 2018; Gomez-Gallego *et al.,* 2021). Some studies have reported improvements in cognition with active MT but at levels that did not reach statistical significance (Aleixo *et al.,* 2022). A recognised benefit of active MT is that PLwD who find it difficult to communicate using conventional language can participate in sessions using rhythms or movements, as opposed to other interventions which might focus more on singing (McDermott *et al.*, 2013). In a recent review and meta-analysis, which included 38 studies, Tsoi *et al.* (2018) separately evaluated the effects of both active and receptive MTs (Tsoi *et al.*, 2018). The review found no significant improvement in cognitive function from engagement in either active or receptive MT. However, improvements in levels of agitation, anxiety and behavioural problems were reported with receptive MT. The authors reported that there was a high degree of clinical heterogeneity across studies, particularly regarding the target populations, intervention content, duration and frequency, which may have influenced the overall findings.

7.4.3 Delivery setting

MT can take place in a variety of settings, including community-based locations and nursing and care homes. Many studies of MT have been carried out with nursing or

care home populations (Cheung *et al.*, 2018; Gomez-Gallego *et al.*, 2021) or with a combination of people in long-term care or community dwellings (Raglio *et al.*, 2015). It has been recommended for wider implementation to improve cognitive function in these types of settings for people with MCI and dementia (Ito *et al.*, 2022). Interventions are often conducted in a group format. However, some individuals may initially be resistant to engagement in unfamiliar or group activities.

7.4.4 Facilitators

Many support organisations now employ music therapists to engage PLwD, and MT training is available to many allied healthcare professionals, including occupational therapists (Burns and Morris, 2018). However, it should be acknowledged that MT is a specific professional practice that involves the creation of a therapeutic relationship between the music therapist and the client, and it consists of assessment, treatment and ongoing evaluation (Raglio, 2010; MacDonald, Kreutz and Mitchell, 2012). By law, every practising music therapist in the UK must have a master's-level qualification through a Health and Care Professions Council-approved programme and be registered with the council to use the protected title ‘music therapist’ (Nordoff and Robbins, 2025). Most music therapists are trained in both active and receptive MT methods (Campbell *et al.*, 2025). In the UK, MT sessions are commonly led by a highly trained, registered music therapist (British Association for Music Therapy, no date).

However, despite these professional standards, some interventions that are labelled as "MT" in research settings do not adhere strictly to these definitions. In some RCTs, music interventions were delivered by staff who were not qualified music therapists, and this blurred the line between formal MT and broad music-based activities. For example, in an RCT by Stedje *et al.* (2023), the authors highlighted the risks of delivering MT interventions without professional training, such as the risk of evoking unintentional negative emotional responses in PLwD. This highlights the importance of ensuring that interventions termed "music therapy" in research are implemented by appropriately qualified professionals to maintain therapeutic integrity and participant safety.

7.4.5 Frequency and duration of sessions

The frequency and duration of MT sessions vary between studies, which adds to heterogeneity in reported outcomes. In a recent review, the duration of sessions was reported to range from 12 to 120 minutes (Ito *et al.*, 2022). A typical MT session lasts for 45 minutes (Ceccato *et al.*, 2012; Gomez-Gallego *et al.*, 2021; Richmond Music Trust, 2025). The frequency of sessions varied among the studies from weekly to an intense schedule of sessions three times a day (Ito *et al.*, 2022; Ting *et al.*, 2024). These frequencies depended in part on the setting and structure of the intervention. Frequency was commonly twice a week (Han *et al.*, 2017; Cheung *et al.*, 2018; Gomez-Gallego *et al.*, 2021). The most important determinant for cognitive improvement was greater frequency of sessions, with studies showing that both the total number of sessions and the number of sessions per week were associated with greater cognitive benefits, with many of these findings reaching statistical significance (Moreno-Morales *et al.*, 2020; Xue *et al.*, 2023; Lu *et al.*, 2024).

In RCTs of MT, the interventions were typically held over six to 12 weeks. While some longer-term interventions over up to 24 weeks have been conducted, evidence for sustained cognitive benefits beyond 12 weeks is limited (Giovagnoli *et al.,* 2018). Most studies assess outcomes such as MMSE at the end of the intervention period rather than after extended follow-ups. Among the relatively few RCTs that have evaluated MT interventions that continued for longer than three months, none have reported significant improvements in MMSE scores, highlighting uncertainty around the long-term effectiveness of MT for cognitive outcomes.

7.4.6 Stage of dementia

Many studies of MT involve populations of people with moderate-stage dementia (Ceccato *et al.*, 2012; Cheung *et al.*, 2018; Tang *et al.*, 2018; Gomez-Gallego *et al.*, 2021). Studies of MT that have involved people with severe dementia are less common (Lyu *et al.*, 2018). Evidence suggests that MT is effective for people with mild to moderate dementia, with most benefits being seen in moderate dementia (Cheung *et al.*, 2018). Additionally, people with MCI have shown improvements in cognitive function and symptoms of depression after involvement in receptive MT (Xue *et al.*, 2023). The sensitivity analysis performed for this study evaluates the model with people with mild and severe stages of dementia.

7.4.7 Acceptability

MT sessions take place either on an individual basis or in a group. Group MT can reduce social isolation by encouraging social interaction (Lin *et al.,* 2011) and promoting relaxation and reducing agitation (Lyu *et al.,* 2018). Individualised sessions consider the person's music preferences and tastes. MT for PLwD can improve cognition, quality of life (Abraha *et al.*, 2017; Lyu *et al.*, 2018; Lin *et al.*, 2023), memory (Larkin, 2001) and language skills (Brotons and Koger, 2000), and reduce behavioural symptoms (Holmes *et al.*, 2006; Sung *et al.*, 2006; McDermott *et al.*, 2013). Participation in musical activities can improve important cognitive areas, including speech, learning, attention and memory, as summarised by Moreno-Morales *et al.* (2020). Music activities are acceptable and enjoyable for PLwD (Aleixo *et al.*, 2022). Indeed, television shows such as *Our Dementia Choir*, which was presented by Vicky McClure in 2018, have helped to raise the profile of singing as a therapy for PLwD, and have highlighted the beneficial effect of community-based music, in particular singing, on quality of life ('Our Dementia Choir', 2018).

7.4.8 Equipment and costs

Equipment costs for MT need to be considered. Depending on the approach used by the music therapists, a range of equipment may need to be purchased, for instance, audio equipment such as speakers or smartphones (Gaviola, Searles and Dilworth, 2022), percussion instruments, microphones, piano, keyboard or song sheets. Adaptations to the equipment may also be necessary for people with additional needs, such as visual or hearing impairment.

If the music therapist uses technology to play the music, then significant technology-related costs may be involved, such as paying for a smartphone to play pre-recorded music and to download or stream music (Gaviola, Searles and Dilworth, 2022). Devices may also require cleaning after use and storage, and maintenance, which can incur additional costs (Gaviola, Searles and Dilworth, 2022).

The environment in which the MT takes place must be considered to ensure that it is calming and comfortable. This may involve additional costs for room hire and travel (Richmond Music Trust, 2025). Other costs involve staff training and administration

time (Richmond Music Trust, 2025), such as to make individualised playlists for participants (Gaviola, Searles and Dilworth, 2022).

Costs of purchasing a music licence may need to be factored in, although in the UK, therapy and healthcare settings do not need licences as the playing of music is considered part of therapeutic care rather than entertainment. If recorded music is played in non-healthcare community-based settings such as community centres, then a licence may be required, according to PPL PRS Ltd, which is a joint venture between Phonographic Performance Limited and the Performing Rights Society for music (PPL PRS, no date).

7.4.9 Variation in MT interventions

Variation in the methodological quality of MT studies has been reported (Cheung *et al.*, 2018; Moreno-Morales *et al.*, 2020). Differences across interventions have included low participant numbers, lack of standardised protocols, variability in the intervention facilitator, and differences in the frequency and duration of sessions (Vink, Bruinsma and Scholten, 2003; Zhang *et al.*, 2017; Cheung *et al.*, 2018; Lam *et al.*, 2020; Moreno-Morales *et al.*, 2020). In the meta-analysis by Ito *et al.* (2022), studies that incorporated movement activities alongside music were not analysed separately from those that used music alone, potentially confounding the results. In addition, the longer-term benefits of MT have not been clearly established due to a lack of high-quality, longitudinal studies (McDermott *et al.,* 2013).

Overall, there is considerable heterogeneity across studies in how MT interventions are designed and delivered. Differences in session frequency, format (group vs. individual), therapeutic approach, and population characteristics present challenges for standardisation and economic modelling. These variations must be considered when interpreting findings and using them to inform model assumptions, which is described in subsequent sections.

Table 7.1 Summary of characteristics of key MT RCTs

Author	Country	Type of MT	Number of participants	Setting	Stage of dementia	Outcome tools	Sessions (frequency & duration)	Key outcomes
Ceccato *et al.* (2012)	Italy	Active MT	51	Community-based	Moderate to severe	Cognitive performance scale	2-x a week for 12 weeks; 45 minutes	Improved attention, language abilities, and overall cognitive function
Cheour *et al.* (2023)	Tunisia	Receptive (music listening via headphones)	28	Community-based	Mild to moderate	ADAS-Cog, MMSE, CMAI, NPI, mood ratings	Daily, 30 mins, 4 weeks	Cognitive function improved
Giovagnoli *et al.* (2018)	Italy	Active MT (Non-verbal instrumental)	45	Neurological Institute (outpatient)	Moderate	MMSE, SIB-Language, NPI	2 x a week, 40 min, 12 weeks	Improved mood/appetite; no change in language Study to see whether adding MT to memantine therapy improved outcomes
Gomez-Gallego *et al.* (2021)	Spain	Active MT vs. receptive MT	90	Nursing home	Mild to moderate AD	MMSE, NPI, BI, GDS	2 x a week, 45 minutes, 12 weeks	AMI improved cognition, behaviour; receptive MT stabilised symptoms
Han *et al.* (2017)	South Korea	Multi-modal (incl. MT)	64	Community	MCI / Mild dementia	MMSE, ADAS-Cog, QoL-AD	3 x a week, 3 hrs, 8 weeks	Improved cognition, behaviour, QoL Also included exercise and cognitive interventions in combination
Kelly and Ahessy (2021)	Ireland	Reminiscence MT	5	Residential care facility	Unspecified	DCM	1 x a week, 45 min, 5 weeks	Improved mood, engagement, interaction

								Exploratory study – not an RCT
Lyu *et al.* (2018)	China	Active MT (Singing& lyric reading)	298	Nursing home	Mild to severe AD	MMSE, NPI, BI	Varied, 3-month programme	Improved cognition & mood; stratified by severity
Moreira *et al* (2023)	Brazil	Receptive (individualised music listening)	43	Community	Memory, global cognition	NPI, mood scales	2 x a week, 30-40 mins, 12 sessions	No significant effect
Prick *et al.* (2024)	Netherlands	Receptive (music at home with caregiver)	158	Community	Problem behaviours	NPI, ZBI, QoL-AD	3 x a week, 30-45 mins, 3 weeks	Restless behaviour and hyperactivity improved
Raglio *et al.* (2015)	Italy	Active MT & individualised receptive MT	120	Various	Moderate to severe	NPI, QoL assessments	2 x a week, 30 mins, 10 weeks	No significant difference between groups. NPI reduced
Van de Winckel *et al.* (2004)	Belgium	Active MT and mixed MT	15	Hospital-based	Mild to severe	MMSE, agitation scales, behavioural observation	1-5 x a week, 30 mins, 12 weeks	Moderate reduction in agitation and behavioural symptoms; some cognitive benefits noted Physical exercise (dance) combined with MT
Xue *et al.* (2023)	China	Receptive MT	80	Community	MCI + depression	MoCA, GDS	4x a week, 8 weeks	Improved MoCA & reduced depression

Key

ADAS-Cog - Alzheimer's Disease Assessment Scale – Cognitive Subscale; CMAI - Cohen-Mansfield Agitation Inventory; BI - Barthel Index; DCM - Dementia Care Mapping; GDS - Geriatric Depression Scale; MMSE - Mini Mental State Examination; MoCA - Montreal Cognitive Assessment; NPI - Neuropsychiatric Inventory; QoL-AD - Quality of Life in Alzheimer's Disease scale; SIB-Language - Severe Impairment Battery – Language subscale; ZBI - Zarit Burden Interview

Table 7.2 Summary of characteristics of key MT systematic reviews and meta-analyses

Author	Type of study	Number of studies	Outcome	Outcome tools identified	Conclusion
Bian *et al.* (2021)	Review and meta-analysis	7	Global cognition	MMSE	MT is likely to improve the global cognitive function of PLwD
Bleibel *et al.* (2023)	Review	8	Cognitive function (AD)	Various including Faces scale, BEHAVE-AD, SIB, MMSE, MoCA	Potential benefits of MT on cognition Greatest effects shown with AMT
Fusar-Poli *et al.* (2018)	Review and meta-analysis	6	Cognition	Various, mostly MMSE	Limited evidence, more studies needed AMT had a positive effect on global cognition
Gassner *et al.* (2022)	Review	10	Cognition, quality of life, mood	Various including: MMSE, MoCA, NPI, BI, GDS	MT showed a small but statistically significant positive effect on overall cognitive function in PLwD
Ito *et al.* (2022)	Systematic review and meta-analysis	19	Cognitive function, neuropsychiatric symptoms, depression, and quality of life	MMSE, SIB, FAB, MoCA	MT yields modest but significant improvements in cognition and neuropsychiatric symptoms; receptive MT had a greater impact on mood, while active MT helped cognition
Jimenez-Palomares *et al.* (2024)	Review	11	Cognition (AD)	Various including MMSE, NPI, HADS, BEHAVE-AD, CDR, GDS, BI, QoL-AD, ADAS-Cog	MT improves cognitive function in people living with AD
Lin *et al.* (2023)	Review and meta-analysis	22	Cognition, quality of life	MMSE, QoL-AD	MT significantly improved cognition, QoL and improved BPSD
Lu *et al.* (2024)	Review and meta-analysis	24	Cognition, anxiety, depression, behaviour, quality of life	CMAI, GDS, BPSD, NPI, MMSE, CMAI, BEHAVE-AD	MT improved cognitive function in cases in which the intervention was at least 12 weeks (16 sessions) and included at least 8 hrs of MT
McDermott *et al.* (2013)	Narrative review	18	Primarily focused on agitation, mood, and engagement	Various: CMAI, NPI, observational tools, qualitative feedback	MT can reduce agitation, improve well-being, and promote social interaction; effectiveness is higher when

					person-centred and individualised
Moreno-Morales *et al.* (2020)	Review and meta-analysis	8	Cognition	MMSE, GDS, ADAS-Cog, QoL-AD	Cognitive function improved. No improvement in QoL during the interventions but positive effects seen after
Salihu *et al.* (2024)	Meta review	20	Cognition, depression, stress and anxiety	Various: GDS, MMSE, NPI	Variable improvement of cognitive functioning, depression, anxiety and stress
Ting *et al.* (2024)	Network meta-analysis	14	Cognition	Mainly MMSE, FAB	Cognitive function significantly improved

Key

ADAS-Cog- Alzheimer's Disease Assessment Scale – Cognitive Subscale; AMT - active music therapy; BEHAVE-AD - Behavioral Pathology in Alzheimer's Disease Rating Scale; CSDD - Cornell Scale for Depression in Dementia; CMAI - Cohen-Mansfield Agitation Inventory; FAB - Frontal Assessment Battery; MMSE - Mini Mental State Examination; NPI - Neuropsychiatric Inventory; QoL-AD - Quality of Life in Alzheimer's disease scale

7.4.9.1 Economic evaluations of music therapy

Economic evaluations of MT are uncommon and those that exist have been conducted in the US (Riedl *et al.*, 2025). The vast majority of MT studies do not include an economic evaluation (Raglio, 2010; Ceccato *et al.*, 2012; Cheung *et al.*, 2018; Lyu *et al.*, 2018). According to a recent, large-scale review of economic evaluations of MT, there remains a lack of research on the cost-effectiveness of MT within healthcare (Riedl *et al.*, 2025).

In papers that have reported economic aspects of MT, heterogeneity of methods, populations and outcomes is typically observed across studies (Riedl *et al.*, 2025). Studies of MT do not typically report costs of providing the intervention (Sakamoto, Ando and Tsutou, 2013; Raglio *et al.*, 2015; Cheung *et al.*, 2018; Lyu *et al.*, 2018; Gomez-Gallego *et al.*, 2021). A review by Tsoi *et al.* (2018) reported that receptive MT was less costly than active MT, but did not report these costs

A cost study of an MT intervention for hospice patients was carried out in a private hospice facility in the US. It reported that the positive effects of MT may have led to cost savings in other areas of care. Medication costs for the MT group were approximately one-third less than for those in the control group, suggesting a reduced need for pain, depression and anti-anxiety medication (Romo and Gifford, 2007). Nursing costs were also reduced as individuals relied less on expensive care from registered nurses and instead received more care from other, less expensive caregivers.

A UK-based study of the provision of group-based arts therapies, including MT, is in progress for psychiatric community-dwelling individuals with various psychiatric diagnoses (Carr *et al.*, 2023). It includes an economic evaluation. However, recruitment was delayed due to COVID-19 and results have not yet been published.

Economic evaluations of MT for PLwD in RCTs are rare; none were identified in this literature review. However, a study by Gaviola, Searles and Dilworth (2022) included the performance of a cost analysis of MT provision for PLwD in long-term care in Australia. It was not a full economic evaluation as no outcomes, such as QALYs, were analysed. The authors found that the average cost was AUD$74 per person, and the figure for each session depended on session length, mode of delivery and travel costs

and time of the therapist. Authors have suggested that group sessions are more cost-effective than individualised sessions; however, this conclusion cannot be confirmed without outcome measures. The authors of the Australian study stated the importance of including therapist wages, travel time and administrative overheads. These findings offer valuable inputs for economic evaluations of MT.

The importance of the economic evaluation of MT in relation to cognitive function has been largely overlooked. As healthcare systems face increasing demands, studies in which interventions are compared to slow cognitive decline must include economic data to inform cost-effectiveness and resource allocation. This is especially important given that music therapists could also support other community groups, and that, therefore, demonstrations of economic value could strengthen the case for wider integration of MT into healthcare pathways.

Despite the growing evidence base of clinical benefits of MT in RCTs and the popularity of modelling approaches, there is a lack of economic models by which MT can be evaluated for PLwD. Recognising this gap, through this thesis, this researcher seeks to add to the body of evidence that assesses the value of MT for PLwD in order to support informed policy and funding decisions.

7.5 Methods

The choice of an MT intervention for the model was informed by the engagement of people with lived experience of dementia through the survey of PLwD, family caregivers and professionals working in the field of dementia (detailed in Chapter 5). While survey results indicated that MT was a popular choice, they were not the deciding factor in the selection of therapies for modelling. The final selection was part of a triangulation approach that integrated evidence from the systematic literature review in Chapter 3, outcomes from the review of clinical effectiveness in Chapter 4 and survey findings in Chapter 5. A triangulation approach that uses multiple data sources can enhance credibility and reduce researcher bias (Doughty and Menage, 2022). It was not possible to evaluate all therapies, so the choice was informed by the preferences of participants in the survey. The number of therapies was limited to two

as this was a manageable number to work on within the timeframe of the research project.

7.5.1 Overview of model type and structure

The model was designed to assess the cost-effectiveness of a 13-week active MT intervention for moderate dementia (MMSE score of 15) that would be delivered to a group of five people in the community. The intervention was aimed at delaying or reducing cognitive decline, with improvements in cognition measured by MMSE score as a key outcome. Additionally, the model would be used to assess the longer-term impact of continuing the intervention, assuming that the improvements were maintained over six months.

The base model was developed in Microsoft Excel using a decision-tree structure (Figure 7.1). A decision-tree modelling approach was selected as the most appropriate to represent the clinical and economic pathways for PLwD in the context of this analysis. While alternative modelling techniques such as Markov models and DES were considered, they were not adopted, due to the limited time horizon and nature of the available data. The decision-tree structure was considered most appropriate to capture the key outcomes and events relevant to the intervention. This approach is consistent with those followed in other studies in dementia and mental health (Kolovos *et al.*, 2017; Nguyen, Comans and Green, 2018).

A purpose-built decision model was chosen as tailored models are more likely to reflect accurately the specific characteristics of non-drug interventions, such as delivery format, intervention adherence and broad care pathways, compared with models adapted from existing frameworks (Briggs, Sculpher and Claxton, 2006). Models can also be designed with an appropriate time horizon to allow adequate consideration of costs and outcomes (Sopina and Sørensen, 2018). The models in the thesis were developed specifically for the purpose and were not based on existing models.

The model assessed an MT intervention to improve cognitive function and its impact on costs and service use over a three-month period. None of the clinical trials relevant to the model had followed up PLwD for longer than three months after the end of the initial MT phase. The type of model chosen was informed by the short-term nature of

performed clinical trials that were relevant to the model. This meant that the decision-tree design was more suitable than would have been a Markov design. While dementia is a progressive condition and cognitive benefits from interventions such as MT may be short-lived, the lack of longer-term follow-up in the published studies means that the duration of cognitive effects beyond three months is uncertain.

The potential longer-term cost-effectiveness of MT was assessed in an additional model, which projected the potential effects of maintaining this improvement over an additional three months (resulting in a total six-month time horizon). At the three-month point, PLwD could either have improved their MMSE scores relative to baseline, show no improvement or have exited the model because they had died. At the six-month point, PLwD could either have maintained an improvement in MMSE score, not maintained an improvement they had made between baseline and three months, continued in the baseline state or exited the model because they had died.

NICE recommendations were adopted during the development of the methodological approach. A CUA approach was used; this method considers costs and health benefits measured using QALYs (NICE, 2022). The structure of the models was informed by recent NICE cost-effectiveness modelling on disease modification therapies for dementia (NICE, 2011). The modelling approach conformed to the guidelines outlined in the CHEERS statement for the reporting of methods and results (Husereau *et al.*, 2022).

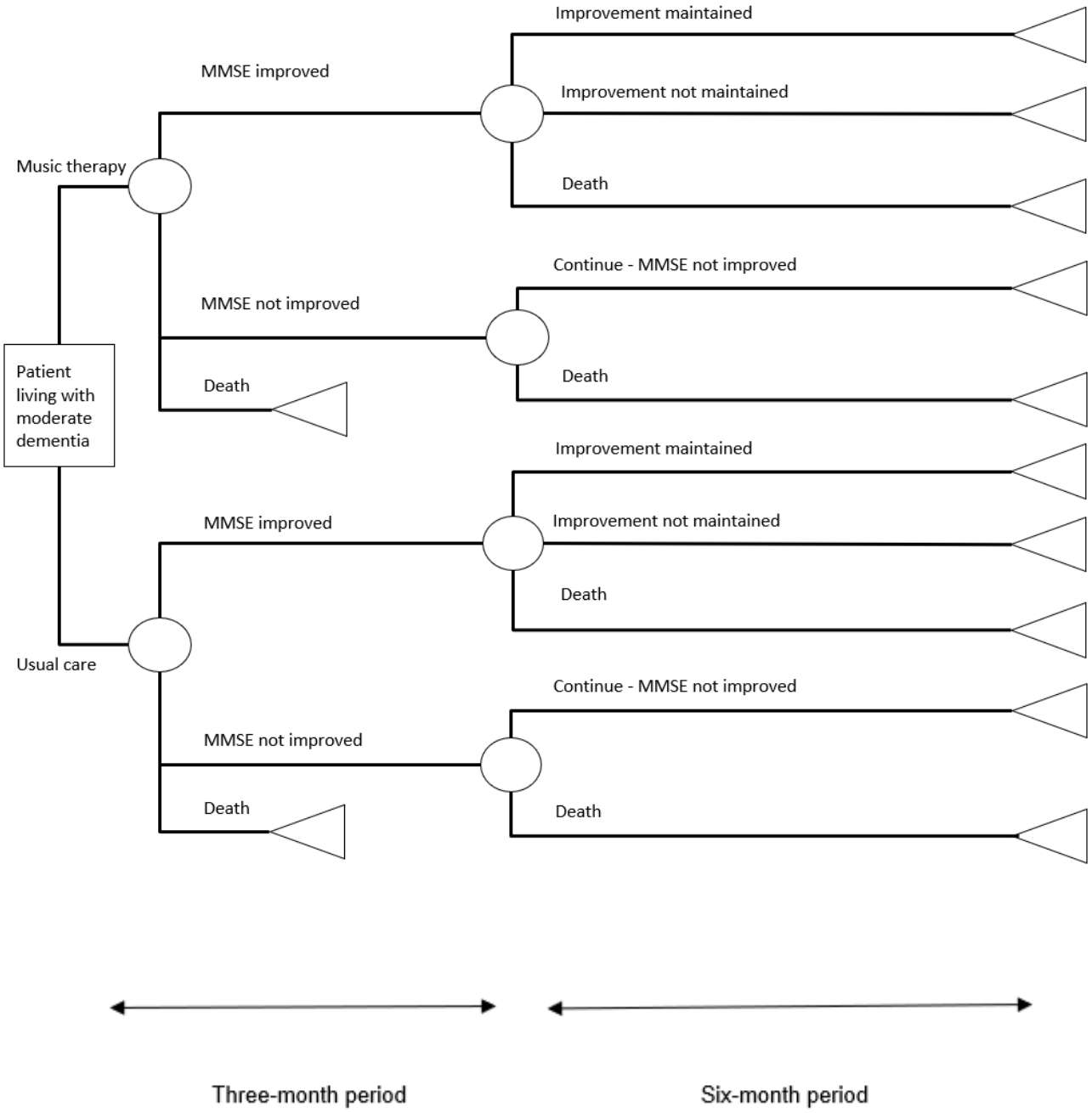


Figure 7.1 Structure of decision model for music therapy

7.5.2 Decision options and pathways

This section outlines the key components of the decision problem that was modelled, including the population, intervention and comparators, and the primary outcomes that were considered. The model structure represents the potential clinical pathways for PLwD who receive MT in a community setting. The decision model compares the costs and outcomes associated with MT with those of usual care, simulating how PLwD may respond over a defined time horizon. The following subsections describe the characteristics of the target population, the treatment options evaluated, the perspective of the analysis, and the time horizon used in the model.

