# Facilitators and barriers to engaging with community support services in dementia: A mixed methods approach of addressing health inequalities

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Doctor in Philosophy in Health Service Research

by

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# Declaration

**Candidate**

Ms. Thaïs Marguerite Emma Caprioli

**Supervisors**

Dr Clarissa Giebel, Dr Stephen Mason and Professor Siobhan Reilly

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'*Vous n'êtes pas encore arrivées mais vous êtes plus proche qu'hier'* – Anonymous

(English translation: You haven't arrived yet, but you are closer than yesterday)

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## Coronavirus pandemic statement

I began studying towards my Ph.D. during the height of the coronavirus (COVID-19) pandemic in 2020 and most of my research was conducted while public health restrictions were in place. While my research was minimally impacted overall, the pandemic is likely to have contributed to the challenges in recruitment experienced.

# Abstract

**Background:** Post-diagnostic support is important to living well with dementia. In the United Kingdom (UK), post-diagnostic support is delivered by a mixture of sectors, providers and care settings. As part of post-diagnostic support, social care and support services can be defined as non-clinical services that assist community-living. Services may include befriending services, peer support groups and respite care. The coronavirus (COVID-19) pandemic invoked significant changes to service delivery methods and the reliance on information communication technology (ICT) increased. The aim of this Ph.D. project was to explore the barriers and facilitators to engaging with community-based social care and support services during the pandemic in UK.

**Methods:** This Ph.D. project comprised of a systematic review and a sequential exploratory mixed method study. The systematic review synthesised how ICT has been used to access post-diagnostic support and explored service recipients' views on accessing services remotely. A remote longitudinal survey, addressed to social care and support providers, compared services and delivery methods employed prior to and during the pandemic at two time points. Data were presented by descriptive statistics. Semi-structured interviews with social care and support providers, people with dementia and unpaid carers were conducted and explored the experiences of delivering and accessing services during the pandemic. Data were analysed by a reflexive thematic analysis.

**Findings:** The systematic review suggests that accessing post-diagnostic support by ICT is feasible for some people with dementia and unpaid carers. Access was often facilitated by providing ICT devices and technological support, and service recipients' views towards accessing post-diagnostic support remotely were mixed. The survey depicted a shift from in-person to remote or hybrid services during the pandemic, and a slight decrease in service use. The telephone remained the most employed format. The use of videoconferencing software significantly increased, notably while public health measures were most restrictive, and was often used alongside telephone calls and emails to remotely deliver services. Semi-structured interviews conveyed the process of adapting services and the resilience demonstrated by social care and support providers to help service recipients address some of their presenting needs. Considerable heterogeneity in access to ICT devices and digital skills across social care and support providers and service recipients was observed. While some service recipients were able to benefit from accessing services remotely, the use of ICT was not suitable for everyone. Social care and support providers' views towards using ICT within future service delivery were mixed, but many identified benefits to capitalise on when remote services are delivered alongside in-person services.

**Implications:** Amidst the current hybrid landscape, balancing the provision of in-person and remote services will ensure that digitally excluded service recipients are not disenfranchised, while empowering service recipients with the option of how to access services. Further research is required

to establish standards of best practice while delivering remote or hybrid services. In the interim, remotely delivering services by employing a varied portfolio of technological and non-technological tools is likely to promote inclusivity. Investing in ICT infrastructure and digitally upskilling the workforce may facilitate the improved use of ICT within service delivery, nevertheless, the wider barriers in access service recipients may experience need to be considered. As the use of ICT is likely to remain a prominent feature within society, service recipients need the opportunity to receive digital training and access adequate devices. To help build a service delivery resilient to future public health crises, sector-specific guidelines advising on service delivery and workforce wellbeing support during emergency situations are required.

# Lay abstract

**Background:** It is important that people with dementia and unpaid carers can access post-diagnostic support to live well with dementia. As part of post-diagnostic support, social care and support services can be defined as non-clinical services that aim to help people with dementia live well in their communities and to support unpaid carers. Services may include peer support groups, day care centres and paid home care. The coronavirus (COVID-19) pandemic greatly changed how services were delivered and many organisations turned towards information communication technology (ICT) to continue to deliver services. This Ph.D. project tried to explore the barriers and facilitators to engaging with community-based social care and support services during the pandemic in the United Kingdom (UK).

**Methods:** This Ph.D. project consisted of a literature review, a survey and an interview study. Firstly, the review tried to understand how ICT has been used to access post-diagnostic support and to explore people with dementia and unpaid carers' views on accessing services remotely. Secondly, social care and support providers were surveyed to understand how services adapted during the pandemic. The survey compared the types of services delivered and how they were delivered before and at two timepoints during the pandemic. Lastly, social care and support providers, people with dementia and unpaid carers were interviewed to further understand how services were delivered and accessed during the pandemic.