7.5.2.1 Population

The target population for the model was people who lived in the community in the UK, with moderate dementia as defined by MMSE scores in accordance with NICE criteria, in which moderate dementia typically scored between 10 and 20 (NICE, 2018a). A baseline MMSE score of 15 was selected to represent a typical individual with moderate dementia. This aligned with the population characteristics used in the study by Gomez-Gallego *et al.* (2021). Evidence from the literature review indicated that active MT can improve cognitive function in individuals at this stage of dementia.

Concluded studies of MT have similarly focused on PLwD in community settings (Cheour *et al.*, 2023; Moreira *et al.*, 2023; Xue *et al.*, 2023; Prick *et al.*, 2024). These studies demonstrate that PLwD in the community can engage with MT in a meaningful way, and that such interventions are associated with improvements in mood, cognitive function, social engagement, and overall quality of life. The evidence from these studies particularly supports the effectiveness of active MT in improving cognitive function amongst people with moderate dementia. Therefore, moderate dementia was selected as the baseline health state for the model, with an MMSE score of 15 used as the reference point, representing a typical score for this stage of the disease.

7.5.2.2 Comparators

The MT intervention that was used in the model was based on active MT delivered through group sessions. Active MT was selected because there is evidence that it is effective for improving cognitive outcomes in PLwD (Fusar-Poli *et al.*, 2018; Bleibel *et*

al., 2023; Ting *et al.*, 2024). Group size was set at five participants per session, which would be delivered by one trained music therapist. This choice reflected current practice in community-based MT sessions offered by a UK provider (Richmond Music Trust, 2025). The duration of each session was 60 minutes; this choice was informed by the study conducted by Cheour *et al.* (2023). The frequency of sessions was set at two sessions per week, based on evidence from published studies (Gomez-Gallego *et al.*, 2021; Moreira *et al.*, 2023).

Usual care involved watching nature videos instead of taking part in the MT. It should be noted that all participants were receiving CST and their usual medications as part of their standard care.

7.5.2.3 Primary outcome

Cognition was selected as the clinical effectiveness outcome for this model, since cognitive decline is a central feature of dementia and strongly influences a person's ability to function, their quality of life, and the level of care they require. Maintenance or improvement in cognitive function can slow disease progression, and this may reduce care costs and ease the burden on caregivers. From an economic perspective, even marginal improvements in cognition can lead to large savings because the need for transfer to long-term care is delayed. Furthermore, cognition is a widely used outcome in studies of NPTs such as MT, making it easier to compare findings and supporting a robust choice of model parameters.

The measurement tool that was used to assess improvement in cognitive function was the MMSE score, to predict service use and costs based on an improvement or decline in cognition. MMSE score has been used in published studies to assess the effect of MT on cognition (Gomez-Gallego *et al.*, 2021; Cheour *et al.*, 2023; Moreira *et al.*, 2023). In an additional analysis, the model was set up to explore whether mental health service use might be reduced if the improvements in cognitive function (measured by MMSE score) that were observed in the three-month model were maintained for a further three months.

7.5.2.4 Perspective and time horizon

Costs were considered from the perspective of the NHS as a healthcare system, so direct healthcare costs associated with inpatient and outpatient use were incorporated. Outcomes were primarily expressed in terms of cognitive improvements, measured through MMSE scores. Associated reductions in costs due to reduced inpatient and outpatient service use were investigated to assess potential healthcare savings following MT. This approach aligns with standard practice in economic evaluations for NHS decision-making (NICE, 2013).

The time horizon for the short-term model was set at three months (12 weeks). This reflected the short-term duration of many MT interventions and outcome measurement timing described in the literature (Lyu *et al.*, 2018; Moreno-Morales *et al.*, 2020; Gomez-Gallego *et al.*, 2021). In these studies, outcomes such as MMSE were assessed immediately after a three-month course of MT, rather than after an extended follow-up period. The longer-term model that was devised for this study evaluated the effects of an additional three months of MT, resulting in a total intervention duration of 26 weeks.

7.5.3 Model inputs

This section outlines the input parameters that were used to populate the decision-tree model, including clinical probabilities, utility values, and cost estimates. These inputs reflected the key events and outcomes associated with the delivery of MT and usual care for PLwD in the community. Data sources included published RCTs, systematic reviews identified in the literature review (section 7.4), and other relevant literature, supplemented by expert opinion if necessary. The parameters presented here form the foundation of the model's calculations and are critical to the determination of cost-effectiveness outcomes.

7.5.3.1 Clinical probabilities

Literature on RCTs, systematic reviews and meta-analyses was reviewed. This review was used to inform the probability of improvement in the model. Data from these sources were synthesised to support the selection of key clinical input parameters that used MMSE scores (Table 7.3 and Table 7.4). For each included RCT, data were

extracted on the intervention type, MT format, session frequency and duration, cognitive outcome measures (e.g., MMSE), reported effect sizes (if available), and the main conclusions. For systematic reviews and meta-analyses, extracted data included the review design, number of studies included, outcomes assessed, reported effect sizes (if available), and the authors' key conclusions.

7.5.3.2 MMSE

The MMSE is a widely used, validated tool for the assessment of changes in cognitive function in PLwD and has been widely employed in previous MT studies (Van de Winckel *et al.*, 2004; Ceccato *et al.*, 2012; Raglio *et al.*, 2015; Gomez-Gallego *et al.*, 2021). MMSE scores have been used by NICE to evaluate therapies and to denote the severity of cognitive impairment (NICE, 2011). In several studies on group MT, the MMSE has been used as the primary outcome measure (Larkin, 2001; Brotons and Marti, 2003).

The MMSE is the most commonly used measure of cognitive ability in trials of AD and MCI treatments, as it is easy to use and quickly administered (Garg *et al.*, 2022). Additionally, the MMSE has been used as the primary outcome in economic models for dementia (McDonnell *et al.*, 2001; Weimer and Sager, 2009; Saito *et al.*, 2014).

A rapid review of the literature on the use of the MMSE in MT studies and reviews was conducted. The key characteristics of each are summarised in Tables 7.3 and 7.4. Use of the MMSE score to measure improvements in cognition from MT was explored further in a recent review and meta-analysis by Ito *et al.* (2022). These researchers examined 19 RCTs and looked at MMSE scores and the various individual cognitive domains that make up cognition. The review included different types of MT intervention including active and passive types and considered a range of MT interventions that had been carried out in community and nursing home settings. The authors concluded that MT showed statistically significant improvements in MMSE, executive function and episodic memory (Ito *et al.*, 2022).

The application of active MT has brought promising improvements in cognition, particularly as measured by MMSE scores (Gomez-Gallego *et al.*, 2021; Ito *et al.*, 2022). However, some studies have shown that the improvements in cognition that were measured by MMSE scores did not reach statistical significance. For instance, a

large multi-centre RCT of an active MT and movement intervention found that cognitive function improved, but changes in MMSE scores failed to reach significance (Cheung *et al.*, 2018). Similarly, an RCT of an active MT intervention for people with mild to moderate dementia in Italy did not demonstrate significant changes in cognition as measured by MMSE, although it did show improvements in memory (Ceccato *et al.*, 2012).

There are criticisms of the MMSE. As the MMSE test is administered verbally, this can cause issues for people with language difficulties such as aphasia, which is common in PLwD. Its results may be inaccurate in people with hearing loss or below-average education levels, who are from culturally diverse populations or have MCI, and it is reliant on the subjective assessment of the examiner (Raiha *et al.*, 2001; Myrberg, Hydén and Samuelsson, 2020). These concerns highlight limitations in the accuracy and applicability of the MMSE; additional criticisms have been raised regarding its reliability in detecting cognitive change over short periods. There is some evidence that MMSE is not a reliable measure of change in cognition over periods of less than three years (Clark *et al.*, 1999). On average, untreated people living with AD typically show a loss of 2.43 MMSE points per year (Miyakawa-Liu *et al.*, 2022). However, it has been suggested that the MMSE score should show a change of more than 3.0 points to be clinically significant and to reflect an actual change in cognition (Clark *et al.*, 1999).

MT has been shown to produce improvements in cognitive function, which may translate into gains in quality of life, making QALYs a potentially appropriate and meaningful measure for this analysis. The process for their incorporation in the model is discussed in Section 7.5.3.1.1.

7.5.3.2.1 Probability that MT will lead to improvement

The probability that the intervention would improve MMSE scores was obtained from a network meta-analysis of MT that had been conducted by Ting *et al.* (2024), which included 14 studies. Although no UK-based studies were included, several mainland European studies were. Most studies in the review were assessed through the use of the Cochrane Risk of Bias tool as having a low-to-moderate RoB.

In the meta-analysis, improvements in MMSE score for active MT were recorded with an SMD of 0.76 (95% CI: 0.32 to 1.21). To incorporate this effect size into the model, the SMD was converted into a probability of improvement, using a method commonly used in healthcare economic modelling to estimate the probability of superiority − the likelihood that a randomly selected individual from the intervention group would have a better outcome than would one from the control group. This was done by assuming a normal distribution of MMSE scores and applying the following formula:

$$p = \Phi\left(\frac{\text{SMD}}{\sqrt{2}}\right)$$

in which:

- Φ is the cumulative distribution function (CDF) of the standard normal distribution
- SMD is the standardised mean difference (0.76)
- square root of 2 ≈ 1.414

$$p = \Phi\left(\frac{0.76}{1.414}\right) = \Phi(0.537) \approx 0.704$$

The cumulative probability, Φ (0.537) ≈ 0.704, was obtained by using the standard normal distribution function; this choice reflected the probability that a randomly selected individual receiving the intervention would have a better outcome than would one receiving usual care. This probability of 0.704 was used as a model input to reflect the effect of MT on cognitive improvement. This approach estimates the probability of superiority, which is the probability that a randomly selected individual from the intervention group would have a better MMSE score than would a randomly selected individual from the usual care group. It does not represent the probability that a given individual will improve but rather reflects the relative effectiveness of the intervention at a group level.

A similar rate of improvement (0.82) was reported in a small-scale three-month study of active MT in Spain (Gomez-Gallego *et al.*, 2021). This finding aligns closely with those of Ting *et al.* (2024) in a meta-analysis that reported an SMD of 0.76 for improvements in MMSE after active MT. The consistency between these two sources

supports the plausibility of the effect size. Meta-analyses provide a high level of evidence through the synthesis of multiple studies, and Ting *et al.* (2024) offered broad generalisability and methodological rigour, so their estimate was selected for the model.

7.5.3.2.2 Probability that usual care will lead to improvement

The rate of improvement of the MMSE score for those who received usual care was taken from the Gomez-Gallego *et al.* (2021) study, in which 6.3% of people in the control group showed improvements.

7.5.3.2.3 Probability of death

Annual probabilities for death for different stages of dementia were sourced (Spackman *et al.*, 2012). These estimates were based on US data that had been published in 2012; these were used due to the lack of more recent or UK-specific, stage-specific, survival data.

These annual probabilities were adapted to the three-month time horizon through the use of a formula described by Briggs, Sculpher and Claxton (2006). A constant hazard was assumed over time, so that the probability of death could be adjusted to a three- and six-month time period in the model. This method assumed that the risk of death remained steady over the period. A standard actuarial method was used, following the formula described by Briggs, Sculpher and Claxton (2006). The standard actuarial method assumes that the risk of an event is spread evenly over time, meaning the hazard remains constant throughout the period. Hence, the probability of the event occurring over time is represented in the equation

$$\text{probability} = 1 - \exp(-rt)$$

In which r is the constant hazard or event rate, t is the time period, and exp is the base of the natural logarithm. The exponential term e to the power of −rt, reflects the probability of the event *not* occurring, so subtracting this from 1 gives the probability that the event *does* occur within the specified time frame. This method is standard and is consistent with recommendations from Drummond *et al.* (2016) and the ISPOR Society for Medical Decision-Making guidelines (2012).

7.5.3.1 Outcome parameters

7.5.3.1.1 Utility values

Cognition measured using MMSE is used as the clinical effectiveness outcome, this is then converted into a utility-based outcome (QALYs) for use in the cost-effectiveness model. The use of QALYs is in line with recommended practice for economic evaluations in healthcare from NICE. A mapping technique was applied linking cognition to utility values/QALYs. To incorporate clinical effectiveness data from the literature into the model, the reported SMD in MMSE scores was converted into a probability to reflect the relative likelihood of cognitive improvement. This probability was required as a model input to represent the effectiveness of the intervention in a way that could be applied to the decision structure. Total expected costs were calculated for both groups. The six-month model explored the impact on costs and effects if the improvements in cognition seen in the three-month model were assumed to continue. The model used QALYs to assess quality of life based on utility values mapped from MMSE scores in both the three- and six-month models. QALYs incorporate both the duration and HRQoL experienced during that period. In line with NICE guidance, QALYs were adopted as the preferred measure of health outcomes for the economic evaluation (NICE, 2013).

Mapping techniques were employed to calculate QALYs by mapping MMSE scores to utility values to create a QoL measure using the method described previously (Chapter 5). Utility scores were first derived by mapping from available cognitive outcomes. These mapped utility scores were then used to calculate QALYs. Specifically, the baseline and follow-up utility values were averaged and adjusted for the three-month time horizon using the following formula:

QALYs = (Baseline utility score + Follow-up utility score) /2 x 0.25

While mapping provides a practical solution when utility data are not directly collected, it introduces additional uncertainty into QALY estimates due to assumptions made in the conversion process. This uncertainty stems from potential variability in how well the mapped relationship reflects actual PLwD experience. Therefore, sensitivity analyses are essential to test the robustness of results based on mapped utility values and to account for this additional layer of uncertainty.

Where possible, the model parameters were informed by data from the literature review of RCTs, systematic reviews and meta-analyses of MT for PLwD (section 7.4). Tables 7.3 and 7.4 summarise the clinical effectiveness evidence of MT based on MMSE outcomes drawn from these studies. Results from these studies reported improvements in cognition as measured by MMSE. Based on this evidence, cognitive function measured by MMSE was selected as the clinical effectiveness outcome in the model. MMSE values were subsequently mapped to utility values to estimate QALYs for the economic evaluation. The primary outcome measure used in the model was the number of QALYs associated with MT versus usual care over a three-month period. Associated healthcare costs were also estimated in order to assess the cost-effectiveness of the intervention.

Table 7.3 Summary of effectiveness of MT as measured by MMSE: RCTs

Author	Intervention type	Format of MT	Session frequency & duration	MMSE effect sizes	Conclusion
Cheour *et al.* (Cheour *et al.*, 2023)	Community-based RCT for males with AD. Group sessions. Compared 3 groups: MT; physical activity; and MT plus physical activity	Receptive (music listening via headphones)	Daily, 30 mins, 4 weeks	SMD = 0.63 (95% CI: 0.11 to 1.15), p = 0.02	Significant increases in MMSE and ADAS-Cog for MT plus physical activity group
Giovagnoli *et al.* (2018) (Giovagnoli *et al.*, 2018)	Outpatient setting. For people with moderate dementia	Active MT (Non-verbal instrumental)	2 x a week, 25 min, 12 weeks	SMD = 0.75 (95% CI: 0.22 to 1.28), p = 0.005	Improved mood/appetite; no change in language
Gomez-Gallego *et al.* (Gomez-Gallego *et al.*, 2021)	Nursing home-based RCT of people with AD. Group sessions. Compared active MT (including dancing) against receptive MT against control. All participants were also receiving CST as standard	Active vs receptive group music	12 weeks, frequency not specified	Probability of improvement = 82%, p < 0.001	Active MT improved cognition & behaviour; receptive MT stabilised symptoms
Han *et al.* (2017) (Han *et al.*, 2017)	Community-based study for people with MCI/mild dementia	Multi-modal (including MT)	3 x a week, 3 hrs, 8 weeks	SMD = 0.42 (95% CI: 0.07 to 0.77), p = 0.018	Improved cognition, behaviour, QoL

Lyu *et al.* (2018) (Lyu *et al.*, 2018)	Nursing home-based, active MT (singing, lyric reading). For people with mild to severe AD	Active MT (singing, lyric reading)	Varied, 3-month programme	SMD = 0.38 (95% CI: 0.05 to 0.71), p = 0.023	Improved cognition & mood; stratified by severity

Key

AD - Alzheimer's Disease; ADAS-Cog - Alzheimer's Disease Assessment Scale – Cognitive Subscale; CI - confidence interval; MCI - mild cognitive impairment; MMSE- mini mental state examination; MT - music therapy; SMD - standardised mean difference; QoL - Quality of life; RCT - randomised controlled trial

Table 7.4 Summary of effectiveness of MT interventions as measured by MMSE scores: systematic reviews and meta-analyses

Author	Study design	No. studies	Outcomes assessed	MMSE effect sizes	Conclusion
Bian *et al.* (Bian *et al.*, 2021)	Review and meta-analysis	7	Global cognition	Cognition: MD 0.86, CI: 0.07 to 1.66, p= 0.03	Likely to improve global cognition, however, more studies needed
Bleibel *et al.* (Bleibel *et al.*, 2023)	Review	8	Cognitive function (AD)	N/A	Active MT was effective for improving cognition
Fusar-Poli *et al.* (Fusar-Poli *et al.*, 2018)	Review and meta-analysis	6	Cognition	Global cognition: SMD: 0.29, CI: 0.02 to 0.57, p= 0.04	Modest positive impact on global cognition. Subgroup analysis of 3 studies showed that active MT showed improved global cognition
Gassner *et al.* (Gassner, Geretsegger and Mayer-Ferbas, 2022)	Review	10	Cognition, quality of life, mood	N/A	Positive effect reported
Jimenez-Palomares *et al.* (Jimenez-Palomares *et al.*, 2024)	Review	11	Cognition (AD)	N/A	Improvements in cognitive function reported for memory, language and orientation

Lin *et al.* (Lin *et al.*, 2023)	Review and meta-analysis	21	Cognition, quality of life	SMD: 0.50, CI: 0.19 to 0.81, p= 0.002	Cognition showed statistically significant improvements
Lu *et al.* (Lu *et al.*, 2024)	Review and meta-analysis	24	Cognition, anxiety, depression, behaviour, quality of life	SMD: 0.53, CI: 0.24 to 0.82, p < 0.001	Statistically significant improvement in cognition
Moreno-Morales *et al.* (Moreno-Morales *et al.*, 2020)	Review and meta-analysis	8	Cognition	SMD: −0.23; CI: −0.44 to −0.02	Small decline in cognitive function. Lack of standardised trials and high heterogeneity may be the cause
Salihu *et al.* (Salihu *et al.*, 2024)	Meta review	20	Cognition, quality of life, MMSE	Cognition (language subscale): SMD: 0.29, CI: 0.02 to 0.57, p=0.04	Small but statistically significant positive effect on language
Ting *et al.* (Ting *et al.*, 2024)	Network meta-analysis	14	Cognition	Active MT with singing: SMD: 0.79; CI: 0.09 to 1.49 Rhythmic MT: SMD: 0.76; CI: 0.32 to 1.21, p < 0.001	Both active MT with singing and rhythmic MT had moderate to large positive impacts on cognition

Key

AD, Alzheimer's Disease; MD, mean difference; CI, confidence interval; MMSE, mini mental state examination; MT, music therapy; SMD, standardised mean difference

7.5.3.1.2 Resource use and costs

Costs associated with the model were measured in 2022 British pounds. MT costs were informed by published studies that reported typical duration and frequency of MT sessions. Service use costs were based on data from the *Unit Costs of Health and Social Care 2022* Manual and supplemented by information from a UK MT provider (Jones *et al.*, 2023; Richmond Music Trust, 2025). No adjustment for inflation was made to these costs, as the most recently published NHS inflation index from the Personal Social Services Research Unit covers only the period up to 2021/2022. Travel costs were not included in the analysis. Costs were not discounted as the time horizon was less than one year.

The cost of the MT intervention included the costs of a music therapist and of equipment. These costs were sourced from an independent UK MT provider and were based on a session delivered to a group of five PLwD over a one-hour period (Richmond Music Trust, 2025). The cost of usual care was assumed to be zero in the model, reflecting the absence of specific resource use or intervention costs reported for this comparator. Usual care typically involved passive activities, such as watching nature videos, and was not associated with additional staffing or material requirements in the included studies.

The cost of death was assumed to be zero, consistent with the approach taken by other dementia economic models (Vandepitte *et al.*, 2020). Direct costs associated with dying, such as palliative care, hospice care or funeral expenses, were not included in the model. Death was treated as a terminal state, with no further costs or health outcomes (utilities) accrued beyond that point. End-of-life care costs were not explicitly modelled. This decision was based on the dementia-specific context, the availability of relevant cost data and the overall structure and purpose of the model.

Costs of inpatient/outpatient care were included, as derived from the analysis of mental health service use data in Chapter 6.

An increase of 1.0 in MMSE score was associated with a £497 reduction in inpatient and outpatient care costs over one year, based on univariate regression analysis of CRIS data (excluding individuals with severe MMSE scores). To apply this in the model, the annual figure was divided by 52 to obtain a weekly cost reduction of approximately £9.56. This was then multiplied by the number of weeks in the

intervention to estimate total cost savings for different MMSE improvements. For example, a 3.0-point MMSE increase over the 12-week intervention period corresponded to an estimated cost reduction of £344.16.

7.5.3.1.3 Model assumptions

Several simplifying assumptions were made to model parameters about the population, treatment effect and mortality in the absence of evidence. A summary of assumptions, justifications and sources used in the economic model is provided in Table 7.5.

PLwD entered the model at a moderate stage of dementia. An assumption was made that a person living with moderate dementia would have an average MMSE score of 15. This was based upon the literature from NICE (2018), which defines stages of AD as mild, moderate, moderately severe or severe based on MMSE score (NICE, 2018b). It was assumed that these MMSE scores would apply to types of dementia other than AD. The starting age of people was 70 years; this was selected to align with the target populations of published studies (Ceccato *et al.*, 2012; Giovagnoli *et al.*, 2018).

Assumptions were made about the treatment effect of the model. It was assumed that the impact of MT interventions on MMSE scores in the community would be the same as if the intervention were carried out in a nursing home. It was also assumed that PLwD would continue to receive MT even if their cognition declined. This was in line with RCTs of MT in which PLwD continued to receive MT even if their cognition declined. Additionally a three-point improvement in MMSE was assumed to demonstrate cognitive improvement in the model.

PLwD who did not improve their MMSE scores in the three-month model were assumed to continue without improvement in the six-month model. Given the progressive nature of dementia and the limited cognitive benefits that are typically associated with pharmacological treatment alone, further improvement in cognition under usual care was considered unlikely.

Assumptions about mortality were also applied within the model. PLwD who died were assumed to incur zero additional costs. Also, it was assumed that people who died

within the model period did so at the halfway timepoint of 6.5 weeks in the three-month model and 18.5 weeks in the six-month model.

Table 7.5 Model assumptions

Parameter	Assumption	Justification	Source
Population	PLwD aged 70 years; moderate stage dementia at model entry	Matches population in published MT studies and NICE definitions	Ceccato *et al*., ; (2012) Giovagnoli *et al.*,(2018); NICE, (2018b)
Treatment effect	The impact of MT interventions on MMSE scores in the community is the same as if the intervention were carried out in a nursing home. MT continued even if cognition declined. Non-responders to MT assumed to continue without improvement	Assumptions reflect disease progression and generalisability across settings	Gomez-Gallego *et al*.(2021); Ting *et al*.(2024)
Mortality	Death assumed at the midpoint of the model (6.5 or 18.5 weeks). No additional costs after death	Used in similar cost-effectiveness models; end-of-life costs excluded	Vandepitte *et al*., (2020); ONS (2025)
Costs	Only NHS provider costs are included. Travel costs excluded Cost of usual care assumed to be zero, as assessment is of the additional costs of the intervention	Focus on direct healthcare costs; travel costs are considered negligible	Jones *et al*., (2023); Richmond Music Trust (2025)

Key

MMSE, mini-mental state examination; MT, music therapy

Table 7.6 Summary of baseline analysis parameters

Parameters	**Value**	**Description**	**Source reference**	**Source type**
MMSE starting score	15	MMSE score of 15 to represent moderate dementia severity	NICE Guidelines, (2018b)	UK guidelines
Mild	24	MMSE score to represent mild dementia severity	As above	As above
Severe	9	MMSE score to represent severe dementia severity	As above	As above
Time horizon	3 months (with an additional model over 6 months)	Reflects short-term outcomes reported in MT trials	Giovagnoli *et al.*,(2018) Gomez-Gallego *et al.*, (2021)	Randomised controlled trial (Italy; Spain)
Duration of MT sessions	60 minutes	Informed by randomised controlled trials, meta-analysis and a systematic review. Duration of sessions ranged from 12 minutes to 120 minutes	Gomez-Gallego *et al*., (2021) Ceccato *et al*.(2012) Ito *et al*. (2022)	Randomised controlled trial, Spain Randomised controlled trial, Italy Review and meta-analysis
Number of MT sessions per week	2	Informed by a data from a meta-analysis of MT. Frequency was shown to range from daily sessions to sessions once a week	Ito *et al*. (2022)	Review and meta-analysis
Probability of MMSE improvement in 12 weeks with MT (MMSE score change of 3 or more points)	0.704	Probability estimated from the results of network meta-analysis	Ting *et al*. (2024)	Calculated from results of network meta-analysis

Probability of MMSE improvement in 12 weeks with Usual Care (MMSE score change of 3 or more points)	0.063	Probability of improvement in MMSE score (characterised by 3 points or more) with usual care	Gomez-Gallego *et al*.(2021)	Randomised controlled trial, Italy
Probability of death with moderate dementia	0.0587	Annual probability with moderate dementia = 21.5% The 3-month probability was then calculated from this using a formula by Briggs *et al.* (2006)	Spackman *et al*. (2012)	Patient-level data, US
Probability of death with mild dementia	0.014	Annual probability with mild dementia = 5.5% The 3-month probability was then calculated from this using a formula by Briggs *et al*. (2006)	Spackman *et al*. (2012)	Patient-level data, US
Probability of death with severe dementia	0.1508	Annual probability with severe dementia = 48% The 3-month probability was then calculated from this using a formula by Briggs *et al*. (2006)	Spackman *et al*. (2012)	Patient-level data, US
Probability of improvement being maintained for another 3 months while MT continues	0.25	This was an estimate, no data on this was available	N/A	N/A
Probability of improvement being maintained with usual care	0.02	This was an estimate, no data on this was available	N/A	N/A
Cost of MT per person per week	£82	Weekly costs of MT, per person. Based on a one-hour group session with a music therapist for five people twice a week. All equipment provided	Richmond Music Trust (2025)	Private MT provider in the UK

Cost of usual care per week	£0	Cost of usual care was assumed to be zero	N/A	N/A
Cost of inpatient/outpatient care with moderate dementia – MMSE score 15 (range 10-20) (per week)	£76	Post-diagnosis yearly figure divided by 52 to get cost for a 1-week period £3,970/52	CRIS data analysis in Chapter 6	Patient-level data, UK
Cost of inpatient/outpatient care with mild dementia – MMSE score 15 (range 10 – 20) (per week)	£53	Post diagnosis yearly figure divided by 52 to get cost for a 1-week period = £2,751/52	As above	Patient-level data, UK
Cost of inpatient/outpatient care with severe dementia – MMSE score 15 (range 10 – 20) (per week)	£90	Post diagnosis yearly figure divided by 52 to get cost for a 1-week period = £4,698/52	As above	Patient-level data, UK
Cost of inpatient/outpatient care with a 3-point increase in MMSE score (per week)	£9.56	Annual cost reduction 1-point MMSE increase = £497 Weekly reduction = £497 / 52 = £9.56 For a 3-point MMSE increase over 12 weeks 3 x 12 x 9.56 = £344.16 Obtained from CRIS data regression (univariate analysis) post-diagnosis figure over 1 year	As above	Patient-level data, UK
Cost of care with death	£0	Death was treated as terminal with no associated cost. Informed by previous modelling studies that have assigned a zero cost to death	Vandepitte *et al*. (2020)	Markov model for dementia

Key

CRIS, Clinical Record Interactive Search; MMSE, mini-mental state examination; MT, music therapy; NICE, National Institute for Health and Care Excellence

7.5.4 Analysis and uncertainty

Results were reported using incremental cost-effectiveness ratios (ICERs) where appropriate. These were assessed against a WTP of £20,000 per QALY, which is a commonly used benchmark to guide decision-making in the UK (NICE, 2013). A range of sensitivity analyses were conducted to test the robustness of the model to variations in key parameters, including intervention effectiveness, costs, and mortality rates.

7.5.4.1 Deterministic sensitivity analysis

There is always uncertainty in the estimation of model inputs of interest, such as improvement in cognitive function. One-way sensitivity analyses were conducted to vary the key model parameters independently and assess their impact on the cost-effectiveness of MT compared with usual care.

Values were increased/decreased by 20% and 50%. However, for cost parameters, asymmetric ranges were applied to better reflect realistic variations. For example, the intervention cost was allowed to increase by up to 50%, but only decreased by 20%. This approach was taken because substantial reductions in cost were considered unlikely due to fixed elements such as staff time, training requirements, and infrastructure. In contrast, cost increases were considered more plausible in implementation settings, where variability due to service expansion, wage inflation, or regional variation in delivery costs might raise overall costs. The asymmetric ranges were incorporated into the tornado diagram to illustrate the impact of cost variation on the ICER.

In the sensitivity analysis for the six-month model, an asymmetric range was applied to the parameter representing the duration of cognitive improvement following the intervention. This reflected the assumption that while benefit might extend beyond the three-month period under ideal conditions, a much shorter duration was considered more likely given the nature of the intervention and disease progression. For example, the shortest duration estimate was set to represent minimal lasting effect, while the longest duration estimate allowed for a longer-lasting benefit, based on results from previous NPT trials. This approach helped to reflect uncertainty in the model around how long treatment effects might realistically continue, while still being informed by

existing evidence. All other parameters were varied symmetrically unless evidence or context suggested otherwise.

7.5.4.2 Parameters for sensitivity analysis - three-month model

Four key parameters were independently varied across plausible ranges for the three-month model, (all ranges of values are detailed later in the results section):

- Probability of improvement - UC
- Probability of improvement - MT
- Cost of the MT intervention
- Probability of death

7.5.4.3 Parameters for sensitivity analysis – six-month model

Four key parameters were independently varied across reasonable ranges for the six-month model:

- Probability of improvement being maintained - UC
- Probability of improvement being maintained - MT
- Cost of the MT intervention
- Probability of death
- Number of weeks in maintenance

7.6 Results

7.6.1 Three-month model

The base case deterministic cost-effectiveness results for MT versus usual care are presented in Table 7.7. At an ICER of £25,237, MT is shown to be more effective but also more costly than usual care.

Table 7.7 Baseline results of the three-month model – initial improvement

Pathway	Weighted costs (£)	Incremental costs	Weighted QALYs*	Incremental QALYs*	ICER
MT	£1,326		0.1346		x
Usual care	£986	£340	0.1211	0.0135	£25,237

** QALYs displayed to 4 decimal places*

7.6.1.1 Results of sensitivity analysis – three-month model

One-way deterministic sensitivity analyses were conducted on the three-month model to vary the key model parameters independently and assess their impact on the cost-effectiveness of MT compared with usual care. Results were presented in a tornado diagram, which ranked parameters by their influence on the ICER (Figure 7.2). Each bar represents the impact of varying a single parameter on the model's outcome whilst all others remained constant. The red vertical line denotes ICER from the base case analysis. Uncertainties in parameter values were estimated for effectiveness, costs and utility values.

The cost of MT had the greatest impact, with higher costs significantly increasing the incremental cost of the intervention. This reflected the fact that cost escalation is more realistic than substantial reductions in cost. The probability of improvement with usual care was also highly influential; when assumed to be more effective, the relative benefit of MT was reduced, negatively affecting cost-effectiveness. In contrast, changes to the probability of improvement with MT and the number of weeks of the intervention had a moderate effect on model outcomes. Parameters including the stage of dementia, associated care costs, and the three-month probability of death had minimal impact.

Sensitivity analysis confirmed that the model was most sensitive to changes in the cost of MT and the effectiveness of usual care. Variations in the duration of the intervention and the probability of improvement with MT had a moderate impact. In contrast, the probability of death and stage of dementia had relatively minimal effects on the results.

These findings suggest that assumptions around the cost and relative effectiveness of MT compared with usual care are key drivers of model uncertainty, and that more

precise data in these areas would strengthen the reliability of future economic evaluations.

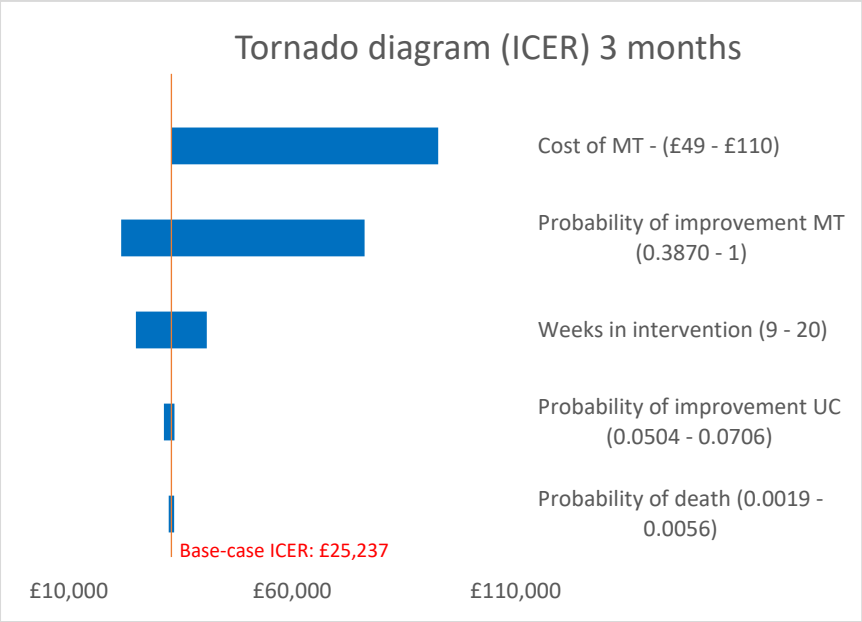


Figure 7.2 Tornado diagram shows key drivers of cost-effectiveness for MT at three months

7.6.2 Six-month model

MT versus usual care was evaluated over an additional three-month period, if the cognitive benefit of MT (measured by MMSE score) was maintained. A summary of the cost-effectiveness of this model is shown below in Table 7.8. Weighted total costs were higher for the MT pathway (£2,542) compared with usual care (£1,885), resulting in increased costs of £657 per person. Gains in QALYs were modest, with an incremental increase of 0.0359, leading to an ICER of £18,335 per QALY.

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Table 7.8 Results of the six-month model – maintenance of improvement

Pathway	Weighted costs (£)	Incremental costs	Weighted QALYs*	Incremental QALYs*	ICER
MT	£2,542		0.2595		
Usual care	£1,885	£657	0.2237	0.0359	£18,335

** QALYs displayed to 4 decimal places*

7.6.2.1 Results of sensitivity analysis – six-month model

One-way deterministic sensitivity analyses were conducted on the six-month model to vary the key model parameters independently and to assess their impact on the cost-effectiveness of MT compared with usual care. Figure 7.3 presents a tornado diagram summarising the results of the one-way sensitivity analyses. Each bar represents the impact of varying a single parameter on the model's outcome whilst all others remain constant.

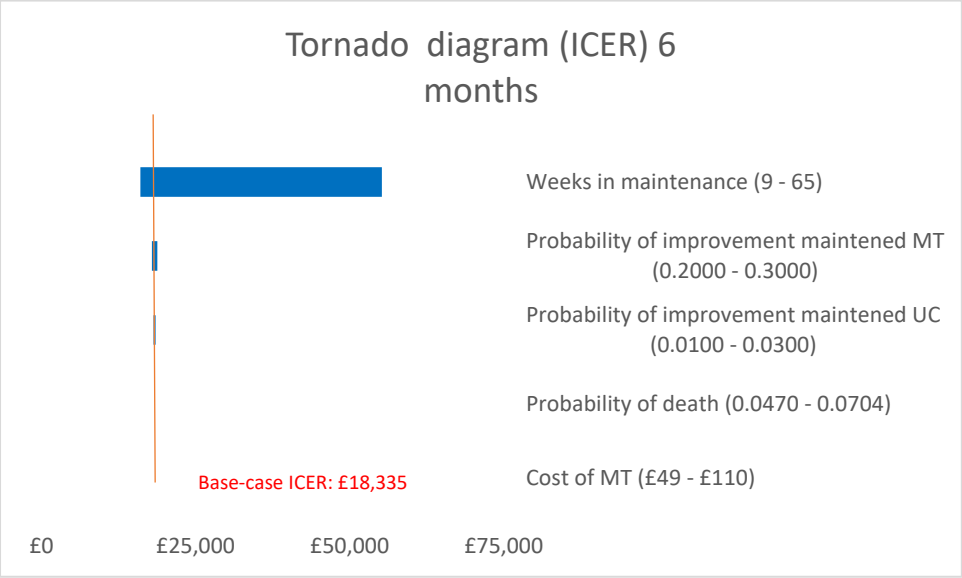


Figure 7.3 Tornado diagram showing key drivers of cost-effectiveness for MT at six months

The maintenance of the intervention for more weeks increased the costs, as expected, because the total intervention costs increased with the longer duration. Parameters for the intervention period in this scenario ranged from 9 weeks to 65 weeks (15 months). Varying the length of the intervention significantly affected the cost-effectiveness, which changed from cost-saving to not cost-effective. This suggests that the model was highly sensitive to how long improvements were maintained. Other parameters had a minor impact with minimal influence on the ICER comparison. Parameters remained robust to the sensitivity analyses that were applied.

Comparison of the results of the three-month and six-month models shows that the cost-effectiveness of MT improved over time with the assumption that cognitive benefits were maintained. In the initial three-month model, MT demonstrated

favourable, modest QALY gains; however, the cost per QALY exceeded typical UK WTP thresholds. Extension of the model to six months, assuming the benefit on MMSE was maintained, resulted in an incremental QALY gain of 0.0359 and an ICER of £18,335. This falls below the commonly cited UK WTP threshold of £20,000 per QALY that is used by NICE for decision-making. Although MT costs increased over the six-month period, the additional QALY gains suggest that MT may offer improved cost-effectiveness over a longer time horizon.

The sensitivity analyses for the three-month and six-month models revealed important differences in how assumptions affected the cost-effectiveness outcomes. The three-month model was highly sensitive to changes in the cost of MT and probability of improvement with usual care. The six-month model was sensitive to changes in the period of the intervention, but otherwise, parameters remained stable to sensitivity analysis. These results were confirmed by the tornado diagrams. Findings highlight the importance of accurate cost inputs and clinical assumptions when evaluating the cost-effectiveness of MT interventions.

7.6.3 Scenario Analysis: Comparison of three-month model results by dementia severity

Separate scenario analyses were conducted for mild and severe dementia to explore the generalisability of results across different dementia severities. These scenarios incorporated several severity-specific parameters for MMSE score, costs and 3-month probability of mortality, this reflected the clinical and economic differences observed in dementia at different stages of severity. The stage of dementia was varied by changing probability of death, costs and MMSE score to reflect each stage of dementia. This gives an idea of generalisability assuming that the effect of MT was the same at each stage of dementia. Results are shown in Table 7.9

In the absence of robust data on how the effectiveness of MT varies by dementia severity, the probability of MMSE improvement with MT was kept constant across all scenarios. This simplifies comparison but it may over or underestimate the true effect in mild or severe cases, where responsiveness to therapy is likely to differ. Therefore, the scenario and sensitivity analyses should be interpreted as exploratory rather than definitive assessments of cost-effectiveness across all stages of dementia.

Table 7.9 Scenario analysis to demonstrate impact of varying the stage of dementia

Scenario	Weighted costs (£)	Incremental QALYs*	ICER
Mild	£344	0.0141	£24,341
Moderate (base)	£340	0.0135	£25,237
Severe	£333	0.0122	£27,380

** QALYs displayed to 4 decimal places*

There was a gradual increase in the ICER from mild (£24,341) to severe dementia (£27,380), reflecting reduced QALY gains and potentially lower responsiveness in more advanced stages. Total costs were slightly lower in severe cases, this is likely due to shorter survival, but QALY gains were also smaller. These results suggest that offering MT earlier in the disease may offer better value for money.

7.7 Discussion

7.7.1 Strengths and limitations

A major strength of the model is that it is one of the first to be devised to evaluate the cost-effectiveness of MT specifically for individuals who live in the community with moderate dementia in a UK context. The model was developed using current clinical evidence, including a recent network meta-analysis and primary studies, and cost inputs were sourced from recognised national databases and real-world service data. A structured modelling approach was used, with deterministic sensitivity analyses conducted to test the robustness of the findings across a range of key assumptions. In the model, the WTP threshold was aligned with NICE guidelines, and this enhanced the relevance of the findings for policy and decision-makers.

There are several limitations to note. The model relied on published effectiveness estimates, which were not drawn from UK-based studies, and there may be differences in health system contexts that affect generalisability. Cost data were sourced from UK databases, but no inflation adjustment was applied beyond 2022 due to the lack of updated NHS inflation indices. The clinical evidence for MT, although growing, still contains a degree of heterogeneity in study design, intervention content,

and outcome measurement. Some of the studies included in the evidence base involved small sample sizes, which may have limited the representativeness of the findings to the wider dementia population.

There is an important distinction between the probability of improvement and the magnitude of improvement as the size of the effect can have a great influence on QALYs. The model assumes a 3-point improvement in MMSE to represent meaningful change in cognition. This threshold was selected as a 3-point change is commonly used in dementia research. However, evidence from recent MT studies typically show improvements of less than this so the 3-point improvement used in the model represents an optimistic effect size. The cost-effectiveness results should be interpreted in this context.

Additionally, while one-way deterministic sensitivity analyses were conducted to assess uncertainty in individual parameters, structural uncertainty related to the choice of model framework, health states and event assumptions was not formally explored. Finally, travel costs for service delivery were not included. It is noted that not all potential costs were considered in the model. Specifically, care home costs, home care provider use, and informal care costs were excluded. These cost categories are likely to be relevant to decision-makers beyond the healthcare perspective. All this may have led to underestimates of the total cost in real-world settings.

7.7.2 Future work and implications

The one-way sensitivity analysis showed that the model was most sensitive to changes in the cost of MT, the probability of improvement with usual care and the period of the intervention. Future research should focus on collecting more detailed, real-world cost data for MT services across different settings and stages of dementia. This would improve the accuracy of future economic models.

The model was not yet been tested with individuals diagnosed with MCI. This is a possible direction for future research. Given that music-based interventions have shown potential benefits in cognitive stimulation and emotional well-being among people with MCI, applying the economic music model to this population could give valuable insights. Future research might explore how this model could be adapted to

address the unique cognitive profiles and needs of individuals with MCI, potentially contributing to more targeted and effective therapeutic approaches.

Although evidence for the clinical effectiveness of MT is increasing, larger, high-quality studies are needed, particularly in the UK. Future studies should be designed to produce more precise estimates of intervention effects, use consistent measures of cognitive outcomes such as the MMSE, and include longer-term follow-up to assess the sustainability of benefits.

While one-way sensitivity analyses were conducted to test the robustness of input parameters, structural uncertainty related to the design of the model itself was not formally explored. In future modelling work, authors should consider testing alternative model structures, such as different definitions of health states, transitions between dementia stages, or broader event pathways, to assess whether the overall conclusions remain consistent under different assumptions.

From a policy perspective, the findings support the potential value of community-based MT programmes for people with moderate dementia. However, more consistent cost reporting and standardised economic evaluations are needed to better inform decision-making.

7.8 Conclusion

An economic model was developed to evaluate the cost-effectiveness of community-based MT for people living with moderate dementia in the UK. The model was developed using current evidence on the clinical benefits of active MT, with costs sourced from UK national datasets and real-world providers.

The findings suggest that MT has the potential to be a cost-effective intervention, offering improvements in cognitive function for PLwD in the community. The sensitivity analyses confirmed that while the short-term results were generally not robust and could vary significantly, the model was more robust at six months. Key factors that influenced the three-month outcome were intervention costs and the effectiveness of usual care. In the longer term, intervention costs became the dominant driver of the model's sensitivity. This reflects the ongoing financial impact of the intervention over time.

While there are limitations, including the use of data published in non-UK studies and a lack of structural uncertainty analysis, the results provide valuable evidence for decision-makers considering the broader adoption of NPTs in dementia care. Overall, the model contributes to the growing body of research that supports the integration of MT into community-based dementia services.

7.9 Chapter summary

In this chapter, the development of an economic model to evaluate the cost-effectiveness of community-based MT for people living with moderate dementia in the UK is described. The selection of MT for economic evaluation was guided by the results of the online survey, which had captured the research priorities of individuals with lived experience of dementia as described in Chapter 5.

In the next chapter, a second economic model is explained, which can be used to evaluate the cost-effectiveness of CTPs for informal caregivers of PLwD.

Chapter 8 Decision-analytic modelling of a training programme versus usual care for family caregivers of PLwD in the UK

8.1 Introduction

The aim of the work described in this chapter was to assess the cost-effectiveness of caregiver training programmes (CTPs) drawing on existing evidence on their outcomes and costs. The selection of the intervention model was informed by the results of a survey of individuals with lived experience of dementia as detailed in Chapter 5. Respondents highlighted the importance of caregiver training and expressed a clear need for further research into such provisions.

As discussed in Chapter 2, many family caregivers report feeling unprepared and unsupported in their roles. The complex and progressive symptoms of dementia can be overwhelming and often lead to caregiver stress, physical health issues, and mental health challenges (Tay *et al.*, 2025). With an ageing population and increasing pressure on formal care services, reliance on informal caregiving continues to grow (Evandrou *et al.*, 2024). This highlights the critical need to address support gaps for family caregivers in dementia care.

8.2 Background

CTPs are structured interventions that are designed to enhance caregivers' knowledge, skills, and confidence. These programmes typically support spouses, adult children, or other family members who provide ongoing care within the community (Sadavoy, Sajedinejad and Chiu, 2022). By empowering caregivers, CTPs can improve caregiver well-being, enhance the caregivers' quality of life, and reduce the BPSD of those they look after (Gitlin *et al.*, 2010b; Livingston *et al.*, 2014b). Additionally, these programmes may contribute to delays in the need to place the person they care for in long-term care (Mittelman *et al.*, 2006). BPSD is a major risk factor for institutionalisation, however there are also other factors such as impaired daily functioning, comorbid physical conditions, caregiver burden, depression and living situation (Mittelman *et al.*, 2006).

Despite evidence supporting the effectiveness of CTPs, relatively few RCTs have been performed to assess their cost-effectiveness. Significant gaps remain in our understanding of how CTPs compare with usual care from an economic perspective. Economic modelling offers a valuable approach by which to address this gap by synthesising data from multiple sources to estimate the costs and benefits of interventions. In the absence of direct economic data, policymakers often use such models to inform decisions about the integration of new interventions into routine care. However, most existing models are focused primarily on clinical outcomes, with limited attention to economic evaluation.

8.3 Aim

The aim was to assess the cost-effectiveness of CTPs for informal caregivers of PLwD compared with usual care (family caregivers who had not received structured caregiver training), using a purpose-built economic model.

The model specifically evaluated the impact of CTPs on BPSD, with a focus on agitation, reflecting extensive evidence that highlights its high prevalence and the significant challenge it poses for caregivers (Tible *et al.*, 2017; Halpern *et al.*, 2019). It assumed that caregivers who participated in CTPs were better equipped with behavioural management strategies, than caregivers that had not attended training, which then led to reductions in the severity and frequency of symptoms of BPSD in the PLwD they were supporting.

The model further assessed how these improvements influenced the period to transition to long-term care, under the assumption that reduced BPSD can delay institutionalisation. Through the integration of clinical and economic data, the model provided a framework for the assessment of the cost-effectiveness of CTPs. This evidence can support policymakers and healthcare commissioners in making informed decisions about the implementation of such programmes within their local health systems.

The chapter is structured to provide a comprehensive examination of CTPs in the context of dementia care. It begins with background information on CTPs and explained their relevance to improving outcomes for PLwD and their caregivers.

Following this, a healthcare economic decision tree model was developed to assess the cost-effectiveness of these programs. The chapter then details the methods used to structure and populate the model, ensuring a transparent and robust analytical framework. Finally, the findings were discussed along with their implications for policy, clinical practice, and directions for future research.

8.4 Overview of CTPs

CTPs are structured interventions that are designed to equip informal caregivers with practical strategies to manage BPSD (Gitlin *et al.*, 2010b). BPSD include agitation, aggression, and wandering; these are common in PLwD and are major contributors to caregiver stress and therefore to early institutionalisation (Mittelman *et al.*, 2006). CTPs typically focus on helping caregivers to identify behavioural triggers and apply techniques such as distraction and redirection to reduce the frequency of occurrence and severity of these behaviours (Gitlin *et al.*, 2010b).

High levels of caregiver burden have been strongly associated with early transitions of PLwD into long-term care facilities (Schulz and Sherwood, 2008). CTPs that teach caregivers how to manage challenging behaviours more effectively than they have done previously can reduce caregiver distress, improve quality of life for the caregiver and PLwD, and make care at home more sustainable (Gitlin *et al.*, 2010a).

In the UK, a variety of CTPs are currently available, many of which are offered free of charge (Dementia UK, 2023). These programmes are delivered by a range of support organisations, including the Alzheimer's Society, Dementia Adventure, Alzheimer Scotland, and Carers Trust. However, there is considerable heterogeneity in the design and delivery of these programmes (Felstead *et al.*, 2022). There are variations in the content of sessions, intended outcomes, delivery methods (e.g., in-person vs. online), frequency and duration of sessions, and the qualifications of training facilitators. This variability presents challenges for the standardisation of CTPs and evaluation of their effectiveness and cost-effectiveness across different settings. It is essential to understand these differences to inform the development of scalable, evidence-based interventions that can be integrated into routine dementia care. In this chapter, this is discussed in relation to the content of sessions, outcomes, method of delivery, frequency and duration of sessions and training facilitators.

To explore the potential effectiveness of CTPs a literature search was conducted in the Medline database to identify relevant RCTs and systematic reviews. The search strategy included the terms dementia or alzheimers or mild cognitive impairment (in title) AND carer train* or Carer prog* (in title) and was limited to studies published between 1st January 2020 and 18th February 2025. Studies were included if they evaluated CTPs for caregivers of PLwD and reported quality of life or health outcomes for PLwD. The reference lists of the included studies were also screened to identify additional relevant publications. Characteristics from these studies were extracted and are presented in Table 8.1 and Table 8.2.

8.4.1 Primary outcomes measured in CTPs

A meta-analysis of caregiver interventions found that effectiveness was moderated by factors such as the number of sessions, intervention setting, the ages of the caregiver and care receiver, caregiver gender, relationship type (spouse of the PLwD vs. their adult child) and the burdens on the caregiver before the addition of caring for someone with dementia (Sorensen, Pinquart and Duberstein, 2002).

CTPs are intended to improve the mental health and well-being of caregivers, while indirectly supporting better outcomes for PLwD. Several studies have reported outcomes for both caregivers and PLwD (Gitlin *et al.,* 2010b; Birkenhager-Gillesse *et al.,* 2022; Teles, Ferreira and Paúl, 2022). The limited research that has been performed in this area has routinely focused on carer-well-being outcomes (e.g. carer quality of life, burden and depression), underpinned by a theoretical assumption that improved carer well-being should have an associated positive effect on those for whom they provide care (Felstead *et al.,* 2022).

There is strong evidence that attendance at CTPs support PLwD to remain at home for longer, by enhancing the skills and confidence of caregivers and addressing factors that might otherwise lead to care home admission (Gitlin *et al.*, 2010b) or earlier institutionalisation (Mohide *et al.*, 1990; Brodaty and Peters, 1991; Mittelman *et al.*, 2006; Livingston *et al.*, 2014b; Birkenhager-Gillesse *et al.*, 2022). While some studies suggest that caregiver outcomes may be more predictive of admission to long-term care than BPSD symptoms alone (Black and Almeida, 2004), these factors are closely linked. BPSD is a key contributor to caregiver burden, and the causes of admission often arise from the interaction between the characteristics of the PLwD, the caregiver,

and the home environment (Toot *et al.*, 2017). Many of these factors are modifiable and may be targeted through caregiver training interventions to reduce the likelihood of long-term care admission (Toot *et al.*, 2017).

About two-thirds of PLwD are reported to experience BPSD (Trivedi *et al.*, 2019), which may include depression, hallucinations, agitation, aggression, and resistance to care. These symptoms can be challenging for both PLwD and caregivers, and are a major cause of distress to both parties (Ballard *et al.*, 2018b). However, the degree to which caregivers are affected by the different symptoms varies. A review found that some BPSD were not as strongly correlated with caregiver well-being as others; depression was shown to be the most distressing symptom and euphoria the least distressing (Feast *et al.*, 2016). However, euphoria can still be problematic, as it may reflect disinhibition, lack of insight, or inappropriate social behaviour in PLwD (Cerejeira, Lagarto and Mukaetova-Ladinska, 2012). Poor cognition and BPSD are associated with increased risk of admission to long-term care, with cognition being the most substantial risk (Toot *et al.*, 2017). BPSD may increase the risk of a move to a care home as the caregiver no longer feels able to meet the needs of the PLwD (Gitlin *et al.*, 2010c; Trivedi *et al.*, 2019).

Management of behavioural symptoms is one of the most significant costs involved in dementia care (Gitlin *et al.*, 2010c). Symptoms may increase service use and direct-care costs (Gitlin *et al.*, 2010c; Kales *et al.*, 2014). BPSD in PLwD are commonly managed with medications such as antipsychotics, antidepressants, and anxiolytics, although these can come with significant risks and side effects (R. Lin *et al.*, 2021). An area of current debate is whether BPSD are not directly due to dementia but rather may be due to the person with dementia trying to communicate unmet care needs (Warren, 2022). However, some studies indicate that receipt of an NPT such as MT (described in the previous chapter) can reduce symptoms but do not eliminate them (Abraha *et al.*, 2017), hence suggesting that BPSD may not be merely reactions to unmet care needs. NICE (2018a) recommends that non-pharmacological approaches, including assessment of environmental factors, should be the first-line treatment for agitation, aggression, distress, and psychosis in PLwD. As well as improving management of BPSD, CTPs have been shown to improve understanding of dementia and enhance caregiving skills (Patel *et al.*, 2023), while also increasing caregiver

confidence to cope with caregiving challenges (Brodaty and Peters, 1991; Sadavoy, Sajedinejad and Chiu, 2022; Teles, Ferreira and Paúl, 2022; O'Hara *et al.*, 2024).

Felstead *et al.* (2022) conducted a systematic literature review, in which they examined the effectiveness of group-based training interventions for informal caregivers regarding management of BPSD. The interventions typically included structured group sessions that were aimed at educating caregivers about dementia, enhancing coping strategies, and promoting communication and problem-solving skills. The primary outcomes that were evaluated were changes in the frequency and severity of BPSD among PLwD, as well as caregiver burden and psychological well-being.

The review identified significant heterogeneity in intervention content, duration, and methodological rigour. However, it found that studies that incorporated structured problem-solving components were more likely to report positive effects on BPSD. Overall, the evidence was limited, and many studies lacked robust designs or standardised outcome measures. The authors concluded that while group-based training showed promising results, especially when delivered over lengthy periods, there was further need for high-quality research to determine its definitive impact on the management of BPSD in PLwD. They called for more research in which BPSD would be the primary study outcome, in order to determine the impact of CTPs on BPSD management (Felstead *et al.*, 2022).

By equipping caregivers with the necessary skills and strategies to manage BPSD, these training programmes can significantly improve the QoL for both caregivers and those they care for. Additionally, the training may delay or reduce the need for institutional care, leading to potential savings in spending on long-term care.

Interventions have evaluated outcomes either for caregivers (Haberstroh *et al.,* 2006; Sadavoy, Sajedinejad and Chiu, 2022; Brooks *et al.,* 2024), for PLwD (Williams, Newman and Hammar, 2018) or for both caregivers and PLwD (Silvestri *et al.,* 2004; Liddle *et al.,* 2012; Birkenhager-Gillesse *et al.,* 2022).

8.4.1.1 Outcome measures for PLwD

Several CTPs have included the assessment of BPSD as a key outcome, recognising that improved caregiver skills and support can indirectly reduce behavioural symptoms in PLwD. These studies typically use the NPI (Gitlin *et al.*, 2010b; Felstead *et al.*, 2022)

or the CMAI to measure changes in BPSD. Other studies have measured quality of life through the use of the three-level version of the EQ-5D (Birkenhager-Gillesse *et al.,* 2022), and the quality of life in the AD scale (Haberstroh *et al.,* 2006). Cognitive function is often assessed using the MMSE (Silvestri *et al.,* 2004). Other studies have explored the impact of CTPs on delays in removal to long-term care or the lengthening of the time to such care, which lead to potential cost savings. The reported reduction in rates of institutionalisation is due to a combination of caregiver-focused and PLwD-focused mechanisms, most of which improve the sustainability of home-based care (Mohide *et al.*, 1990; Mittelman *et al.*, 2006; Livingston *et al.*, 2014b).

8.4.1.2 Outcome measures for caregivers

A range of outcome measures are typically used to assess the effectiveness of CTPs for caregivers or PLwD. Several instruments have been employed specifically to evaluate the quality of caregivers' lives and their burden, including the three-level EQ-5D for HRQoL (Birkenhager-Gillesse *et al.,* 2022), self-reported quality-of-life measures (Sadavoy, Sajedinejad and Chiu, 2022; Brooks *et al.,* 2024) and the ZBI for caregiver burden (Silvestri *et al.,* 2004).

Programmes commonly report improvements in caregiver quality of life and reductions in levels of depression, stress and caregiver burden (Sadavoy, Sajedinejad and Chiu, 2022; Brooks *et al.,* 2024). Evidence suggests that CTPs that reduce the burden of stress on caregivers enable them to continue to provide care at home beyond what is offered by caregivers without such training, and the transfer into residential or nursing homes is delayed (Gallagher-Thompson *et al.*, 2012).

8.4.2 Therapeutic approaches

The content of CTPs can focus on different aspects of caregiving. It can include psychoeducational sessions (Birkenhager-Gillesse *et al.,* 2022), coping strategies and techniques for management of behavioural symptoms (Burns *et al.*, 2003; Gitlin *et al.*, 2010b) or communication skills (Done and Thomas, 2001) or a combination of these. Sessions may also involve activities such as group work, modelling and role play (Belle *et al.,* 2006; Birkenhager-Gillesse *et al.,* 2022).

The findings indicate that interventions that target only the behaviour of the care recipient may not be sufficient to relieve caregiver burden and that caregiving issues

must also be addressed (Burns *et al.*, 2003). These issues include physical and emotional strain (Tay *et al.*, 2025). Organisers of CTPs have found that spousal caregivers make more improvements in psychological and emotional outcomes than do non-spouses (Belle *et al.*, 2006).

8.4.3 Delivery approach and setting

Training programmes may be offered through a variety of methods: in-person (Brodaty and Peters, 1991; Done and Thomas, 2001; Burns *et al.*, 2003; Klodnicka Kouri, Ducharme and Giroux, 2011), online (Teles, Ferreira and Paúl, 2022; Patel *et al.*, 2023), via video conferencing (Brooks *et al.*, 2024) or through virtual reality (O'Hara *et al.,* 2024). Group settings can help to foster a support network and peer support, reduce social isolation and help caregivers cope emotionally and practically. Sessions are commonly held in small groups (Felstead *et al.*, 2022; Sadavoy, Sajedinejad and Chiu, 2022), which have been recommended by NICE as the most effective format (NICE, 2018a).

Many CTPs are carried out in community settings, which may be home-based (Mohide *et al.*, 1990; Gitlin *et al.*, 2008, 2010a) or clinical (Silvestri *et al.*, 2004; Livingston *et al.*, 2014b). In the case of the Birkenhager-Gillesse *et al.* (2022) study, both the caregiver and the PLwD were admitted to hospital for the intervention. There have also been residential training programmes (Brodaty and Peters, 1991; Birkenhager-Gillesse *et al.*, 2022).

8.4.4 Facilitators

Sessions can be facilitated by professionals such as geriatricians, psychologists and occupational therapists (Gitlin *et al.,* 2010a; Birkenhager-Gillesse *et al.,* 2022) or by community support staff (Teri *et al.,* 2005). In a study by Collins-Pisano *et al.* (2024), the feasibility of training former family caregivers to deliver CTPs was tested. It was reported that this was feasible, although improvements in caregiver burden did not reach significance (Collins-Pisano *et al.,* 2024). A study by Loi *et al.* (2022) used psychology graduates to deliver the intervention. Routine care, is often used as a comparator in evaluations of CTPs to evaluate their added value (Birkenhager-Gillesse *et al.,* 2022).

8.4.5 Frequency and duration of sessions

The number of training sessions and the duration of programmes varied. Some programmes consisted of as few as one session (Sadavoy, Sajedinejad and Chiu, 2022; Patel *et al.*, 2023; O'Hara *et al.*, 2024) and others as many as 14 (Birkenhager-Gillesse *et al.*, 2022). Duration of programmes ranged from a few days (Birkenhager-Gillesse *et al.*, 2022) to two years (Burns *et al.*, 2003). The most common duration was 10-12 weeks (Mohide *et al.*, 1990; Gitlin *et al.*, 2010b; Sadavoy, Sajedinejad and Chiu, 2022; Brooks *et al.*, 2024).

8.4.6 Timing and acceptability of CTPs

The timing of CTPs in relation to the stage of dementia is important in determining their impact and relevance. Evidence suggests that early implementation, especially in the mild to moderate stages of dementia, is most beneficial (Teri *et al.*, 2005; Livingston *et al.*, 2014b). At this stage, caregivers are often in the process of dealing with the diagnosis and may experience increasing distress and uncertainty about how they can support the person with dementia effectively. Delivery of CTPs in the early stages of dementia can provide caregivers with essential coping strategies, communication skills, and an understanding of disease progression before care demands intensify (Livingston *et al.*, 2014a). This can help to prevent or delay crisis-driven decisions and lower the risk of institutionalisation (Livingston *et al.*, 2014a). If CTPs are delivered too early, caregivers may find it difficult to engage with the content as the relevance may not yet be apparent, but if they are given too late, caregiving demands may have become overwhelming.

In terms of acceptability of the CTP, caregivers have shown preference for receiving training as opposed to joining a support group; training can feel like an active process in which caregivers can learn and progress, whereas a support group may be viewed as giving up and accepting that they cannot change anything (Haberstroh *et al.,* 2006). Language differences can hinder caregivers' access to information and support. CTPs are more effective when they take into account the cultural backgrounds and specific needs of caregivers from diverse ethnic groups (Belle *et al.*, 2006).

A review by Evans *et al.* (2024) looked at CTPs in low- and middle-income countries The authors recommended that more work be done on understanding interventions

and developing culturally tailored programmes that were adapted to the specific needs of people in these areas. A study by Patel *et al.* (2023) looked at the feasibility and acceptability of an online, single-session CTP. It showed good acceptability to caregivers and non-significant improvements in caregiver well-being; however, it was not sufficiently powered to be used to determine improvements in outcomes (Patel *et al.*, 2023).

8.4.7 Equipment and associated costs

Some RCTs of CTPs have included details about the costs of the intervention (Gitlin *et al.*, 2010c; Birkenhager-Gillesse *et al.*, 2022) as did a training programme for staff in nursing homes (Williams *et al.*, 2017). Other RCTs have included an evaluation of the cost-effectiveness of the intervention (Gitlin *et al.*, 2010a; Williams *et al.*, 2017).

Implementation of CTPs can involve fixed as well as variable costs. The largest component is usually staffing costs (Birkenhager-Gillesse *et al.,* 2022), particularly in terms of salaries for facilitators such as clinical psychologists or dementia care specialists. If a CTP involves an in-person workshop (Done and Thomas, 2001), there may be hire costs for meeting rooms and for basic equipment including chairs, projectors, flip charts, and printed materials or manuals.

For web-based or mixed-method CTPs, information technology infrastructure can be a key driver of costs. This can include expenses for licences for video conferencing platforms, access to secure online learning portals, and provision of technical support. Tablets or laptops may be required for participants who do not have access to devices, especially in underserved populations.

Resources for the training can include printed materials such as leaflets, which should be accounted for in the intervention cost (Done and Thomas, 2001; Burns *et al.,* 2003). Some studies have also included the cost of administrative time required to prepare these materials (Williams *et al.*, 2017). Additionally, development costs should be included, especially for manualised interventions, which require the creation of evidence-based content, pilot testing, and professional editing. If the programme incorporates multilingual materials or culturally adapted content, there may be

additional costs associated with translation, cultural adaptation, and validation to ensure accuracy and relevance across target populations.

Food and drink costs may also need to be included if the intervention is in-person. Birkenhager *et al.* cited costs as staff salaries (62%), rent for accommodation (24%), overheads (4%) and food and drink costs (10%) (Birkenhager-Gillesse *et al.*, 2022). The total cost of the intervention was €1000 per dyad, for a one-week intervention with five or six couples participating (Birkenhager-Gillesse *et al.*, 2022).

Finally, indirect costs—such as transport reimbursement for caregivers attending face-to-face sessions, provision of childcare or respite services, and the cost of printed certification—can affect both the uptake of the programme and its long-term feasibility.

8.4.8 Access to CTPs

Research has found that access to these types of programmes is limited, and that there is insufficient funding to support their widespread implementation (Prince *et al.*, 2014; Livingston *et al.*, 2024). Several major dementia organisations, including the Alzheimer's Society and Dementia UK offer CTPs. Some local health authorities offer training as well as support groups; however, the format and content of these vary greatly. NICE suggests that caregivers find CTPs delivered in groups to be most effective (NICE, 2018a). Current NICE guidelines state that informal caregivers of PLwD should be offered psychoeducation and skills training at the time of diagnosis NICE, 2018a). However, research suggests that caregivers are frequently not offered training until well after diagnosis, even though many would prefer and benefit from receiving it at an earlier stage (Patel *et al.*, 2023).

8.4.9 Summary of key CTPs

The literature review identified key studies that have evaluated the impact of CTPs for PLwD (section 8.4). The results of this literature review are summarised in Table 8.1 and Table 8.2. While there have been other small or more recent studies, the major RCTs that have informed current evidence and guidelines are included. The literature review also identified studies that looked specifically at BPSD outcomes for PLwD (Table 8.3).

The STrAtegies for RelaTives (START) randomised trial developed by Livingston *et al.* (2014b), evaluated the effectiveness of a manual-based psychological training programme aimed at improving the mental health of caregivers of PLwD (Livingston *et al.*, 2014b). The programme significantly reduced levels of anxiety and depression among caregivers compared with usual care. Outcomes were measured using HADS. Caregivers in the intervention group showed clinically meaningful improvements, and the benefits were sustained over the eight-month follow-up period. Although secondary outcomes of quality of life and BPSD for PLwD showed some improvements, these were not statistically significant.

Another programme, the Tailored Activity Program (TAP), taught caregivers to develop personal strategies to manage symptoms of dementia, based on the PLwD's preferences and specific triggers (Gitlin *et al.*, 2009). Other studies of CTPs showed improvements in communication between the person with dementia and the caregiver (Williams, Newman and Hammar, 2018), and a reduction in caregiver stress and burden (Burns *et al.*, 2003). However, a recent review of CTPs concluded that there was weak evidence that they reduced BPSD (Felstead *et al.*, 2022).

A US study by Mittleman *et al.* (1996) looked at long-term effectiveness of a CTP for improving caregiver well-being, and the impact of this on delaying transfer to long-term care in people with AD, over a ten-year period (Mittelman *et al.*, 1996, 2006). It showed a 23% reduction in the rate of nursing home admissions for people whose spouses had completed the training compared with usual care. The authors suggested that this effect may be linked to improvements in caregivers' satisfaction with social support, reduced depression, and better responses to BPSD symptoms in PLwD, although no formal mediation analysis was reported.

Overall, the evidence suggests that CTPs could be effective in improving caregiver mental health, reducing caregiver stress and burden and in some cases improving communication with PLwD. While the strongest evidence related to reductions in caregiver anxiety and depression, in large trials such as START, other benefits included delayed transfer to long-term care and improvements in caregiver coping with behavioural symptoms. Although existing literature shows limited or inconsistent evidence for direct improvements in PLwD outcomes such as quality of life or behavioural symptoms, the model assumes that enhanced caregiver skills can lead to

indirect benefits for PLwD, including modest improvements in these outcomes. This assumption addresses gaps in the evidence base and reflects the model pathway through which CTPs may improve wellbeing for PLwD.

Table 8.1 Summary of characteristics of key RCTs of CTPs (with outcomes for PLwD)

Author	Country	Intervention Specifics	Number of participants	Setting	Outcome tools	Session duration, number of sessions	Key outcomes
Birkenhager-Gillesse *et al.* (2022) Cost-effectiveness of dementia training for caregivers in caregiver-patient dyads: A randomised controlled study	Netherlands	Caregiver training including dementia education and coping strategies (multi-day training delivered while caregivers and PLwD stayed on-site in a holiday setting)	109 dyads	Community-based	EQ-5D-3L, DQI	10 days, 14 sessions	Nursing home admissions lowered, less use of healthcare resources. Increased QALYs for caregivers and PLwD. Cost-effective
Gitlin *et al.* (2008) (TAP – pilot study) Tailored Activities to Manage Neuropsychiatric Behaviors in Persons with Dementia and Reduce Caregiver Burden: A Randomised Pilot Study	US	Occupational therapy led. Individualised, tailored activities	60 dyads	Home-based	Various including DRS, Carer Vigilance scale	4 months, 8 sessions	Reduced caregiver burden, improved the daily functioning of PLwD
Gitlin *et al.*, (2010b) Targeting and Managing Behavioral Symptoms in Individuals with Dementia: A Randomised Trial of a Nonpharmacologic Intervention (TAP)	US	Occupational therapy-led	272 dyads	Home-based	ZBI, CES-D, PCI	16 weeks	Improvement in targeted behaviours of BPSD, caregivers also showed reduced depression
Gitlin *et al.* (2010a)	US	Occupational therapy and nurse led. Mixed methods including	237 dyads	Home-based	FIM, QoL-AD (proxy), Agitated	4 months,10 sessions	Improved caregiver well-being and confidence. Some reductions in caregiver distress.

A Biobehavioral Home-Based Intervention and the Well-being of Patients With Dementia and Their Caregivers: The COPE Randomized Trial (COPE - built on the principles of TAP)		online behavioural support programme			behaviour in dementia scale, PCI		Improved PLwD functioning in terms of IADLs. Improvement in PLwD QoL or reduction in BPSD frequency was not statistically significant, although there was a positive trend to a reduction in frequency of agitated behaviours. Evaluated as cost-effective
Livingston *et al.* (2014b) (STrAtegies for RelaTives) study: a pragmatic randomised controlled trial to determine the clinical effectiveness and cost-effectiveness of a manual-based coping strategy programme in promoting the mental health of caregivers of people with dementia (START)	UK	Manual-based coping strategy. Individual sessions with psychological strategies (START). Face-to-face training	260 caregivers	Community-based (clinical or community settings)	HADS, QoL, CDR, QoL-AD, ZBI	8 weeks, 8 sessions	Reduced depression/anxiety for caregivers and improved QoL. No significant changes in BPSD for PLwD. Reduced institutionalisation. Caregivers had maintained reduced levels of depression and anxiety 6 years after the intervention. PLwD outcomes were not significant. Shown to be cost-effective
Mittelman *et al.* (2006)	US	Counselling, support group, and support for spousal caregivers	406 dyads	Community-based	Various including GDS	4 months (with ongoing support after this period), not stated	Delayed transfer to long-term care, improved caregiver well-being
Mohide *et al.* (1990)	Canada	Case management and family support intervention delivered in-home	60 dyads	Home-based	CES-D, various others	12 months, weekly sessions initially	Reduced caregiver burden, delayed placement

Silvestri *et al.* (2004)	Italy	Individualised behaviour management training to reduce PLwD symptoms	26 dyads	Geriatric care centre	IADL, E-BEHAVE-AD, MMSE	12 weeks, 6 sessions	Showed statistically significant reduction in BPSD for PLwD (limited by small study sample & insufficient detail in reporting)
Teri *et al.* (2005)	US	Exercise and behaviour management techniques	95 dyads	Home/community	NPI, CES-D	8 weeks, 8 weekly sessions (followed by 4 months of follow-up phone calls)	Improved caregiver mood and reduced behavioural symptoms in care recipients. NPI used but scores not reported. (Rated as high quality in some reviews)
Williams *et al.* (2018)	US	Psychoeducational intervention (communication intervention)	15 dyads	Home-based	Communication scales	10 weeks, 10 sessions	Significant improvement in communication skills for caregivers. Small study

Key

BEHAVE-AD - Behavioral Pathology in Alzheimer's Disease Rating Scale; BPSD - Behavioural and Psychological Symptoms of Dementia; CES-D - Center for Epidemiologic Studies Depression Scale; CDR - Clinical Dementia Rating; DQI - Dementia Quality of Life Instrument; DRS - Dementia Rating Scale; DRD - Dementia Rating Scale; FIM - Functional Independence Measure; GDS - Global Deterioration Scale; GHQ - General Health Questionnaire; HADS - Hospital Anxiety and Depression Scale; IADL - Instrumental Activities of Daily Living; MMSE – Mini mental state examination; NHP - Nottingham Health Profile; NPI - Neuropsychiatric Inventory; PCI - Perceived Change Index; QALYs Quality-adjusted life years; QoL - Quality of Life; QoL-AD - Quality of Life in Alzheimer's Disease scale; ZBI - Zarit Burden Interview

Table 8.2 Summary of characteristics of key reviews of CTPs (with outcomes for PLwD)

Author	**Type of study**	**Number of studies**	**Outcome**	**Outcome tools**	**Conclusion**
Felstead *et al.*(2022)	Systematic review	10	Caregiver burden, psychological well-being, PLwD behavioural and psychological symptoms	NPI, DEMQOL, HADS	Small but significant effect on reducing caregiver burden. Positive results for PLwD, improved BPSD outcomes

Key

NPI - Neuropsychiatric Inventory; DEMQOL - Dementia Quality of Life Measure; HADS - Hospital Anxiety and Depression Scale

Table 8.3 Overview of CTPs with outcomes on BPSD for PLwD

Author	Country	Intervention Specifics	Number of participants	Setting	Outcome tools	Session duration, number of sessions	Key outcomes
Gitlin *et al* (2010a) A Biobehavioral Home-Based Intervention and the Well-being of Patients With Dementia and Their Caregivers: The COPE Randomised Trial (COPE - built on the principles of TAP)	US	Occupational therapy and nurse led. Mixed methods including online behavioural support programme	237 dyads	Home-based	FIM, QoL-AD (proxy), Agitated behaviour in dementia scale, PCI	4 months,10 sessions	Improved PLwD functioning in terms of IADLs. Reduction in PLwD QoL or BPSD frequency was not statistically significant, although there was a positive trend to a reduction in frequency of agitated behaviours At 4 months, 62.7% of dyads in the COPE intervention group eliminated one or more caregiver-identified problems, compared to 44.9% in the control group. Statistically significant improvements were observed in functional dependence for COPE patients (baseline to 4 months) compared with control group patients (adjusted mean difference, 0.24; CI, 0.03–0.44; P = 0.02; Cohen d = 0.21), representing a small effect. Improvement occurred mostly for IADLs (adjusted mean difference, 0.32; 95% CI, 0.09–0.55; P = 0.007; Cohen d = 0.43), a moderate effect. Cost-effective
Gitlin *et al.* (2008) (TAP – pilot study) Tailored Activities to Manage Neuropsychiatric Behaviors in Persons with Dementia and Reduce Caregiver Burden: A Randomized Pilot Study	US	Occupational therapy-led tailored activity training> individualised, tailored activities. Face-to-face training	60 dyads	Home-based	Various including PCI, DASS-21, DRS, Carer Vigilance scale	4 months, 8 sessions	Improved the daily functioning of PLwD Reduced agitation measured by NPI but some results not significant

Gitlin *et al*., (2010b) Targeting and Managing Behavioral Symptoms in Individuals with Dementia: A Randomized Trial of a Nonpharmacologic Intervention	US	Occupational therapy-led	272 dyads	Home-based	ZBI, CES-D, PCI	16 weeks	Improvement in targeted behaviours of BPSD, caregivers also showed reduced depression
Silvestri *et al.* (2004)	Italy	Individualised behaviour management training to reduce PLwD disturbances	26 dyads	Geriatric care centre	IADL, E-BEHAVE-AD, MMSE	12 weeks, 6 sessions	Showed statistically significant reduction in BPSD for PLwD (limited by small study sample & insufficient detail in reporting)
Teri *et al.* (2005)	US	Exercise and behaviour management techniques	95 dyads	Home/community	NPI, CES-D	8 weeks, 8 weekly sessions (followed by 4 months of follow-up phone calls)	Reduced behavioural symptoms in PLwD. Results maintained at 6 months Improvements for memory, and proxy reported QoL-AD High quality, reasonable number of participants

Key

BEHAVE-AD - Behavioral Pathology in Alzheimer's Disease Rating Scale; BPSD - Behavioural and Psychological Symptoms of Dementia; CES-D - Center for Epidemiologic Studies Depression Scale; DASS-21, DRS; FIM - Functional Independence Measure IADL, MMSE - Mini Mental State Examination; NPI - Neuropsychiatric Inventory; PCI, QoL-AD - Quality of Life in Alzheimer's Disease scale; ZBI - Zarit Burden Interview

8.4.10 Economic evaluations of CTPs

Several CTPs have undergone CEA evaluation. The START CTP was shown to be both clinically and cost-effective, offering a practical intervention to support caregivers' psychological well-being (Livingston *et al.*, 2014b). The intervention included an economic evaluation that showed it was cost-effective for improving quality of life for caregivers, both short- and long-term. Following on from this, Knapp *et al.* (2024) modelled the potential effect of scaling up the START intervention to offer it to all eligible caregivers in England. The authors found that although scaling up the intervention would incur costs, it would significantly reduce public sector costs, increase the numbers of QALYs gained and improve the lives of family caregivers (Knapp *et al.,* 2024). The START programme has since been recommended by NICE to support family caregivers of PLwD. With regard to intervention costs, a study by Knapp *et al.* (2016) used existing cost estimates to assume a cost of £274 per person, representing the cost of delivering a psychosocial intervention designed to support people with dementia in community settings. This figure helps inform assumptions in economic evaluations of similar programmes.

Birkenhager-Gillesse *et al.* (2022) assessed the cost-effectiveness of 'More at Home with Dementia', a multi-component, five-day residential training programme in the Netherlands for informal caregivers of PLwD. The intervention was found to be cost-effective in delaying institutionalisation (Birkenhager-Gillesse *et al.*, 2022). However, this effect was not maintained at the two-year follow-up period.

Martikainen *et al.* (2004) modelled a cognitive-behavioural CTP that was designed to delay or prevent admissions for people with mild AD in Finland (Martikainen, Valtonen and Pirttilä, 2004). They modelled effects on caregivers as well as PLwD and found improvements in caregiver HRQoL, with a high probability of the intervention being cost-effective at standard WTP thresholds. A five-year time horizon was used to model delays in institutionalisation and maintenance of quality of life. Although the individual outcomes did not reach statistical significance, the economic evaluation strongly supported its cost-effectiveness.

To summarise, economic evaluations of CTPs for caregivers of PLwD indicate potential cost-effectiveness, particularly in reducing caregiver burden and delaying institutionalisation (Mohide *et al.*, 1990; Mittelman *et al.*, 2006; Livingston *et al.*, 2014b;

Birkenhager-Gillesse *et al.*, 2022). However, the current evidence base is limited, and further research with robust economic analyses is needed to substantiate these findings. By equipping caregivers with the necessary skills and strategies to manage BPSD, these training programmes can potentially improve the QoL for both caregivers and the PLwD they support.

8.5 Methods

8.5.1 Overview of model structure and type

To add to the current evidence base on the cost-effectiveness of CTPs, an economic model was designed to evaluate an intervention for caregivers supporting PLwD with moderate stage dementia. The intervention chosen for the model was designed to improve caregivers' coping strategies for managing BPSD, with improvements in BPSD measured as a key outcome. Additionally, the model was designed to assess the impact of these improvements on delaying the transition of the PLwD to long-term care.

The structure of the model was informed by published cost-effectiveness models in dementia, including those developed to evaluate disease-modifying drug therapies (NICE, 2011) and psychosocial interventions (Vandepitte *et al.*, 2020). Economic models for drug therapies, such as those used by NICE to assess cholinesterase inhibitors and memantine, typically apply Markov frameworks to simulate disease progression according to dementia severity stage, linking cognitive decline to health outcomes and costs. These approaches provided a foundation for the structuring of the current model. The modelling approach conformed to the guidelines outlined in the CHEERS statement for reporting methods and results (Husereau *et al.*, 2022).

The base model was developed in Microsoft Excel using a decision-tree structure (Figure 8.1). The model was approached from the perspective of impact on BPSD in a person with dementia as a result of their caregiver attending a CTP. The model used a cost-utility analysis, a specific type of cost-effectiveness analysis that measured costs and health benefits in terms of QALYs (NICE, 2022). The model compared the cost-effectiveness of a training and education programme for family caregivers of PLwD with usual care (family caregivers who had not received training). The model simulated a hypothetical cohort of PLwD with BPSD. A change in BPSD was used as

the primary outcome measure. The model assumed that the CTP would reduce the number of BPSD symptoms in PLwD. This reduction in BPSD was linked to a lower risk of transfer to long-term care, as well as changes in mental health service use, including both outpatient and inpatient admissions. In turn, these affected overall costs and the predicted place of residence (own home or care home), over the model period.

The model assessed the impact of a CTP intervention on costs and service use over a three-month period. The second part of the model then projected the potential effects of maintaining this improvement over an additional three months, assuming the improvements in BPSD were maintained. This assumption formed the basis of the 6-month model and was not tested in sensitivity analysis as the model was intended to explore a best-case scenario where the intervention effect was maintained.

At the three-month point, PLwD could either have improved their BPSD or see no improvement/a worsening of BPSD or could exit the model due to death. At the six-month point, PLwD could either transfer to long-term care, remain living at home or exit the model as they had died. The inclusion of mortality data was based on existing Markov models of CTPs, which included mortality outcomes for PLwD (Martikainen, Valtonen and Pirttilä, 2004; Gannon *et al.*, 2025). The model was informed by previous models of PLwD (Martikainen, Valtonen and Pirttilä, 2004).

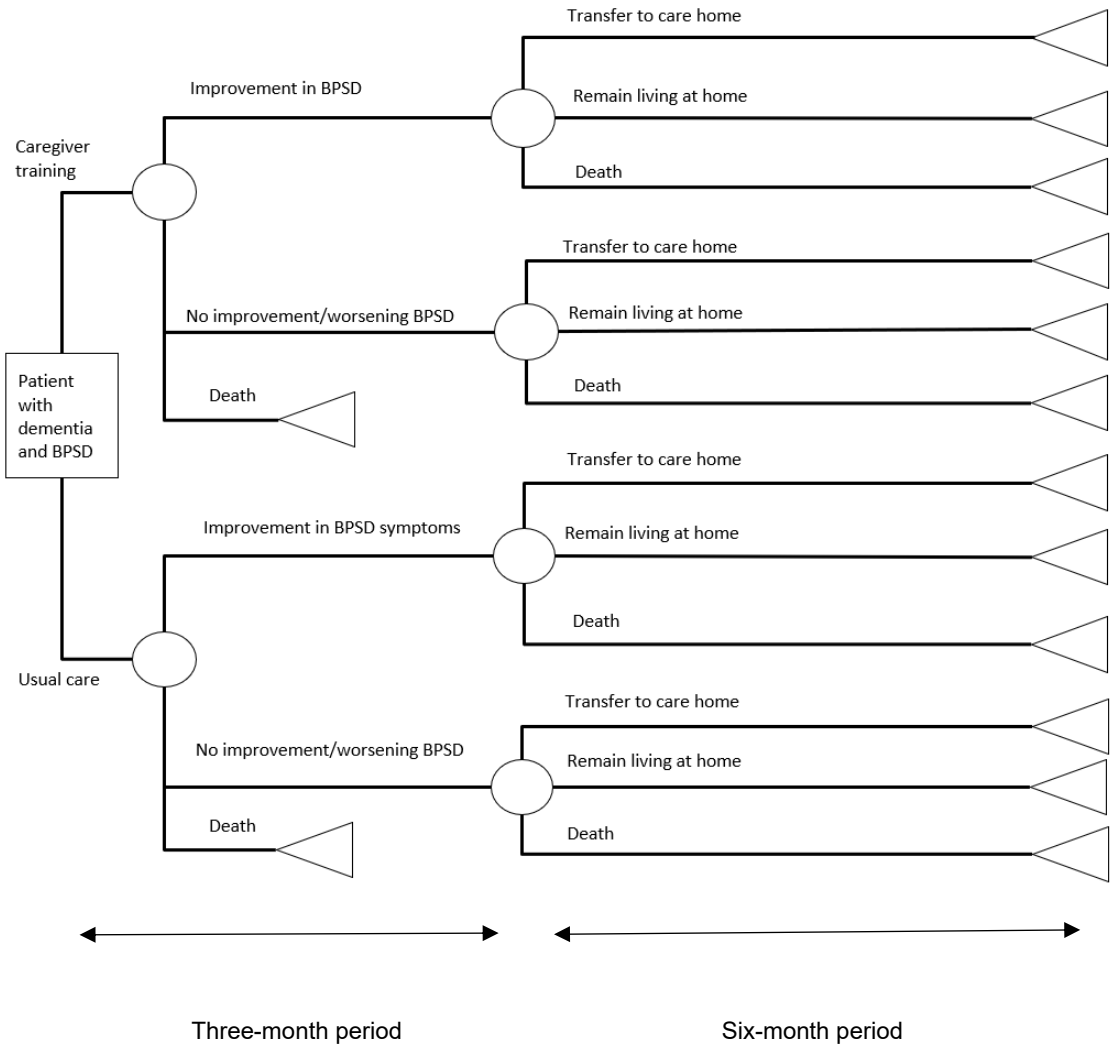


Figure 8.1 Structure of decision model for CTPs

8.5.2 Decision options and pathways

8.5.2.1 Target population

The population for the model was a hypothetical cohort of UK community-dwelling PLwD, whose informal caregivers received either CTP or usual care. The training intervention was for the caregiver, but the outcomes were measured for the PLwD. The PLwD was assumed to have moderate stage dementia and symptoms of BPSD as reported by their caregiver.

8.5.2.2 Comparators

The training intervention in the model was designed as an in-person training programme delivered in the community. It was assumed to comprise eight sessions over three months, based on the format and content of previously published studies

(Mohide *et al.*, 1990; Silvestri *et al.*, 2004) and delivered by occupational therapists. The assumed format of the sessions was informed by a recent RCT and involved an initial evaluation of the PLwD and their communication with their caregiver (Gitlin *et al.*, 2010a). Caregivers were then offered education in stress management techniques to help them manage care challenges such as resistance to care. Simple activities to engage PLwD during tasks, for example, meal preparation, were developed. Caregivers were given advice about how to modify techniques to prepare for future dementia decline. Usual care was defined as not receiving structured caregiver training.

8.5.2.3 Primary outcome

The primary outcome used was reduction in BPSD as measured by the EQ-5D score. BPSD was chosen as the clinical effectiveness outcome as it has been used successfully in several non-pharmacological studies as an outcome (Beeri *et al.*, 2002; Gitlin *et al.*, 2010c), and is considered responsive to change following effective caregiver interventions. Group-based training interventions for informal caregivers have been evaluated for their impact on the management of BPSD. A systematic review by Felstead *et al.* (2022) highlighted the need for more research in which BPSD is the primary outcome, to better determine the effectiveness of CTPs in addressing these symptoms (Felstead *et al.*, 2022).

BPSD symptom severity can be measured in various ways, commonly by NPI (Chien and Lee, 2008; Javadpour, Ahmadzadeh and Bahredar, 2009; Terracciano *et al.*, 2020) and the Revised Memory and Behaviour problem checklist (Hébert *et al.*, 2003). NPI evaluates key domains including agitation, aggression, depression, anxiety, delusions, hallucinations, irritability, euphoria, aberrant motor behaviour, apathy and sleep disturbances. It is widely used in clinical trials and intervention studies due to its comprehensive coverage of BPSD and its ability to reflect changes in symptomatology over time.

8.5.2.4 Study perspective and time horizon

Costs were considered from the perspective of the health and social care perspective, incorporating nursing home costs, inpatient and outpatient service use, and intervention costs. The time horizon was three months, in common with published

studies (Mohide *et al.*, 1990; Gitlin *et al.*, 2010b; Sadavoy, Sajedinejad and Chiu, 2022; Brooks *et al.*, 2024). The model was evaluated in two parts, short-term (three months) and long-term (six months), which was considered sufficient to capture the outcomes that would determine the effectiveness of the CTP. The extended model evaluated the longer-term effects of the training.

The literature review (section 8.4) informed the model parameters. One systematic review, by Felstead *et al*., (2022) examined the effectiveness of group-based training interventions for informal caregivers regarding management of BPSD. The interventions typically included structured group sessions that were aimed at educating caregivers about dementia, enhancing coping strategies, and promoting communication and problem-solving skills. The primary outcomes that were evaluated were changes in the frequency and severity of BPSD among PLwD, as well as caregiver burden and psychological well-being. The review identified significant heterogeneity in intervention content, duration, and methodological rigour. However, it found that studies that incorporated structured problem-solving components were more likely to report positive effects on BPSD. Overall, the evidence was limited, and many studies lacked robust designs or standardised outcome measures. The authors concluded that while group-based training showed promising results, especially when delivered over lengthy periods, there was further need for high-quality research to determine its definitive impact on the management of BPSD in PLwD. They called for more research in which BPSD would be the primary study outcome, to determine the impact of CTPs on BPSD management (Felstead *et al.*, 2022).

The EQ-5D is a widely used instrument for measuring health-related quality of life, including in dementia research. Although it was not specifically designed to capture BPSD, its anxiety/depression dimension is often used as a proxy for aspects of BPSD such as mood and emotional disturbances. Changes in EQ-5D scores, particularly in the anxiety/depression domain, can reflect improvements or deteriorations in BPSD during interventions, and are frequently converted into utility values for economic evaluations. The EQ-5D health state scores can be converted to utility values using country-specific value sets or algorithms, which assign weights to each dimension level combination to produce a single summary index score used in economic evaluations (Economics Network, no date) .

There is evidence that CTPs lengthen the time to institutionalisation, so this was chosen as a model outcome. Evidence of an impact on BPSD as measured by NPI was identified in the literature review. Given the reported improvements in BPSD, this was selected as the clinical effectiveness outcome for the CTP model. Accordingly, the model was designed with the specific aim of reducing BPSD in PLwD.

8.5.2.4.1 Summary of effectiveness of caregiver training on BPSD

The literature review (section 8.4) identified several key RCTs and systematic reviews evaluating the impact of CTPs on BPSD, these are summarised below. Although additional smaller or more recent studies are available, this review focused on the major RCTs that inform current evidence and clinical guidelines. Results are summarised in Table 8.4 and Table 8.5.

Table 8.4 Summary of effectiveness of CTPs that measured BPSD – RCTs

Author	Country	Intervention	Number of Participants	Session duration and frequency	Outcome	Assessment tools	Effect size	Conclusion
Gallagher-Thompson *et al.* (2012)	US	Coping strategies training for Hispanic caregivers	140 caregivers	12 weekly sessions	Caregiver distress and BPSD	NPI, HADS	SMD = 0.32 (95% CI: 0.11 to 0.53), p < 0.01	Stress management training reduced distress and improved management of BPSD
Gitlin *et al.* (2010b) COPE	US	Home-based caregiver training in the management of dementia behaviours	272 dyads (carer and PLwD)	9 sessions over 6 months	Reduction in BPSD	NPI	SMD = 0.45 (95% CI: 0.24 to 0.66), p < 0.001	Intervention reduced frequency and severity of BPSD and improved caregiver confidence
Mittelman *et al.* (2006)	US	Counselling and support for caregivers	406 caregivers	Ongoing (initial sessions plus ad-hoc support)	Delay in nursing home placement and reduction in behavioural symptoms	NPI	No standardised SMD; p = 0.02 for delay to nursing home; BPSD trend positive but not quantified	Counselling delayed institutionalisation and improved behaviour management
Sadavoy *et al.* (2022)	Canada	Culturally adapted CTP for dementia caregivers	60 caregivers	8 weekly sessions	Changes in BPSD and caregiver burden	NPI, ZBI	Not reported (positive trend, p < 0.05 for caregiver outcomes; BPSD not independently tested with SMD)	CTP improved caregiver outcomes and reduced BPSD
Teri *et al.* (2005)	US	STAR caregiver training programme (communication and behaviour management skills)	406 caregivers	8 weekly sessions	Reduction in depressive symptoms and BPSD	NPI, CES-D	SMD = 0.39 (95% CI: 0.20 to 0.58), p < 0.001	STAR programme reduced BPSD and caregiver depression

Key

BPSD - Behavioural and Psychological Symptoms of Dementia; CES-D - Center for Epidemiologic Studies Depression Scale; CTP - Caregiver Training Programme; HADS - Hospital Anxiety and Depression Scale; NPI - Neuropsychiatric Inventory; PLwD - People living with dementia; RCT - Randomised Controlled Trial; SMD - Standardised Mean Difference; ZBI - Zarit Burden Interview

The key systematic reviews and meta-analyses in which the impact of CPTs on BPSD was evaluated, are summarised below.

Table 8.5 Summary of effectiveness of CTPs that measure BPSD - systematic reviews and meta-analyses

Author	Type of Study	No. studies	Outcome	Assessment tools	Effect sizes	Conclusion
Brodaty and Arasaratnam (2012)	Systematic review and meta-analysis	29 studies	Reduction in BPSD	NPI, BPSD measures	SMD = –0.34 (95% CI: –0.49 to –0.18), p < 0.001	Caregiver interventions were associated with modest but significant reductions in BPSD.
Pinquart and Sörensen (2006)	Meta-analysis	127 studies	Caregiver burden, depression, and BPSD	Various (including NPI, ZBI, CES-D)	SMD for BPSD = 0.15 (95% CI: 0.09 to 0.22), p < 0.001	Interventions improved caregiver outcomes and showed small improvements in BPSD.
Sörensen, Pinquart, and Duberstein (2002)	Meta-analysis	78 studies	Caregiver mental health and behavioural symptoms	Various (ZBI, CES-D, QoL tools)	SMD = 0.16 (95% CI: 0.11 to 0.21), p < 0.001	Psychosocial interventions reduced caregiver burden and depression, with some improvements in BPSD.

Key

BPSD -Behavioural and Psychological Symptoms of Dementia; CES-D - Center for Epidemiologic Studies Depression Scale; CTP - Caregiver Training Programme; NPI - Neuropsychiatric Inventory; QoL - Quality of Life; ZBI - Zarit Burden Interview

Studies have shown mixed results in terms of effectiveness of CTPs for PLwD. Frias *et al.* (2020) performed a systematic review, which found that CTPs could lead to reductions in levels of anxiety and depression and improved quality of life. The authors also found that psychoeducational training interventions could be beneficial to caregivers and enable them to improve their understanding of dementia, develop their problem-solving skills and help them to access social support (Frias *et al.*, 2020). However, Felstead *et al.* (2022) found weak evidence regarding whether or not attendance at CTPs could lead to improvement in symptoms of BPSD.

CTPs have been shown to improve how caregivers react to and manage BPSD in PLwD whom they are caring for. Studies have reported a lengthening in the time to nursing home placement (Birkenhager-Gillesse *et al.,* 2022) and a reduction in the number of BPSD after caregivers have received training compared with cases where PLwD have received usual care (Gitlin *et al.*, 2010b).

8.5.3 Model inputs

The probability parameters used in the model were informed by evidence from several published trials that had examined interventions or service use among PLwD (Mittelman *et al.*, 2006; Scarmeas *et al.*, 2007; Gitlin *et al.*, 2010b; Clevenger *et al.*, 2018). These are now detailed.

8.5.3.1.1 Probability of improvement

The probability of improvement in BPSD was informed by an RCT, which evaluated a CTP for caregivers of PLwD (Gitlin *et al.*, 2010b). In this study, 62.7% of dyads in the intervention group eliminated one or more caregiver-identified problems, compared to 44.9% in the control group.

The definition of improvement in BPSD was defined according to Teri *et al.* (2005), who considered a positive change as a reduction in at least one of the three domains: frequency, severity or caregiver reactivity (Teri *et al.*, 2005). This qualitative definition was adopted as the conceptual criterion for improvement in the model. Therefore, the model translated Teri *et al*.'s definition into a measurable health gain through improvements in EQ-5D scores, this allowed conversion to health-related quality of life outcomes for economic evaluation.

8.5.3.1.2 Probability of transfer to care home

The reduction in care home admissions was modelled as being dependent on change in BPSD symptoms. A reduction in BPSD was assumed to reduce the likelihood of transfer to long-term care. The probabilities that PLwD would be transferred to care homes were informed by a study of caregiver counselling and support interventions for people with AD to determine whether the intervention had delayed transition to long-term care (Mittelman *et al.*, 2006). Mittelman *et al*. (2006) evaluated a caregiver counselling intervention involving six sessions over 4 months. They reported that 99 people in the intervention group were admitted (24%) compared to only 11 people in the control group (27%). The CTP was delivered during the first four months, but the benefits persisted long term. Although the study did not report short-term probabilities, the findings were used to inform the direction and size of effect in the model. While the original analysis covered a follow-up period of up to 12-years, the model applied an adjusted probability over a 4-month timeframe.

An adjusted 3-month probability of transition to long-term care was derived using the method described by Briggs *et al*. (2006). To convert the probability, a constant hazard was assumed over time, allowing the probability of transfer to care home to be adjusted to three- and six-month periods in the model. This method assumed that the risk of transition to long-term care remained steady over the period. A standard actuarial method was used, following the formula described by (Briggs, Sculpher and Claxton, 2006), in which the probability of the event occurring over time is represented as:

probability = 1 - exp (- rt)

In this expression, p represents the probability of the event occurring over time, t,r is the constant hazard or event rate, t is the time period, and e is the base of the natural logarithm. The exponential term e to the power of xp(−rt,) reflects the probability of the event not occurring, so subtracting this from 1 gives the probability that the event does occur within the specified time frame. This method is widely used in economic healthcare evaluations.

8.5.3.1.3 Probability of death

The same probability of death source was used in both the MT and CTP models to ensure consistency in modelling assumptions. This parameter was adopted from the

MT model described in Chapter 7; it reflects estimated short-term mortality risk for people who live in the community with moderate dementia. Given the short time horizon used and the lack of evidence that either intervention had a direct impact on mortality, it was considered appropriate to apply a common probability of death across both models. The value was derived from published data on age-specific mortality rates in individuals with dementia, adjusted to reflect a three-month time frame. Inclusion of this parameter allowed for a more comprehensive estimation of costs and QALYs, even though the direct impact on model outcomes would be minimal due to the low event rate within the modelled period. Annual probabilities of death and institutionalisation across different stages of dementia severity were sourced from Spackman *et al*.,(2012). The study reported mortality rates of 5.5%, 21.5%, and 48.0% per year for mild, moderate, and severe dementia, respectively. These estimates were used to guide stage-specific progression in the model. Although these estimates are based on data from 2012, they remain relevant for modelling purposes due to the continued lack of more recent, stage-specific survival data. These estimates have been used in other model estimates for community dwelling PLwD (Luo *et al.*, 2025). To account for uncertainty, the probability was varied in sensitivity analysis.

8.5.4 Outcome parameters

The economic outcome analysed in the model was QALYs, derived from utility scores which reflected changes in BPSD symptoms. QALYs were used in line with common practice for economic evaluations in health care. BPSD reduction was used to estimate improvements in health-related quality of life. Total expected costs were calculated separately for both intervention and usual care groups over the three-month period. The six-month model explored the impact on transfer to care home if the improvements in BPSD symptoms seen in the three-month model were assumed to continue.

8.5.4.1 Utility values

The clinical effectiveness outcome measure used to capture the benefits of the CTP was BPSD which was then translated into utility values (EQ-5D) for the estimation of QALYs in the economic model.

8.5.4.2 Mapping BPSD to utility values and deriving QALYs

The initial utility for the model was calculated using recommended practice for mapping EQ-5D to utilities. Changes in HRQoL were then estimated, based on plausible average utility values and assumed changes in BPSD, with the anxiety/depression dimension of the EQ-5D used as a proxy indicator of direction of change. This approach reflects expected overall changes in quality of life rather than precise recalculation of full EQ-5D health state codes, and so represents a simplification. The magnitude of change in utility was not taken directly from the EQ-5D dimension weights but was applied as a fixed effect size of 0.05–0.1. To reflect this, the utility was lowered by 0.05 in the intervention arm and 0.1 in the UC arm, representing a smaller decline in the intervention arm due to the assumed beneficial effect of CTPs in reducing BPSD-related distress. These utility values were then used to estimate QALYs over the model time horizon.

This two-step method allowed the translation of symptom improvements (or declines) into utility values and, subsequently, into QALYs.

QALYs were calculated using the formula:

QALY= average utility x Time (in years)

This approach enabled the adjustment of the model to account for the impact of symptom changes on quality of life, in the absence of direct utility measurement. The same method was extended to the six-month model, assuming that any utility change observed in the first three months was maintained for the second three-month period. Key parameters were tested in sensitivity analysis.

For the six-month time horizon (0.25 + 0.25 years), the quality of life (utility) was assumed to be less for people living in a care home than for people living at home. This is supported by previous RCTs which reported lower EQ-5D scores among care home residents (Olsen *et al.*, 2016; Pérez-Ros and Martínez-Arnau, 2020). Pérez-Ros and Martínez-Arnau (2020) reported a mean EQ-5D-3L utility of 0.31 (SD 0.37) among nursing home residents with cognitive impairment. Olsen *et al*. (2016) found similar trends, with significantly lower self-reported quality of life among care home residents compared to PLwD in the community. These findings reflect reduced autonomy and higher levels of dependency in institutional settings.

8.5.4.3 Estimations of resources and costs

Costs used in the model were measured in 2022 British pounds. Costs were not discounted as the time horizon was less than one year. The cost of the CTP was informed by published evidence from the TAPS study (Gitlin, *et al.*, 2010c). The average cost was reported as $941 (1990 USD). Adjusted to 2024 prices using an inflation calculator, this equates to £1,331.52 per dyad.

The costs of a care home stay was informed by published data on NHS services and costs (Jones *et al.*, 2023; NHS England, 2023b). Weekly reported costs were calculated by averaging three types of provision: £916 for a private sector residential care home, £1,442 for local authority own-provision residential care, and £1,212 for a private sector nursing home. This figure was used to reflect a representative estimate of typical long-term care costs across settings.

The cost of usual care was assumed to be the same in both arms of the model and was therefore excluded from the cost calculations. Usual care included routine care received at the GP, without any additional staffing or resource requirements, which was assumed not to differ between groups or require additional resources.

8.5.4.4 Model assumptions

Several assumptions about the population, treatment effect and mortality were made in the model. A summary of assumptions used is provided in Table 8.6. Assumptions of treatment effects were applied. It was assumed that the CTP was provided in addition to usual care. It was assumed that if a person with dementia was transferred to a care home, during the intervention period, they would receive six sessions of the CTP intervention instead of eight. This assumption was based on the expectation that some sessions would no longer be appropriate for caregivers following admission, particularly those sessions focused on home-based strategies.

Fixed utility values were applied to reflect typical quality of life for each health state, this allowed a consistent estimation of QALYs across the model time horizon. The model structure included one arm for individuals with symptom improvement and a second arm for people with no improvement or worsening. In the absence of detailed

data, weighted utility values were used for the no improvement group/worsening group to reflect a mix of individuals with stable or worsening symptoms.

Table 8.6 Summary of assumptions applied to the model

Parameter	Assumption	Justification	Source
Population	PLwD had moderate stage dementia with BPSD symptoms at model entry	Matches population in similar published CTPs	Teri *et al*., (2005)
Treatment effect	If transfer to care home occurred, this is assumed to happen at the three-month timepoint	Assumptions reflect disease progression and generalisability across settings	Mittelman *et al*., (2006)
Maintenance of treatment effect	It was assumed that the effect of the intervention on BPSD symptoms, and the associated utility gain, was maintained over the second 3-month period.	Based on follow-up data from the START trial, which reported sustained reductions in caregiver anxiety and depression at 8 months post-intervention	Livingston *et al*., (2014)
Mortality	Death assumed at midpoint of model (6.5 or 18.5 weeks). No additional costs after death	Used in similar cost-effectiveness models; end-of-life costs excluded	Vandepitte *et al*., (2020); ONS (2025)
Costs	Only NHS and care home stay costs included. Travel costs were excluded for both the intervention and usual care arms	Focus on direct healthcare costs; travel costs considered negligible	Jones *et al*., (2023) Richmond Music Trust., (2025)

8.5.5 Summary of model parameters

Table 8.7 Parameters used within the model

Parameters	Value	Description	Source reference	Source type
Time horizon	Initial period - 3 months	Reflects typical short-term programme lengths in CTPs	Silvestri *et al*., (2004) Williams, Newman and Hammar., (2018)	Time horizon

Size of BPSD benefit	Positive change in BPSD symptoms defined as a reduction in at least 1 of the 3 domains (frequency, severity or caregiver reactivity)	Quantifying the size of the BPSD benefit. Positive change in BPSD symptoms defined as a reduction in at least 1 of the 3 domains (frequency, severity or caregiver reactivity)	Teri *et al* (2005)	Randomised controlled trial, US
Probability of improvement in BPSD symptoms with CTP	0.627	Probability of improvement in BPSD symptoms - CTP	Gitlin *et al*., (2010a)	Randomised controlled trial, US
Probability of no improvement/worsening in BPSD symptoms with CTP	0.373	Residual probability of no improvement/worsening in BPSD symptoms with CTP	As above	As above
Probability of improvement/no change in BPSD symptoms with UC	0.551	Residual probability of improvement/no change in BPSD symptoms with UC	Gitlin *et al*., (2010a)	Randomised controlled trial, US
Probability of no improvement/worsening in BPSD symptoms with UC	0.449	Probability of no improvement/worsening in BPSD symptoms - UC	As above	As above
Probability of transfer to care home with improvement - CTP	0.24	The probability of transfer to a care home was modelled as being dependent on change in BPSD symptoms. A reduction in symptoms was assumed to reduce the likelihood of admission, this is consistent with evidence that BPSD is a key driver of institutionalisation. 12-year probability: 0.24 Converted to 3-month probability using Briggs 3-month probability 0.57	Mittelman *et al*., (2006)	Randomised controlled trial, US

Probability of transfer to care home with improvement - UC	0.27	12-year probability: 0.27 Converted to 3-month probability using Briggs 3-month probability 0.65	Mittelman *et al*., (2006)	Randomised controlled trial, US
Probability of transfer to care home - with NO improvement in symptoms CT	0.28	Assumed to represent likely probability on transfer to long-term care	N/A	N/A
Probability of transfer to care home - with NO improvement in symptoms UC	0.4	Assumed to represent likely probability on transfer to long-term care	N/A	N/A
Probability of death with moderate dementia	0.0587	Annual probability with moderate dementia = 21.5% The 3-month probability was then calculated from this using a formula by Briggs *et al*. (2006)	As above	As above
Cost of CTP (total cost of intervention)	£1,332	Cost of training intervention (£167 per session, 8 sessions = £1,332	Gitlin *et al*., (2010a)	Randomised controlled trial, US
Cost of usual care	£0	Cost of usual care assumed to be zero in both arms of the model	N/A	N/A
Cost of care home stay (per week)	£1,190	Calculation of mean care costs (per week). Calculated from an average cost of private sector residential care home, private sector nursing home and local authority residential care home	Jones *et al*., (2023)	Published NHS cost data
Cost of remaining living at home	£0	This is assumed to be zero, with the only costs being the cost of care detailed below	N/A	N/A
Cost of care with moderate dementia (per week)	£76	This figure was informed by the results of a CRIS database analysis of mental health service use (detailed in Chapter 6)	This figure was informed by the results of a CRIS database analysis of mental health	Patient-level data, UK

			service use (detailed in Chapter 6)	
Cost of care with death	£0	Death was treated as terminal with no associated cost. Informed by previous modelling studies that have assigned a zero cost to death	Vandepitte *et al*. (2020)	Markov model for dementia
QoL utility score for a PLwD with BPSD symptoms (baseline)	0.35	Calculated using a standard method to convert a typical EQ-5D score of a PLwD to utility	(Economics Network, no date)	Recommended practice for mapping detailed health states onto HRQoL estimates
QoL utility scores for people with *improvement* in BPSD (CTP)	0.45	Assumed to represent a typical EQ-5D score of a PLwD with has an improvement in BPSD	N/A	N/A
QoL utility scores for people with *no improvement/worsening BPSD* (CTP)	0.34	Assumed to represent a weighted average EQ-5D score for a PLwD with either no improvement or worsening BPSD symptoms.	N/A	N/A
QoL utility scores for people with *improvement* in BPSD (UC)	0.39	Assumed to represent a typical EQ-5D score of a PLwD with has an improvement in BPSD	N/A	N/A
QoL utility scores for people with *no improvement/worsening BPSD* (UC)	0.3	Assumed to represent a weighted average EQ-5D score for a PLwD with either no improvement or worsening BPSD symptoms.	N/A	N/A
QoL utility scores for people with *improvement* in BPSD who then transfer to *long-term care* (CTP)	0.4	Assumed to represent a typical EQ-5D score	N/A	N/A
QoL utility scores for people with *improvement* in BPSD *who then remain living at home* (CTP)	0.45	Assumed to represent a typical EQ-5D score	N/A	N/A
QoL utility scores for people living with *no improvement/worsening*	0.28	Assumed to represent a typical EQ-5D score	N/A	N/A

BPSD who then transfer to *long-term care* (CTP)				
QoL utility scores for people with *no improvement/worsening* BPSD *who then remain living at home* (CTP)	0.35	Assumed to represent a typical EQ-5D score	N/A	N/A
QoL utility scores for people with *improvement* in BPSD who then transfer to *long-term care* (UC)	0.29	Assumed to represent a typical EQ-5D score	N/A	N/A
QoL utility scores for people with *improvement* in BPSD *who then remain living at home* (UC)	0.39	Assumed to represent a typical EQ-5D score	N/A	N/A
QoL utility scores for people living with *no improvement/worsening* BPSD who then transfer to *long-term care* (UC)	0.2	Assumed to represent a typical EQ-5D score	N/A	N/A
QoL utility scores for people with *no improvement/worsening* BPSD *who then remain living at home* (UC)	0.3	Assumed to represent a typical EQ-5D score	N/A	N/A

Key

BPSD - Behavioural and psychological symptoms of dementia, CTP – caregiver training programme, EQ-5D - EuroQol 5 Dimensions; HRQoL - Health-Related Quality of Life; UC – usual care

8.5.6 Analysis and uncertainty

The economic model was developed and analysed using Microsoft Excel. One-way sensitivity analyses were conducted to vary the key model parameters independently and to test assumptions. Uncertainty is anticipated in the estimation of model inputs, including improvements in BPSD. Similar uncertainty applies to cost estimates, utility values, and probabilities. These parameters influence both costs and outcomes in the model, therefore sensitivity analyses were conducted to test the impact of varying these inputs.

One-way deterministic sensitivity analyses were conducted on the three-month model to independently vary the key parameters independently and assess their impact on the cost-effectiveness of CTPs compared with usual care. Parameter values were varied by 20% and 50% to explore uncertainty. For cost-related inputs, asymmetric variation ranges were applied to better reflect plausible real-world fluctuations. For instance, the intervention cost was allowed to increase by up to 50%, but only decrease by 20%, acknowledging that significant cost reductions are unlikely due to fixed components such as staffing, training, and infrastructure. Conversely, cost increases were deemed more likely in practice, driven by factors such as service scale-up, wage growth, and regional cost differences. These asymmetric assumptions were reflected in the tornado diagram to illustrate their influence on the ICER. This approach was used to assess the robustness of model outcomes to uncertainty in key inputs, and to identify which parameters had the greatest influence on the ICER.

Different parameters were included in the three- and six-month sensitivity analyses to reflect the distinct structures and outcomes of each model.

8.5.6.1 Parameters for sensitivity analysis - three-month model

Four key parameters were independently varied across plausible ranges for the three-month model, (ranges of values are detailed later in the results section):

- Probability of improvement in BPSD symptoms - UC
- Probability of improvement in BPSD symptoms - CTP
- Cost of the CTP intervention
- Probability of death

8.5.6.2 Parameters for sensitivity analysis – six-month model

Four key parameters were independently varied across reasonable ranges for the six-month model:

- Probability of transfer to care home - UC
- Probability of transfer to care home - CTP
- Cost of the CTP intervention
- Probability of death

8.6 Results

8.6.1 Three-month model

The base case deterministic and probabilistic cost-effectiveness results for caregiver training versus usual care are presented. A summary of cost-effectiveness for the caregiver training, including the ICER result, is shown in Table 8.8.

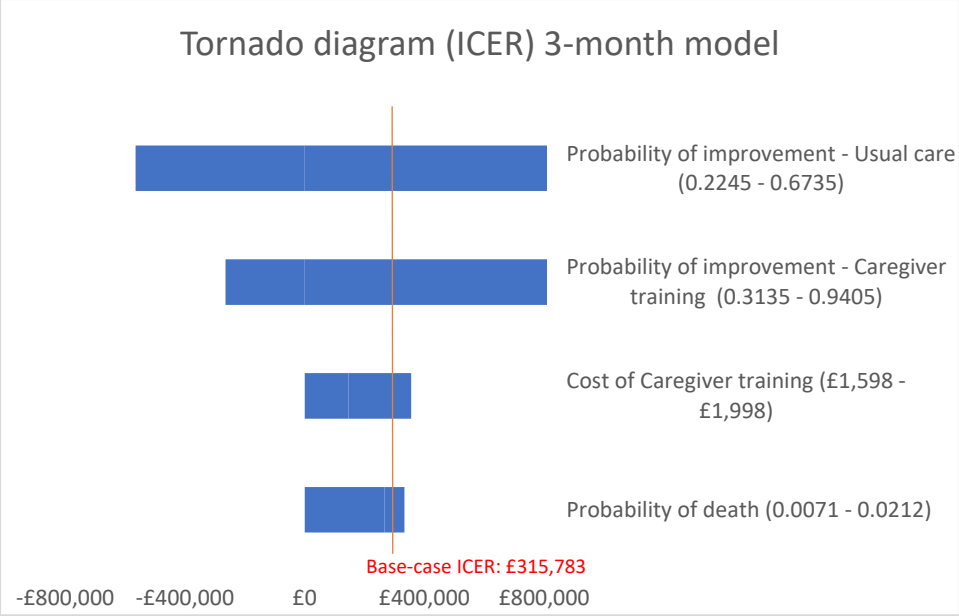
Table 8.8 Summary results of the CTP three-month decision-tree model

Pathway	Weighted costs (£)	Incremental costs	Weighted QALYs*	Incremental QALYs*	ICER
Caregiver training	£2,222		0.0919		x
Usual care	£939	£1,283	0.0878	0.0041	£315,783

** QALYs displayed to 4 decimal places*

8.6.1.1 Results of sensitivity analysis – three-month model

Results were presented in a tornado diagram, which ranked parameters by their influence on the ICER. The results showed that the model was most sensitive to changes in probability of improvement. It was less sensitive to changes cost and probability of death.



8.6.2 Six-month model

The base case and sensitivity results for the six-month model are presented. The baseline model at six months was associated with lower costs and greater health benefits compared with usual care. The results indicate that the intervention may be cost saving or be cost-effective in the long-term, offering both improved outcomes and reduced healthcare expenditure.

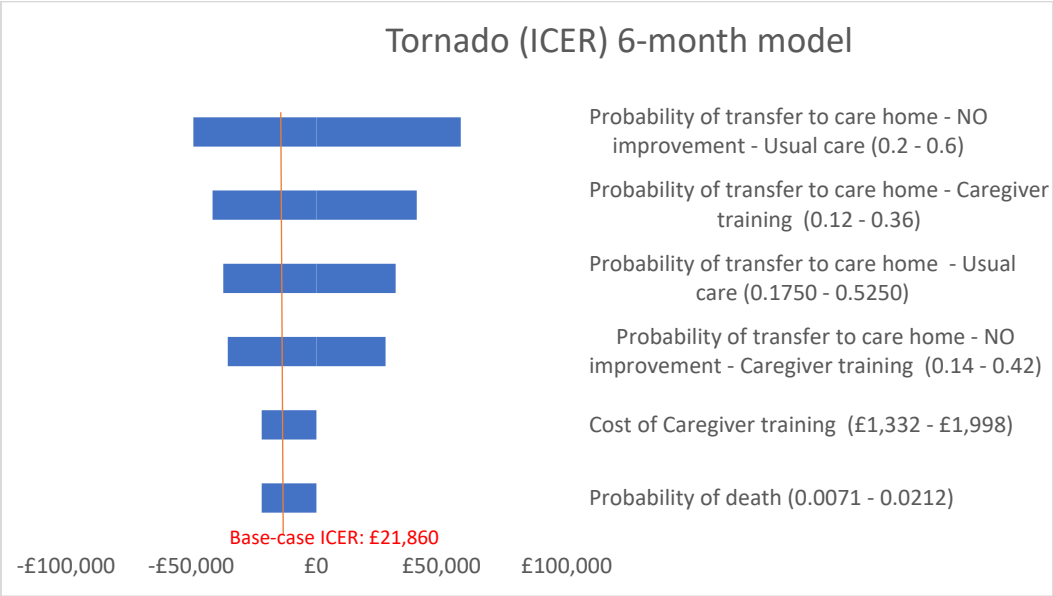
Table 8.9 Summary results of the CTP six-month decision-tree model

Pathway	Weighted costs (£)	Incremental costs	Weighted QALYs*	Incremental QALYs*	ICER
Caregiver training	£2,583		0.1826		x
Usual care	£3,100	-£517	0.1590	0.0237	-£21,860

8.6.2.1 Results of sensitivity analysis – six-month model

Results of the sensitivity analysis were presented in a tornado diagram, which ranks parameters by their influence on the ICER. Results showed that the model was most sensitive to changes in probability of care home admission. Mortality and the cost of the training had less influence on model outcomes, suggesting that the model was robust to uncertainty in those areas. This indicated that the overall cost-effectiveness result was primarily driven by assumptions around the probability of care home admission. These findings underscore the importance of accurately estimating

probabilities related to care home admission when interpreting the cost-effectiveness of the intervention.



8.7 Discussion

8.7.1 Strengths and limitations

The intervention in the model was grounded in established clinical and psychological frameworks, so its credibility and potential for real-world effectiveness were enhanced. The CTPs had a preventative focus; by targeting caregivers early in the care pathway, attendance at a CTP may reduce the use of services driven by crises and delay transfer to long-term care for PLwD. It also helps caregivers, who are in many cases part of an under-supported group who play a critical role in dementia care, by improving their knowledge, confidence, and resilience. When comparing the results of the three-month and six-month models, the cost-effectiveness of attendance at CTPs improved over time. However, while the CTP interventions may be cost-effective in the long term, they require initial investments in the form of staff training, coordination, and possibly digital infrastructure, which may be a barrier in underfunded areas.

The model structure included a pathway by which attendance at a CTP reduced BPSD and hence a lower probability of care home admission. However, the study that was

used to inform effectiveness reported a direct association between CTPs and a reduction in care-home admission rates, without specifically linking this to changes in BPSD. Therefore, while BPSD was included in the model as a plausible step in the pathway, based on clinical understanding of dementia progression and caregiver burden, this is not confirmed in the evidence. The model structure should therefore be interpreted with caution in this respect, and further research could help to clarify the extent to which BPSD plays a role in this relationship.

The six-month model findings showed that the model was sensitive to estimates of probability of care home admission. This underscores the importance of accurately estimating probabilities related to care home admission when interpreting the cost-effectiveness of the intervention.

The crosswalk method was used to convert baseline EQ-5D responses into utility values, following recommended practice for mapping detailed health states onto HRQoL estimates. However, due to complexity and limitations in available data, the approach was subsequently adapted to assume the direction and plausible magnitude of change in utility based on symptom improvement or decline, this may have introduced potential uncertainty.

It is acknowledged that not all potential costs were considered in the model. In particular, home care provider use and informal care costs were excluded. These categories are likely to be significant for decision-makers who consider broader societal impacts beyond the healthcare system. As a result, the total cost estimates may be lower than what would be observed in real-world scenarios.

The model was not tested with individuals diagnosed with MCI. While the model was run for PLwD moderate dementia, where the primary outcome was BPSD, it was not applied to people with MCI. The reason for this is that MCI does not always progress to dementia and individuals with MCI are less likely to exhibit BPSD. This gap suggests a potential for future research to adapt and evaluate the model for the MCI population, with a focus on outcomes such as cognitive engagement, quality of life, or emotional well-being. Similarly, the model was not run for people with severe dementia, as the CTP evaluated in the model is unlikely to be effective for this group. In advanced dementia, cognitive and functional decline often limits the benefit of caregiver-focused

training in managing BPSD, and care priorities shift toward palliative or intensive care, requiring different intervention approaches and modelling assumptions.

8.8 Conclusion

An economic model was developed to evaluate the cost-effectiveness of CTPs for caregivers of PLwD in the UK. The model was developed using current evidence on the clinical benefits of CTPs, with costs sourced from UK national datasets and real-world providers. The evidence presented has shown that caregiver training for individuals who support PLwD can be effective at reducing caregiver burden and improving their coping strategies during their caring. This, in turn, can reduce rates of admission to long-term care for PLwD.

8.9 Chapter summary

An economic model was presented by which the cost-effectiveness of CTPs for informal caregivers of PLwD in the UK was evaluated. Model results were presented and the implications for future practice were discussed.

The final chapter presents a comprehensive discussion of the work described throughout the thesis, drawing together the key findings given in each of the preceding chapters. It reflects on the implications of the research in relation to existing literature, policy, and practice, with particular attention to the economic evaluation of NPTs for PLwD. In the chapter, the strengths and limitations of the methodological approaches used are also critically examined. In addition, directions for future research are identified and recommendations are made regarding how the findings can inform evidence-based decision-making in dementia care, within the UK context and beyond.

Chapter 9 Discussion

9.1 Overview

In this chapter, the research findings are discussed with consideration of existing research. This research was intended to address four questions, listed here.

1. Which NPTs for people with dementia or MCI are evidenced to be cost-effective?
2. How cost-effective are NPTs for PLwD?
3. What are the service use costs and predictors for PLwD in a UK setting?
4. Which NPTs do people with lived experience of dementia value and prioritise?

9.2 Summary of thesis findings

Chapter 1 has introduced the background literature for the thesis. It outlines the growing global economic burden of dementia. It highlights the emerging evidence supporting the effectiveness of NPTs for reducing dementia-related symptoms.

Chapter 2 contains a broad review of the literature to provide context for the thesis. The epidemiology and economic burden of dementia, current models of dementia care, and the challenges faced by informal caregivers are examined. Relevant policy developments are reviewed, and growing interest in NPTs is outlined.

Chapter 3 contains a publication of a systematic literature review and review of reviews of economic evaluations of NPTs for dementia and MCI. For this work, 37 economic evaluations and four reviews were identified as relevant. NPTs were across distinct forms of care: cognition, training, multi-component, assistive technology, and other areas (specialist dementia care, group living, home care vs. care home). Maintenance CST was the intervention with the strongest evidence of cost-effectiveness. However, a lack of robust economic evaluations of NPTs was identified alongside limited use of decision-analytic modelling in the dementia care context, highlighting a critical gap that the author of this thesis has sought to address.

Chapter 4 presents a review of the clinical effectiveness of NPTs for PLwD. The review identified therapies that demonstrated positive outcomes in regard to the management of dementia-related symptoms. The findings of the systematic and clinical

effectiveness reviews that were undertaken highlighted several therapies that warranted further cost-effectiveness evaluation. From these, a list of clinically effective and cost-effective therapies was compiled, which formed the basis of an online survey that was developed to determine the research preferences of people with lived experience of dementia.

Survey development is detailed in Chapter 5. A total of 50 PLwD, family caregivers and people who worked in dementia care were included as survey participants. A PPI group was set up, and its members used their lived experiences of dementia to greatly enhance the accessibility of the survey. The survey results showed that MT and caregiver training were interventions that people with lived experience of dementia most wanted to see further research on. The results of the survey were used to inform the research priorities for the modelling evaluations, which are explained in Chapter 7 and Chapter 8.

Chapter 6 contains an analysis of data regarding the use of mental health services that were offered by a large mental health provider in the UK. The analysis determined patterns of care and associated costs before and after a dementia diagnosis. The findings showed a marked increase in service use after diagnosis, reflecting the progressive nature of dementia and the growing complexity of care needs over time. This analysis provided important context for understanding the real-world resource implications of dementia and informed the costing assumptions that were used in the economic models.

Chapter 7 describes an evaluation of the cost-effectiveness of active MT in the UK from the perspective of the health and social care perspective. A decision-tree model was developed to compare active MT with usual care (i.e. no MT), with a focus on short-term changes to cognitive function and related costs. The model was developed with the input of the best available clinical and economic data, and parameters were derived from published sources and relevant datasets. The results suggested that over a three-month period active MT was associated with an ICER of approximately £25,237 per QALY gained, just above the commonly accepted UK cost-effectiveness threshold. This chapter contributed new evidence to the existing literature, and the results suggested that although supply of active MT did not meet commonly accepted

cost-effectiveness criteria in the short-term, it has the potential to be cost-effective in the longer-term.

Chapter 8 contains an evaluation of the cost-effectiveness of an informal CTP from a health and social care perspective A decision-tree model was developed to compare the cost-effectiveness of gaining the training with usual care (no training). The best available clinical and economic evidence was sourced to inform the model and its parameters. The model estimated changes to BPSD and related costs. The model suggested that, compared with usual care, attendance at a CTP by caregivers showed long-term benefits and was cost-effective over six months.

9.3 Global challenge of dementia and policy response

The rising cost of dementia care is a global challenge, and countries are responding by developing strategies to meet this challenge. Governments particularly in low- and middle-income countries, must strengthen their funding and policies to support care, although this may be hindered by limited resources. In the UK, long-term dementia care costs largely fall on families due to limited integration of social care with the healthcare system. Integrated care can improve outcomes and reduce costs by coordinating services; however, the implementation of such integration requires significant investment, which is challenging with existing budget constraints.

This challenge is particularly relevant in the context of the UK 10-year dementia plan, developed in 2022, it was intended to boost research into dementia to improve outcomes for PLwD. The plan sought not only to boost research into dementia, but also to translate this research into improved outcomes for PLwD and their caregivers. Recognising the increasing prevalence of dementia in an ageing population, the plan aimed to ensure that timely and accurate diagnoses would be made, allowing for earlier intervention and better management of dementia. A key objective of the plan was to foster collaboration between key stakeholders across the health, social care, and research sectors, to enable coordinated action. Policymakers were encouraged to prioritise dementia in health and social care agendas, while also ensuring that new strategies reflected the needs and preferences of those directly affected by the disease. Importantly, the plan underscored the need to engage people with lived experience of dementia, including individuals diagnosed with dementia, their families,

and caregivers, in the consultation and policy development process. Their insights and experiences were viewed as crucial for shaping effective, compassionate, and person-centred approaches to dementia care, support, and research priorities. However, despite the plan's stated aims of promoting engagement and research, significant concerns persist regarding its practical implementation. Critics argue that while the plan articulates broad goals, it lacks concrete, actionable strategies, particularly in areas such as funding allocation, workforce development, and the establishment of measurable outcomes. Additionally, there is ongoing debate about the extent to which individuals with lived experience of dementia have been genuinely involved in shaping the policy. Some suggest that consultation efforts may have been more symbolic than substantive, raising questions about the authenticity and inclusivity of the policymaking process.

These concerns are especially concerning given the growing economic and social burden of dementia in the UK. Dementia is one of the most expensive health conditions due to its progressive nature and long-term care needs. Dementia costs in the UK are a major economic and social challenge. There is increasing pressure on NHS resources, which will worsen as costs are expected to rise significantly as the number of PLwD rises. The costs of dementia comprise healthcare and social care costs, and unpaid informal caregiving. Current funding models for dementia care may become unsustainable as the number of PLwD rises, leading to calls for urgent policy reform.

9.4 Addressing the cost of dementia care

The analysis of the costs of patient use of services served to demonstrate the costs and service use by PLwD pre- and post-diagnosis (Chapter 6). Many PLwD used inpatient and outpatient services in the lead up to diagnosis, but afterwards, as their condition progressed, their use of services became more focused on inpatient services. The findings of the thesis align with previous research, which suggests that inpatient care costs for people with dementia are higher after diagnosis. The data analysis helped to demonstrate the costs and pressure on services, and this boosted the case for use of effective non-drug therapies.

The average cost of an inpatient care in the UK, as calculated in this thesis, was £43,477 per year. This is in line with other studies, which have reported annual costs

of £46,050 for each patient with severe dementia (Wittenberg *et al.*, 2019), although this study included costs of social care and unpaid care as well as healthcare costs. Patients with dementia spend longer in hospital on average than do other patients, which increases costs. An increased number of inpatient and outpatient visits further increased these costs.

Early diagnosis and prevention of dementia can delay progression and reduce the rate of hospital admissions. Increasing public awareness of dementia through public health campaigns can lead to earlier diagnoses, which can lead to reduced healthcare cost.

The findings of this study align with those of previous research, which suggests that living alone is associated with higher rates of hospital admissions (Knapp *et al.,* 2016). This reflects the importance of social and caregiving support for PLwD at home to prevent them from having to be admitted to hospital.

9.5 Addressing implementation barriers and the economic potential of NPTs

Recent decisions by the NHS to reject funding for new drug therapies for AD that show limited effectiveness in a small number of individuals have highlighted the importance of cost-effectiveness in healthcare decision-making (Gallagher and Roxby, 2024). For many PLwD and their families, such news is disappointing. In this context, there may be increased interest in NPTs, particularly those that demonstrate meaningful benefits and acceptable costs.

NPTs play a crucial role in improving the quality of life for PLwD and managing their symptoms. NPTs are widely recommended as complements to existing drug therapies as part of holistic dementia care. However, the diversity of NPTs, which vary in delivery format, intensity, duration and setting, creates challenges for assessing their cost-effectiveness. This heterogeneity limits the generalisability of findings from across studies and complicates policy decisions.

To address these challenges, better funding policies and consistent evaluation frameworks are needed. Initiatives to expand community-based dementia programmes such as day centres and dementia cafés can help PLwD and families to gain more support in their communities. Dementia-friendly communities provide

valued support for both caregivers and PLwD that can reduce reliance on formal care services.

However, integration of NPTs into routine dementia care may be limited by funding and resource constraints. Some NPTs may require initial investment, such as specialist training or equipment or structured programmes, which can make them expensive. Despite growing evidence of the benefits of NPTs, their cost-effectiveness remains a key concern for healthcare providers and policymakers.

Nonetheless, NPTs offer the potential for meaningful economic and social return. Evidence suggests that they can help PLwD to maintain cognitive function and to keep their independence, both of which may delay the need for long-term care and reduce the cost to the public of care homes (Jennings *et al.,* 2019; Jutkowitz *et al.,* 2023). They can also prevent hospital admissions and reduce the risk of falls (Burton *et al.*, 2015). In addition, NPTs have been shown to reduce behavioural symptoms and ease caregivers' burdens. This may enable caregivers to remain in employment, which would improve economic productivity. Investment in accessible, community-based NPTs may therefore represent a cost-saving strategy by delaying institutionalisation and reducing long-term care costs.

9.6 Addressing barriers of NPTs

While NPTs offer valuable benefits for PLwD, their implementation presents several challenges. Not every therapy suits every person, and the acceptability of NPTs is influenced by personal preferences, cultural factors, accessibility and perceived effectiveness. For example, MT is often well-received by PLwD, as demonstrated by high levels of adherence and attendance (Prieto Álvarez, 2022).

Increased public awareness of NPTs may help to improve their acceptance and facilitate their integration into healthcare systems. To improve accessibility, NPTs should be embedded within existing health and social care services. Community-based programmes such as dementia cafés and group MT offer cost-effective ways to deliver these therapies and can reduce reliance on private, often expensive, therapy providers.

However, the availability of therapies may vary depending on location, with access particularly limited in rural or underserved areas. Additionally, the format and setting of therapies can affect the outcomes. Many NPTs are delivered in a group format and require active participation, which may not suit all individuals. Some people may feel uncomfortable engaging in unfamiliar activities or taking part in group events, and these issues may affect rates of uptake and effectiveness.

9.7 Informing the provision of music therapy with economic evidence

The modelling data is crucial, as it employs methods to assess cost-effectiveness, which may have influenced NHS decision-makers to deem new dementia drugs not cost-effective. The models in the thesis illustrate scenarios in which MT and CTPs would be cost-effective. The survey results in this thesis indicated that many people with lived experience of dementia would find MT an acceptable intervention. The modelling data is presented clearly and robustly. Currently, there are no published models of the cost-effectiveness of MT. Decision-makers can use these modelling data to shape future service provision.

9.8 Informing the provision of caregiver training with economic evidence

Training and support provision for informal caregivers can lower their reliance on professional care. It can also reduce the use of services by both PLwD and caregivers. Investment in early intervention, diagnosis and caregiver support can help to reduce costs and improve the quality of life for PLwD.

9.9 Methodological reflection

The author of this thesis employed a multi-method approach to address the research objectives. A well-established, existing database of patients was analysed to examine patterns of mental health service use and its costs before and after diagnosis (Chapter 6). This provided valuable insights into dementia care pathways and resource implications for a diverse urban population that can be used to inform future planning and improvements in both primary and secondary care support for PLwD. Data from

this analysis were also used to inform the cost-of-care parameters for the economic evaluation models.

It is important to highlight that this thesis was founded on the perspectives of people with lived experience of dementia. Their input was sought from the outset; they were involved in the survey development as members of the PPI group and as research participants. The survey was then used to gather the perspectives of people with lived experience of dementia, regarding their preferences and priorities for NPTs. This method facilitated the collection of rich, experience-based data that informed model development and priority setting for economic evaluation.

Ethical considerations were prioritised throughout the research. Informed consent, confidentiality and sensitivity to the needs of a vulnerable population were carefully managed, with additional safeguards in place to support participation by people with cognitive impairment.

For both modelling evaluations, parameters were informed by existing published evidence, ensuring that the analyses were grounded in robust and credible data. These were used to evaluate the potential for expanding or introducing new NPTs into UK dementia care practice. This evidence-based approach supports informed decision-making and helps policymakers prioritise interventions that offer both clinical value and economic efficiency.

The economic evaluation of MT as presented in Chapter 7 is particularly significant, as it provides the first comprehensive assessment of the cost-effectiveness of this therapy in the context of dementia. The clinical benefits of music therapy have been well documented, but there has been a lack of robust economic evaluation to determine its financial impact on healthcare systems. The research provides policy- and decision-makers with essential data that supports the integration of MT into standard dementia care practices. As the first economic evaluation of MT, this study provides a framework for further research. The chapter addresses critical gaps in the literature by providing valuable insights into the financial and clinical feasibility of MT; the knowledge gained can lead to more informed policy decisions and potentially broader adoption of this therapy in dementia care than is currently the case.

9.10 Limitations

The service use that is reported in Chapter 6 may have been significantly impacted by the COVID-19 pandemic, which caused widespread disruptions to health and social care services. These disruptions may have affected access, delivery patterns and the overall volume of services utilised during the study period. During the pandemic, access to routine dementia care, community support groups and NPTs was limited due to restrictions, staff shortages and the reallocation of healthcare resources. This is likely to have impacted patterns of service use among PLwD and their caregivers. With limited access to formal care services, family caregivers may have taken on a greater number of caring responsibilities, and this may have influenced patterns of healthcare use. Inpatient admissions would have been affected by the prioritisation of COVID-19 patients and the reluctance of PLwD and their caregivers to attend hospital due to concerns regarding infection risk. This may have led to services being underused during the pandemic. Also, memory clinic services were reduced during the pandemic. To summarise, patterns of service use that are reported in Chapter 6 may have shown atypical patterns of healthcare utilisation because of the pandemic.

The lack of standardisation in existing studies of NPTs, particularly MT, posed a challenge to the effective synthesis of results. Variability in intervention format, delivery, setting and outcome measures made it difficult to draw consistent conclusions across studies. As a result, several assumptions were required during development of the MT model that is explained in Chapter 7. In the absence of detailed cost and outcome data specific to MT, it was assumed that community-based delivery was equivalent to that in nursing home settings in terms of effectiveness and cost of delivery. These assumptions were tested in deterministic sensitivity analyses to assess the robustness of the model outcomes and to explore the impact of key uncertainties on cost-effectiveness estimates.

In addition to data-related limitations, the survey data collection also presented challenges related to sample representativeness. The survey sampling strategy had some limitations, particularly in terms of diversity. Participants in the survey sample predominantly identified as White with mild dementia. Notably, there was no one with severe dementia in the sample. This lack of diversity presents possible limitations in the generalisability of the findings as the acceptability of NPTs may be influenced by

cultural beliefs, preferences and accessibility within different communities. Cultural factors can significantly influence attitudes towards dementia care and therapies and may impact acceptance and engagement (Gallagher-Thompson *et al.*, 2012). Ethnic minorities have similarly been underrepresented in other dementia research projects (Brijnath *et al.*, 2022). Delivery of NPTs may need to be adapted to meet local needs across diverse populations.

Lastly, all potential costs that may be affected by provision of NPTs were not measured. Outside of healthcare costs, costs of social care such as care homes, home care and social work support that may have been affected were not evidenced. Decision-makers with responsibility for accounting for these costs (the providers themselves or local authorities commissioning these services) cannot therefore use this evidence to judge cost-effectiveness of services over which they have authority. Likewise informal carer costs were not included and so costs incurred by carers in offering support to relatives are not visible for decision-makers to judge and are hidden from judgement.

9.11 Implications

The findings of this thesis have important implications for dementia care and healthcare policy. Findings align with those of previous research, which has suggested that enhancing caregiver support and improving dementia care within the community can help to reduce healthcare costs, particularly by reducing the high numbers and durations of hospital admissions (Knapp *et al.*, 2016), as demonstrated in Chapter 6.

This thesis contributes new data through the creation of innovative models and advances our understanding of the cost-effectiveness of carer training interventions and MT. The insights gained are highly relevant to policy- and decision-makers who are involved in the planning and development of dementia services and NPTs. By positioning NPTs as a critical resource in dementia care, this thesis highlights their potential to slow the decline in cognitive function and improve quality of life.

As well as clinical benefits, NPTs also have important financial implications. NPTs can reduce the severity of behavioural symptoms, which often lead to costly hospital admissions (Knapp *et al.*, 2016). NPTs can offer a cost-effective way to manage the growing financial burden of dementia. The thesis offers valuable insights into how

dementia care services could be shaped within a broad framework of dementia healthcare provision.

Further, evidence presented in this thesis highlights the financial implications of integrating NPTs into routine dementia care. Overall, the thesis highlights that NPTs could play a key role in cutting dementia-related healthcare costs, and this could lead to a more sustainable model of dementia care as prevalence rises.

9.12 Generalisability of results

This thesis is set within a UK context, and the economic models presented in Chapter 7 and 8 were primarily informed by UK data. While the findings provide valuable insights into the cost-effectiveness of NPTs within the UK healthcare system, their applicability to other countries may require changes to the models. Results in other countries may be affected by differences in healthcare structures and demographic profiles, cultural considerations and economic situations.

The economic models used the typical UK WTP thresholds (£20,000–£30,000 per QALY), these are low compared to other countries. The reason for this difference could be attributed to the perspective adopted in economic evaluation. Typically, NICE uses a health system or health-and-social-care perspective, which excludes wider societal costs such as productivity losses and informal care. In countries where societal perspectives are taken as standard, WTP thresholds are often higher, which may lead to different conclusions regarding the relative cost-effectiveness of MT and similar NPTs. As a result, the projected cost savings may not be directly generalisable to international settings. However, the model structures that are described in this thesis reflect the usual clinical pathway for PLwD, hence, the models can be easily adapted for use in other countries.

The majority of participants in the survey that was used to determine research priorities identified as being of White ethnicity, and individuals with advanced dementia were poorly represented. The survey provides valuable insights, but this demographic imbalance may limit the extent to which the findings can be generalised to more ethnically diverse populations or those living with more complex stages of dementia. Differences in cultural perspectives, caregiving roles, and healthcare access may influence the priorities and needs of underrepresented groups. Similarly, individuals

with advanced dementia may face challenges that were less likely to be reflected in the survey responses. As such, the findings may not fully capture the diversity of experiences across the wide population of PLwD and their caregivers.

The thesis utilised data from the CRIS system, a well-established healthcare database that is broadly representative of the broad population of PLwD in the UK. The sample included participants with diverse demographics, ethnic backgrounds and varying stages of dementia, supporting the broader applicability of the findings to other UK settings. These findings are supported by prior research using the CRIS dataset, notably by Knapp *et al*., (2016), who investigated patterns of service use in PLwD. These researchers identified predictors of admissions of PLwD to hospital and care homes. The predictors included cognitive and functional decline, mental health symptoms, and social factors such as living alone. Importantly, they found that reduced access to community support may increase the risk of costly and often unwanted transfer to long-term care. This aligns with the emphasis in this thesis on the potential value of preventative interventions, such as caregiver training, to reduce the burden on health- and social care systems by supporting PLwD to remain living in the community for as long as possible.

9.13 Future work

Future priority setting exercises in research may benefit from more targeted efforts to engage underrepresented groups including individuals from ethnically diverse backgrounds and those living with advanced or complex stages of dementia. Inclusion of people with more diverse experiences of living with dementia can help to ensure that emerging research agendas more accurately reflect the full range of experiences, needs, and preferences within the dementia community. This would support the development of interventions and policies that are both inclusive and responsive to the diverse populations that are affected by dementia across the UK. This would be essential in the evaluation of the acceptability and relevance of NPTs across different communities.

Further research should also consider comparing post-pandemic data with pre-pandemic benchmarks to assess whether patterns of service use have returned to

pre-pandemic levels or whether there has been a long-term change in dementia-related healthcare utilisation.

9.14 Conclusions

As the global number of PLwD continues to grow, governments and healthcare systems must prioritise investment in effective models of care such as integrated care systems, dementia-friendly communities, and NPTs such as caregiver training and MT. Strategic investment in resources and infrastructure may reduce healthcare costs while improving PLwD and caregiver outcomes. Effective funding of and resource allocation for these approaches could help ensure that people who live with dementia are enabled to access high-quality services that can improve their quality of life and symptom control in a supportive environment.

In the UK, NPTs are a promising and cost-effective approach to dementia care. There is potential to save costs in terms of fewer hospital admissions, delayed transfer to long-term care and reduced reliance on medications to treat dementia symptoms. Social care costs could also be reduced if people who live with dementia were enabled to remain at home for longer than is currently possible. Interventions such as carer training programmes could reduce carer burden and its associated costs.

However, the current focus of dementia treatments in the NHS remains largely centred on pharmaceutical therapies. Many of these are costly and have side effects. The widespread adoption of NPTs in standard dementia care pathways is limited by a lack of funding. NPTs could have significant economic benefits as they can reduce healthcare costs and improve PLwD outcomes, but achievement of these benefits would require shifts in policy and the application of sustainable funding models. Further research and long-term evaluations are also essential to build a stronger evidence base for the cost-effectiveness of NPTs like MT, thereby supporting their integration into mainstream dementia care.

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APPENDICES

Appendix 1 Ethical approvals from University of Greenwich Research Ethics Committee

1.1 Ethical approval for research proposal

Ms Gillian Eaglestone
Faculty of Education, Health and Human Science.
University of Greenwich
Greenwich Campus

Direct Line 020 8331 8860
Email researchethics@gre.ac.uk
Our Ref: UREC
Date: 09 August 2022

Dear Gillian,

University Research Ethics Committee – Application

TITLE OF RESEARCH: Assessing the Cost-effectiveness of Non-Pharmacological Community Interventions for Persons Living with Dementia using a Modelling Simulation Approach

I am writing to confirm that the above application has been **approved** by Chair's Action on behalf of the Committee and that you have permission to proceed.

I am advised by the Committee to remind you of the following points:

- You must notify the Committee immediately of any information received by you, or of which you become aware, which would cast doubt upon, or alter, any information contained in the original application, or a later amendment, submitted to the Committee and/or which would raise questions about the safety and/or continued conduct of the research.
- You must comply with Data Protection legislation.
- You must refer proposed amendments to the protocol to the Committee for further review and obtain the Committee's approval thereto prior to implementation (except only in cases of emergency when the welfare of the subject is paramount).
- You are authorised to present this University of Greenwich Research Ethics Committee letter of approval to outside bodies in support of any application for further research clearance.

On behalf of the Committee may I wish you success in your project.

Yours sincerely

Peter Garrod
Secretary, University Research Ethics Committee

1.2 Ethical approval from the University of Greenwich – for amendment to survey and recruitment methods

UNIVERSITY of GREENWICH

Ms Gillian Eaglestone
Institute for Lifecourse Development
Faculty of Education, Health & Human Sciences
University of Greenwich
Greenwich Campus

Direct Line 020 8331 8860
Email researchethics@gre.ac.uk
Our Ref: UREB/
Date: 10 July 2023

Dear Ms Eaglestone

University Research Ethics Board – Application to Amend Research Proposal

TITLE OF RESEARCH: Assessing the Cost-effectiveness of Non-Pharmacological Community Interventions for Persons living with Dementia using a Modelling Simulation Approach

I am pleased to confirm that your application to amend your research proposal as follows:

- To amend/add questions to the PLWD/carer survey
- To carry out the survey by telephone as well as online

was **approved** by Chair's Action on behalf of the Board and that you have permission to proceed.

- You must notify the Board immediately of any information received by you, or of which you become aware, which would cast doubt upon, or alter, any information contained in the original application, or a later amendment, submitted to the Board and/or which would raise questions about the safety and/or continued conduct of the research.
- You must comply with Data Protection legislation.
- You must refer proposed amendments to the protocol to the Board for further review and obtain the Board's approval thereto prior to implementation (except only in cases of emergency when the welfare of the subject is paramount).
- You are authorised to present this University of Greenwich Research Ethics Board letter of approval to outside bodies in support of any application for further research clearance.

On behalf of the Board may I wish you success in your project.

Yours sincerely

[redacted]

Peter Garrod
Secretary, University Research Ethics Board

1.3 Ethical approval from the University of Greenwich - non-substantial amendment to add Join Dementia Research

From University of Greenwich Faculty Research Ethics Committee non-substantial amendment approval received 01/11/2022

Good morning

I would like to submit an amendment please to request that Join Dementia Research is added as a recruitment method for my study. Please see attached file note for further details.

Best wishes

Gill

Gill Eaglestone
PhD Student
Faculty of Education, Health & Human Sciences
University of Greenwich

From: FEHHS-Research Ethics <FEH-researchethics@greenwich.ac.uk>
Sent: 01 November 2022 10:34
To: Gillian Eaglestone <G.L.Eaglestone@greenwich.ac.uk>
Subject: RE: Amendment to existing research programme

Morning Gill

Just letting you know that one of the FREC Co Chairs has reviewed the attachments and are fine with the changes you have made. Thanks

Regards,

Dinaz

Dinaz Hoey

Appendix 2 Materials for the surveys of people with lived experience of dementia

2.1 Information sheet and consent form for the survey of Family Caregivers and People Living with Dementia

Participant Information Sheet

Title of project: Assessing the cost-effectiveness of non-pharmacological community interventions for persons living with dementia using a modelling simulation approach

Short title: Assessing the cost and effectiveness of interventions for dementia

Name and contact details of the project leader: Gill Eaglestone, G.L.Eaglestone@greenwich.ac.uk

If you would like help with the following information and completing the survey please contact Gill here to arrange an online meeting if that would be helpful.

Invitation to participate in a research project
You are being invited to take part in a project being carried out by Gill Eaglestone a PhD student at the University of Greenwich, supervised by Professor Paul McCrone. Please take your time to read the following information and discuss it with your family or friends if you wish before you decide whether to take part. Please contact Gill here if you have any questions.

What is the purpose of the project?
We are looking at interventions aimed to help people living with dementia, this includes activities such as art, music, singing; therapies such as massage and cognitive stimulation therapy (CST); and training programmes for carers. Research has already been done on how effective these are but not on whether they are good value for money. Organisations often need to know the cost and the value for money of interventions when planning what they can offer to people.

After reading the existing research we have drawn up a list of twelve interventions that need more research into their value for money, but we can't look at all of them. We would like to ask persons living with dementia and family caregivers to vote for the ones they think are important to be researched further. We will then take the top three voted for and simulate the cost of providing these over ten years. This will demonstrate which would potentially be effective and provide good value for money to use in the future.

Do I have to take part?
No, your participation in this project is entirely voluntary and you do not have to take part if you don't want to.

What will the project involve if I take part?
If you would like take part we will ask you to complete a short survey and vote for the interventions/activities you think are most important for us to research further. Your responses will be kept completely confidential and we won't be able to identify you from any of the answers that you give. The survey will take you around twenty

minutes to complete. Once you submit your answers at the end of the survey you will be unable to change them or withdraw them from the project.

What are the possible benefits of taking part?
By taking part you will have the opportunity to have your say about the interventions/activities that you feel are important and help to shape the direction of the research project.

What are the possible disadvantages and risks of taking part?
We do not foresee any risk associated with taking part in the project.

What will happen if I don't want to carry on with the survey?
If you change your mind and want to stop the survey at any time you can do this by closing this internet browser page and your answers will not be recorded.

What will happen to the results of the project?
At the end of the project we will analyse all the information and publish our findings in academic journals and at relevant conferences. If you would like to receive a summary of the findings at the end of the project please contact Gill here

Who has reviewed the project?
The project has been reviewed and approved by University of Greenwich Faculty Research Ethics Committee (FRDCEHHS/20/M-5/4).

What if something goes wrong?
If you are unhappy with any aspect of this study or you wish to raise a complaint, please contact Gill here. If you feel your concerns are not being addressed properly please contact Professor Paul McCrone here

Questions?
If you have any questions or would like to discuss the project before you take part please contact Gill here

Consent Form
I agree that:

I am aged 18 years old or over
I have read the above information about this project
I have had an opportunity to ask questions and discuss this project
I have received satisfactory answers to all my questions
I have received enough information about this project
I agree to take part in this project

2.2 Information sheet and consent form for the survey of People Working in Dementia

Title of project: Assessing the Cost-effectiveness of Non-Pharmacological Community Interventions for Persons Living with Dementia using a Modelling Simulation Approach

Short Title: Assessing the cost and effectiveness of non-drug interventions for dementia

Name and contact details of the project leader: Gill Eaglestone, G.L.Eaglestone@greenwich.ac.uk

Invitation to participate in a research project

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What is the purpose of the project?

We are looking at non-drug interventions for people living with dementia such as art, cognitive stimulation therapy (CST), staff training, music and singing amongst others. We are interested in understanding which interventions are effective and good value for money. This is because whilst a lot of research has already been done on the effects of non-drug interventions there is often a lack of research on whether they provide value for money. When planning which interventions to provide, organisations need information not just on an intervention's effectiveness but on its costs and value for money as well.

We have read the research that has already been done in this area and have drawn up a list of twelve interventions that are effective but need further research on their value for money. But we can't look at all twelve. We would like to ask persons living with dementia, family members and people working in the field of dementia to choose the three interventions that they feel are most important to be researched further. The results of the survey will decide which three interventions are chosen. We will then build a model to estimate the cost of providing these three interventions over ten years. This will demonstrate which interventions would potentially be effective and provide good value for money for use in the future.

Do I have to take part?
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What are the possible benefits of taking part?
By taking part you will have the opportunity to have your say about the interventions that you feel are important and help to shape the direction of the research project.

What are the possible disadvantages and risks of taking part?
We do not foresee any risk associated with taking part in the project.

What will happen if I don't want to carry on with the survey?
If you change your mind and want to stop the survey at any time you can do this by closing this internet browser page and your answers will not be recorded.

What will happen to the results of the project?
At the end of the project we will analyse all the information and publish our findings in academic journals and at relevant conferences. If you would like to receive a summary of the findings at the end of the project please email Gill.

Who has reviewed the project?
The project has been reviewed and approved by University of Greenwich Faculty Research Ethics Committee (FRDCEHHS/20/M-5/4).

What if something goes wrong?
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Questions?
If you have any questions or would like to discuss the project before you take part please contact Gill at: G.L.Eaglestone@greenwich.ac.uk

Consent Form
By clicking the button below, you agree that:

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I have read the above information about this project
I have had an opportunity to ask questions and discuss this project
I have received satisfactory answers to all my questions
I have received enough information about this project
I agree to take part in this project

2.3 Survey for Family caregivers/People Living with Dementia

Q1.

Title of project: Assessing the cost-effectiveness of non-pharmacological community interventions for persons living with dementia using a modelling simulation approach

Short title: Assessing the cost and effectiveness of interventions for dementia

Name and contact details of the project leader: Gill Eaglestone, G.L.Eaglestone@greenwich.ac.uk

If you would like help with the following information and completing the survey please contact Gill here to arrange an online meeting if that would be helpful.

Invitation to participate in a research project
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What is the purpose of the project?
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After reading the existing research we have drawn up a list of twelve interventions that need more research into their value for money, but we can't look at all of them. We would like to ask persons living with dementia and family caregivers to vote for the ones they think are important to be researched further. We will then take the top three voted for and simulate the cost of providing these over ten years. This will demonstrate which would potentially be effective and provide good value for money to use in the future.

Do I have to take part?
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What will the project involve if I take part?
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What are the possible benefits of taking part?
By taking part you will have the opportunity to have your say about the interventions/activities that you feel are important and help to shape the direction of the research project.

What are the possible disadvantages and risks of taking part?
We do not foresee any risk associated with taking part in the project.

What will happen if I don't want to carry on with the survey?
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What will happen to the results of the project?
At the end of the project we will analyse all the information and publish our findings in academic journals and at relevant conferences. If you would like to receive a summary of the findings at the end of the project please contact Gill here

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What if something goes wrong?
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Questions?
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Consent Form
By clicking the button below, you agree that:

I am aged 18 years old or over
I have read the above information about this project
I have had an opportunity to ask questions and discuss this project
I have received satisfactory answers to all my questions
I have received enough information about this project
I agree to take part in this project

Yes I consent, begin the study

No I do not consent and do not wish to participate (please exit the survey)

Q2. Are you a person living with dementia?

- Yes
- No
- I am completing the survey with/on behalf of someone living with dementia

Q3. Do you care for a person living with dementia?

- Yes
- No
- I have in the past

Q4. Are you completing this survey with your own details and views or those of the person with dementia?

- My own
- The person living with dementia

Q5. Is your dementia mild, moderate or severe?

- Mild
- Moderate
- Severe
- Unsure

Q6. What is your age?

Q7. What is your gender?

- Male
- Female
- Or do you describe yourself in another way? (write in gender identity)
- Prefer not to say

Q8. What is your ethnicity?

Q9. I would like to vote for more research on art, music and singing activities

- Yes
- No

Q10. I would like to vote for more research on cooking and storytelling

- Yes
- No

Q11. I would like to vote for more research on exercise, occupational therapy or massage

- No - none of these
- Yes - exercise
- Yes - occupational therapy (this helps people to stay independent with tasks like getting dressed and preparing meals)
- Yes - massage

Q12. I would like to vote for more research on an activity which involves memory training, peer support, positive thinking and education

Yes

No

Q13. I would like to vote for more research on pet/animal therapy

Yes

No

Q14. I would like to vote for more research on cognitive stimulation therapy (this involves puzzles, games, discussing events)

Yes

No

Q15. I would like to vote for more research on dementia training for carers

No

Yes for carers in nursing homes and residential care homes

Yes for family carers (people who care for family members with dementia)

Q16. I would like to vote for more research on dementia care management (where people with dementia receive specialist dementia care from GP's and nurses in the community rather than at hospital).

Yes

No

Q17. How did you find out about this research project?

Join Dementia Research

Other (please write)

Q18. Please confirm that you are happy with the choices that you have selected. Once you have submitted your survey you will be unable to withdraw it or change your answers

Yes I am happy, Please submit my answers

No, please use the back button to edit your answers

Thank you for taking part in the survey, your responses have been submitted

The following organisations provide support to both persons living with dementia and family members:

The Alzheimer Society: https://www.alzheimers.org.uk/get-support

The Alzheimer Society Dementia Advisors Telephone: 0333 150 3456

DEEP: https://www.dementiavoices.org.uk

Young Dementia Network: https://www.youngdementianetwork.org/

Dementia Carers Count: https://dementiacarers.org.uk/

This research was supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration Kent, Surrey, Sussex

Thank you, once again for taking part in this project

2.4 Survey for People Working in Dementia

Title of project: Assessing the Cost-effectiveness of Non-Pharmacological Community Interventions for Persons Living with Dementia using a Modelling Simulation Approach

Short Title: Assessing the cost and effectiveness of non-drug interventions for dementia

Name and contact details of the project leader: Gill Eaglestone, G.L.Eaglestone@greenwich.ac.uk

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What is the purpose of the project?

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What are the possible disadvantages and risks of taking part?
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Questions?
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Consent Form
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I have had an opportunity to ask questions and discuss this project
I have received satisfactory answers to all my questions
I have received enough information about this project
I agree to take part in this project

I consent, begin the study

I do not consent and do not wish to participate (please exit the survey)

Do you work in dementia?

Yes

No

Below is the list of interventions which you can vote for us to look at more in our research. Please choose up to 3 which you think should be a priority

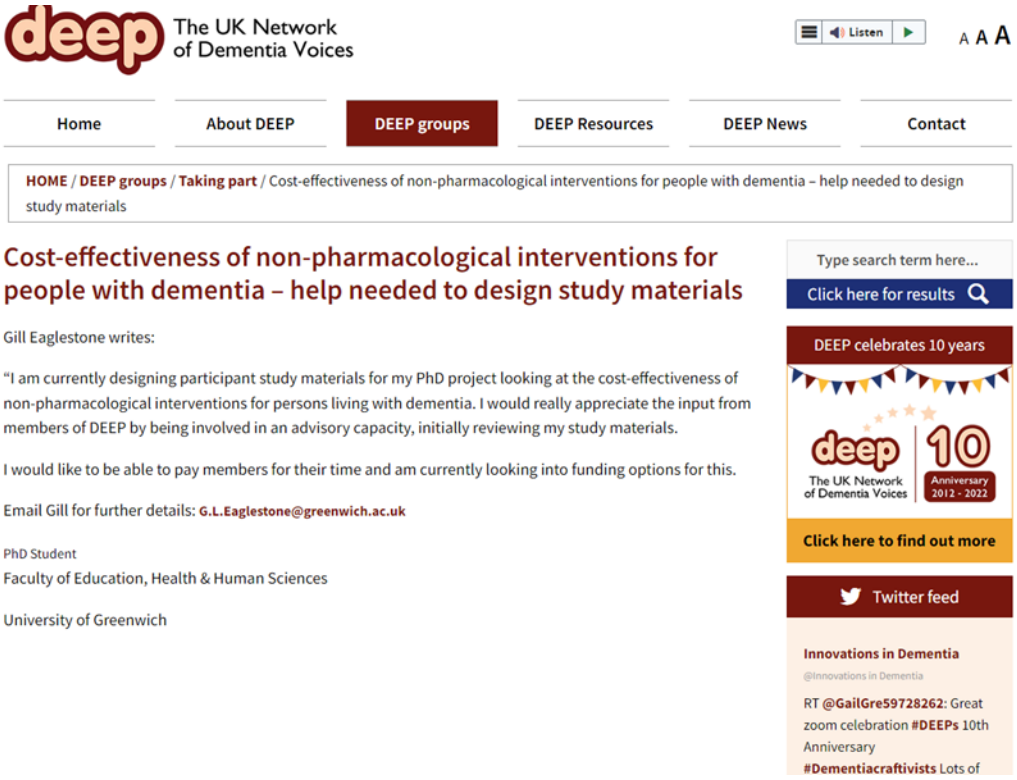
- Combined interventions (for example music and art therapy together)
- Dementia care management (a programme where a person's dementia care is managed in the community by GP's and specially trained nurses)
- Group activities (storytelling, cooking)
- Group exercise classes
- Group music and singing
- Maintenance Cognitive Stimulation therapy (continuing with cognitive stimulation therapy. This involves word puzzles, games and discussing events for example)
- Multi-modal interventions (focuses on cognition, behaviour and education with activities such as positive thinking, memory training and active lifestyle education)
- Occupational therapy (helping people to stay independent with tasks like getting dressed and preparing meals)
- Pet therapy (interacting with animals such as rabbits, cats, dogs, horses)
- Sensory therapies (massage, art and music)
- Training and education programmes for family caregivers (specialist dementia care training)
- Training for staff in care homes and nursing homes (specialist dementia care training programmes)

Please confirm that you are happy with the interventions that you have selected.
Once you have submitted your survey you will be unable to withdraw it or change your answers

- Yes, submit
- No, please use the back button to edit your answers

Appendix 3 Materials for PPI contributors

3.1 Recruitment advertisement for PPI contributors



deep The UK Network of Dementia Voices

Listen A A A

Home | About DEEP | DEEP groups | DEEP Resources | DEEP News | Contact

HOME / DEEP groups / Taking part / Cost-effectiveness of non-pharmacological interventions for people with dementia – help needed to design study materials

Cost-effectiveness of non-pharmacological interventions for people with dementia – help needed to design study materials

Gill Eaglestone writes:

"I am currently designing participant study materials for my PhD project looking at the cost-effectiveness of non-pharmacological interventions for persons living with dementia. I would really appreciate the input from members of DEEP by being involved in an advisory capacity, initially reviewing my study materials.

I would like to be able to pay members for their time and am currently looking into funding options for this.

Email Gill for further details: G.L.Eaglestone@greenwich.ac.uk

PhD Student
Faculty of Education, Health & Human Sciences

University of Greenwich

Type search term here...
Click here for results

DEEP celebrates 10 years
deep The UK Network of Dementia Voices 10 Anniversary 2012 - 2022
Click here to find out more

Twitter feed

Innovations in Dementia
@Innovations in Dementia
RT @GailGre59728262: Great zoom celebration #DEEPs 10th Anniversary #Dementiacraftivists Lots of

3.2 Lay summary and activities for PPI contributors

Dear XX

Thank you very much for your email. It is great to hear from you. It would be great if you would be interested to join a small advisory group for the project, giving me your opinion on aspects of the project, for example the suitability of study materials and survey design. I would anticipate it taking about 4-6 hours of your time in total over the project and I would be able to offer you Love to Shop vouchers as an appreciation of your time.

There is some more information about the project below.

Title: Assessing the cost-effectiveness of non-pharmacological interventions for persons living with dementia

Many different non-drug therapies are available to people with dementia. At the moment it is not clear which one's benefit people but also provide good value for money. The aim of this project is to find out.

I have looked at the research that has already been carried out and have drawn up a list of possible dementia therapies to look at. Next, I will ask the views of people living with dementia to help me decide which therapies they feel are most important for me to look at in the next part of the project. I will also ask the family members who care for them, and people working in dementia. I will do this by sending an online survey to ask people to think about their experience of these therapies.

As part of the project, I will also be using hospital data about 2 groups of people living with dementia. This data will include their characteristics such as age, gender and diagnosis, their medications, which other health conditions they had and the hospital services they used over 10 years.

Once I have the results from the online surveys, I will know which 3 therapies the participants would like me to focus my research on. The next part of the project will be a model and the purpose of this is to test the cost of the different therapies chosen by the participants. It will combine the data from the research I have read and the hospital data.

By looking at the results of the model I will be able to see which of the therapies benefit people and are also good value for money. Therapies may be found which are not usually offered to people living with dementia and a strong case could then be made for starting to offer them.

Please let me know what whether you would like to join the advisory group or if you have any questions

Best wishes

3.3 Newsletter for PPI contributors

October 2023

NEWSLETTER

Non-drug Interventions for People with Dementia

Top News

- Survey Recruitment has now finished
- Top interventions voted for in the survey were:

Music
Training for family carers

Publication!

The project has just published its first paper, a systematic literature review in PharmacoEconomics Open. Click **here** to read this

Conference

A poster presentation was given at **The Alzheimer Europe Conference** in Finland. This presented a draft of the decision tree which will be used to model the costs of using **music therapy** to improve symptoms of dementia.

Next Steps

The next phase of the project will be modelling the **costs of training for family carers.**

The project is due to complete in April next year.

A big **Thank You** to you all for all of your help, support and advice with the project so far!

NIHR | Applied Research Collaboration Kent, Surrey and Sussex

This research was supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration Kent, Surrey, Sussex. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

UNIVERSITY of GREENWICH

ILD | Institute for Lifecourse Development

Appendix 4 Honorary contracts for analysis of patient data

4.1 Honorary contract with South London and Maudsley NHS Foundation Trust (SLaM)

WORKING TOGETHER

NHS
South London and Maudsley
NHS Foundation Trust

Private and Confidential
Ms Gillian Lorraine Eaglestone
47 The Street
Boughton
Faversham
Kent
ME13 9BA
United Kingdom

Monday, 7th March 2022

Dear Ms Gillian Eaglestone,

Re: Honorary CRIS Researcher

I am pleased to confirm the arrangements for you to carry out your Honorary Attachment under the supervision of **Debbie Cummings** within:

Biomedical Research Centre- DeCrespigny Park

South London and Maudsley NHS Foundation Trust with effect from:

7-Mar-2022 – 7-Mar-2023

You will have access to patient data.

Your supervisor/manager will ensure that you are familiar with all relevant HR and Operational Policies and Procedures of the Trust, that you work in accordance with these, and conduct your work to the standards of behaviour and performance required by the Trust. Please also read the 'Conditions of Attachment' enclosed.

If you agree to accept this clinical placement, please could you sign both copies of this letter, returning one copy to me as your acceptance of these arrangements and retaining the second for your own information.

I hope you enjoy your placement.

Miss Lauren Allan
Joint HR Transactional Services Advisor

4.2 Honorary contract extension - South London and Maudsley NHS Foundation Trust (SLaM)

[EXTERNAL] RE: Honorary Contract - Gillian Eaglestone - extended until 20-JUN-2024

This message was sent with High importance.

Flag for follow up.

H HRTransactions <HRTransactions@slam.nhs.uk>
To: Cummings, Debbie <Debbie.Cummings@slam.nhs.uk>
Cc: Gillian Eaglestone
Tue 20/06/2023 10:40

This message originated from outside the University. Treat links and attachments with caution.

Hi Debbie,

Thanks for your email and I hope you're well.

I extended Gillian's honorary contract for another year from today's date, which is a maximum we can do at a time. Please keep this email for your records.

Best wishes.

Marta

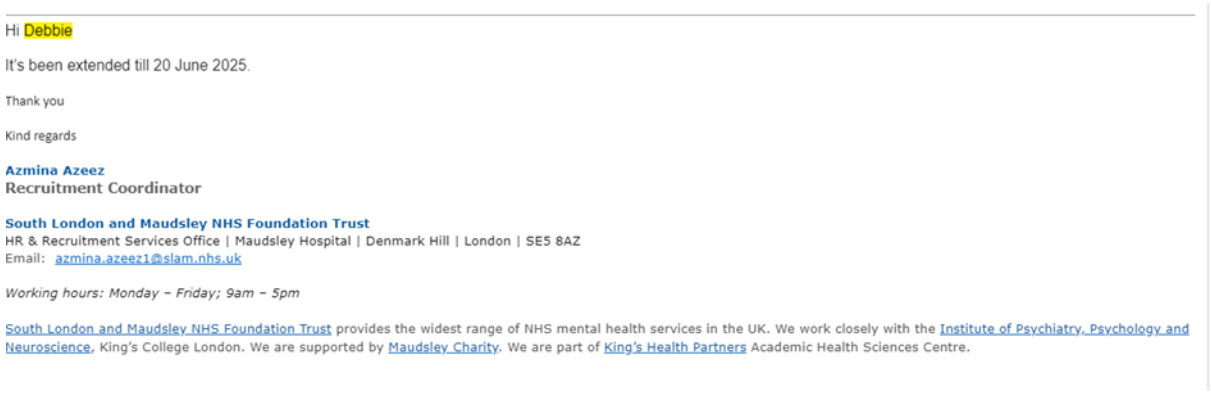
Marta Subocz
HR Transactional Services Advisor
South London and Maudsley NHS Foundation Trust
HR Transactional Services, 6th Floor, Jeanette Wallace House, 1 Edridge Road, Croydon, CR0 1FE
Please note my working days are **Monday to Thursday**.
In my absence please email HRTransactions@slam.nhs.uk and one of the team will reply.

Our HR Values and Behaviour Charter

Working With You · Following Through · Listening and Valuing Others · Caring & Compassionate · Honest and Open

4.3 Honorary contract further extensions - South London and Maudsley NHS Foundation Trust (SLaM)

Extension to June 2025



Hi Debbie

It's been extended till 20 June 2025.

Thank you

Kind regards

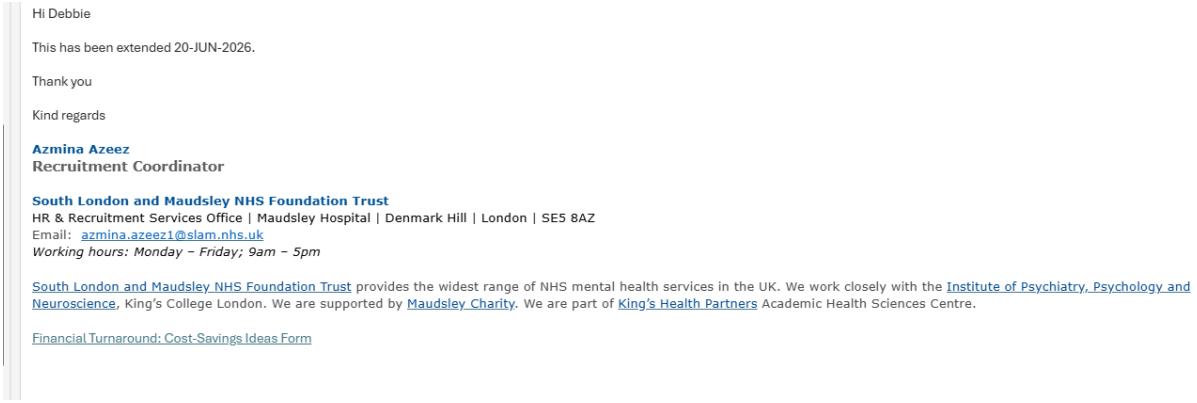
Azmina Azeez
Recruitment Coordinator

South London and Maudsley NHS Foundation Trust
HR & Recruitment Services Office | Maudsley Hospital | Denmark Hill | London | SE5 8AZ
Email: azmina.azeez1@slam.nhs.uk

Working hours: Monday – Friday; 9am – 5pm

South London and Maudsley NHS Foundation Trust provides the widest range of NHS mental health services in the UK. We work closely with the Institute of Psychiatry, Psychology and Neuroscience, King's College London. We are supported by Maudsley Charity. We are part of King's Health Partners Academic Health Sciences Centre.

Extension to June 2026



Hi Debbie

This has been extended 20-JUN-2026.

Thank you

Kind regards

Azmina Azeez
Recruitment Coordinator

South London and Maudsley NHS Foundation Trust
HR & Recruitment Services Office | Maudsley Hospital | Denmark Hill | London | SE5 8AZ
Email: azmina.azeez1@slam.nhs.uk
Working hours: Monday – Friday; 9am – 5pm

South London and Maudsley NHS Foundation Trust provides the widest range of NHS mental health services in the UK. We work closely with the Institute of Psychiatry, Psychology and Neuroscience, King's College London. We are supported by Maudsley Charity. We are part of King's Health Partners Academic Health Sciences Centre.

Financial Turnaround: Cost-Savings Ideas Form

Appendix 5 Continuing professional development

5.1 List of publications and presentations

Jiang H, Eaglestone G, McCrone P, Carr C, Stoner C. (2024) How are nature-based interventions defined in mild cognitive impairment and dementia studies? A conceptual systematic review and novel taxonomy. Dementia (London). 2024 Jul 24:14713012241261788.

Eaglestone, G., Gkaintatzi, E., Jiang, H. *et al*. (2023) Cost-Effectiveness of Non-pharmacological Interventions for Mild Cognitive Impairment and Dementia: A Systematic Review of Economic Evaluations and a Review of Reviews. PharmacoEconomics Open.

Eaglestone, G., McCrone P, Pacella RE, Stoner CR. (2023) Modelling the cost and effectiveness of non-pharmacological interventions for dementia and mild cognitive impairment. Poster presented at Alzheimer Europe International Conference, Helsinki, Finland.

5.2 Poster presentation: Modelling the cost and effectiveness of non-pharmacological interventions for dementia and mild cognitive impairment – Presented at Alzheimer Europe in Helsinki (2023)

POS4-70

Modelling the Cost and Effectiveness of Non-pharmacological Interventions for Dementia and Mild Cognitive Impairment

Authors: Ms Gillian Eaglestone[1], Prof Paul McCrone[1], Prof Rosana E. Pacella[1], Dr Charlotte R. Stoner[1]
Institutions: [1]Institute for Lifecourse Development, University of Greenwich, UK

Background

Non-pharmacological interventions for people living with dementia (PLwD) can be effective at improving cognitive function, quality of life and reducing symptoms of depression [1]. However, costs of dementia healthcare are increasing [2] and a lack of economic data can present challenges to decision makers when ensuring that PLwD have access to effective interventions [3]. Decision modelling can provide decision makers with important economic evidence on the cost-effectiveness of different intervention options [4].

Aim

This project uses decision modelling to review the cost-effectiveness of non-pharmacological interventions for PLwD or mild cognitive impairment (MCI).

Methods

Project stages:

- ✓ Systematic literature review and review of reviews
- ✓ Clinical effectiveness review
- ✓ Survey
- • Secondary patient data analysis (in progress)
- • Modelling simulation (in progress)

Survey:

Online quantitative survey to inform priorities for the modelling simulation. PLwD, family carers and people working in dementia (n=50) voted for interventions they wanted to see further research on.

Music and **training for family carers** received the most votes.

Secondary patient data:

Patient data from a cohort of 18,962 patients analysed.

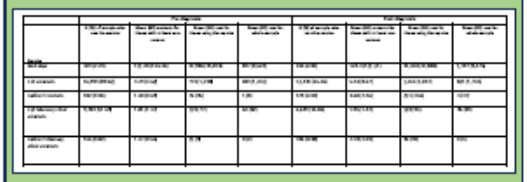
- ➢ Over 18 years old
- ➢ Mental health service users at a UK NHS Trust
- ➢ Primary diagnosis of MCI or dementia
- ➢ Service use pre and post diagnosis over 10 years

Results

Tables below show service utilisation and costs from the patient data analysis. Costs were estimated using Unit Costs of Health and Social Care 2022 Manual [5].

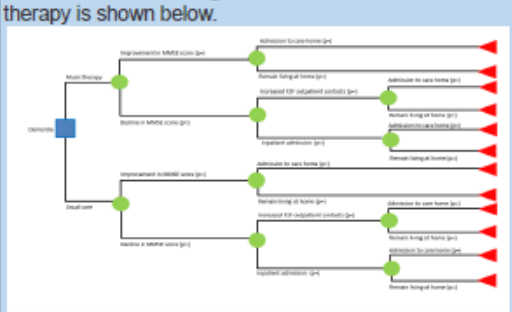
Costs

Service utilisation costs



Modelling

A decision tree showing the model structure for music therapy is shown below.



Data from published music studies and the secondary patient data will be used to populate the model, predicting the probability and costs for each end point of the model.

Conclusions

Policy and decision makers increasingly rely on health decision models to compare different interventions.

Our model can be used as part of the decision-making process for introducing/expanding interventions for PLwD.

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NIHR | National Institute for Health and Care Research

UNIVERSITY of GREENWICH

ILD | Institute for Lifecourse Development

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Appendix 6 Inclusion/exclusion reasons - Literature Review Chapter 3

6.1 Table of full text exclusions with reasons

Author	Exclusion Reason
Araw *et al.*,(2015)	Not a non-pharmacological intervention
Banerjee and Wittenberg, (2009)	Prevention/early detection of dementia
Dowd *et al.*,(2018)	Health outcomes not reported
Gaviola, Searles and Dilworth,(2022)	Health outcomes not reported
Gomes et al.,(2019)	Prevention/early detection of dementia
Gomes et al.,(2017)	Preliminary trial results only
Handels et al.,(2023)	No economic data
Harris, (2023)	Letter/commentary
Klimova et al.,(2016)	Prevention/early detection of dementia
Knapp et al.,(2022)	No economic data
Meeuwsen et al.,(2013)	Not a non-pharmacological intervention
Rosa et al.,(2019)	Health outcomes not reported
Sogaard et al.,(2014)	Prevention/early detection of dementia
van Duinen-van den IJssel *et al.*,(2020)	Health outcomes not reported
Wong et al., (2023)	Prevention/early detection of dementia