**Findings:** Firstly, the review suggests that using ICT to access post-diagnostic support is helpful for some people with dementia and unpaid carers. Receiving ICT devices from study teams and/or ongoing technological support often helped people with dementia and unpaid carers access services remotely. Secondly, the survey showed the transition from in-person to remote or hybrid services, and slightly fewer people with dementia and unpaid carers accessed services during the pandemic. The telephone was the most used format to deliver services, but the use of videoconferencing software greatly increased, especially when the public health measures were very restrictive. Lastly, the interviews showed social care and support providers' resilience to help meet some of the needs experienced by people with dementia and unpaid carers during the pandemic. The interviews also showed that access to ICT formats and/or knowing how to use ICT greatly varied across social care and support providers, people with dementia and unpaid carers. While some people with dementia and unpaid carers were able to use ICT to access support, it was not suitable for everyone. Beyond the pandemic, social care and support providers' views on using ICT to deliver services were mixed, but many identified benefits ICT could bring when remote services are delivered alongside in-person services.

**Implications:** To avoid leaving some people with dementia and unpaid carers behind, it is important that the delivery of in-person and remote services are carefully balanced during the current hybrid landscape. More research is needed to devise guidelines of best practice when delivering remote or

hybrid services, but, for the moment, delivering remote services using a mixture of technological and non-technological formats may increase access to services. Social care and support organisations need to be equipped with an adequate ICT setup and deliver ICT training to providers. This may help the use of ICT when delivering services, but it is also important to consider the wider barriers people with dementia and unpaid carers may face when accessing services. In addition, it will be important that people with dementia and unpaid carers can access devices and receive training on how to use ICT. Lastly, to help prepare for future public health crises, guidelines outlining how to deliver services and wellbeing support for providers during emergency situations are needed.

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# List of abbreviations

- ADL – Activities of daily living
- APPG - All Party Parliamentary Group
- BBC – British Broadcasting Corporation
- BGS - British Geriatrics Society
- BPSD - Behavioural and psychological symptoms of dementia
- BSG - British Society of Gerontology
- CCGs – Clinical Commissioning Groups
- CDC – Centers for Disease Control and Prevention
- CHAIN - Contacts, Help, Advice and Information Network
- COVID-19 – coronavirus
- COREQ – Consolidated criteria for Reporting Qualitative research checklist
- CROSS- Consensus-Based Checklist for Reporting of Survey Studies
- DHSC – Department of Health and Social Care
- DSM-V - Diagnostic and Statistical Manual of Mental Disorders version five
- EEA – European Environmental Agency
- GBP – British Pound Sterling
- GRIPP - Guidance for Reporting Involvement of Patients and the Public
- HIAT - Health Inequalities Assessment Tool
- IADL – Instrumental activities of daily living
- ICS – Integrated Care Systems
- ICT – Information Communication Technology
- ICF – International Classification of Functioning, Disability and Health
- IMD – Index of Multiple Deprivation
- LA – Local Authority
- MCA – Mental Capacity Act
- MCI – Mild Cognitive Impairment
- MMAT - Mixed Method Appraisal Tool
- NAO – National Audit Office
- NHS – National Health Service
- NHS – National Health Service
- NICE – National Institute of Care Excellence
- NIHR - National Institute for Health and Care Research
- NIHR ARC NWC - National Institute of Health and Care Research Applied Research Collaboration North West Coast
- NIST – National Institute of Standards and Technology

- NCVO - The National Council for voluntary Organisations
- OECD – Organisation for Economic Co-operation and development
- PPI – Patient and Public Involvement
- PRISMA - Preferred Reporting Items of Systematic Reviews and Meta-analysis
- SCIE – Social Care Institute Excellence
- SDWG - Scottish Dementia Working Group
- SPICE – Setting, Population, Intervention, Comparison and Evaluation
- SPICe - Scottish Parliament Information Centre
- T1 – timepoint one
- T2 – timepoint two
- TA – Thematic Analysis
- UK – United Kingdom
- UNESCO – United Nations Educational, Scientific and Cultural Organization
- VPN – Virtual private network
- WHA – World Health Assembly
- WHO – World Health Organization

# Glossary

**Activities of daily living (ADL):** Refers to basic activities required to independently care for one's physical needs and include personal hygiene, dressing, toileting, ambulating and eating (Edemekong et al., 2023).

**Ageing in place:** The choice and '*… ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level'* (Centres of Disease Control and Prevention [CDC], 2009).

**Assistive technology:** Refers to *'…products or systems that support and assist individuals with disabilities, restricted mobility or other impairments to perform functions that might otherwise be difficult or impossible*' (Medicines & Healthcare products Regulatory Agency, 2023).

**Caregiving burden:** Can be defined as '*the level of multifaceted strain perceived by the caregiver from caring for a family member and/or a loved one over time'* (Liu et al., 2020, p.442).

**Commercial-off-the-shelf technology**: Can be defined as '*a software and/or hardware product that is commercially ready-made and available for sale, lease, or license to the general public*' (National Institute of Standards and Technology [NIST], n.d.).

**Community-based social care and support provider:** Someone who is involved, either directly or indirectly, in the delivery of community-based social care and support services to people with dementia and/or unpaid carers in a paid or unpaid (volunteer) capacity.

**Community-based social care and support services:** Forms part of post-diagnostic support, community-based social care and support can be defined as non-clinical services that seek to support community-dwelling people with dementia live well for as long as possible and to delay entry to long-term care facilities. Community-based social care and support services also addresses the needs of current and former unpaid carers. In the United Kingdom (UK), services are largely provided by Local Authorities (LA) and Third sector and may include: paid home care, day care centres, befriending services and peer support groups.

**'Cost of living' crisis:** Refers to the rising prices of everyday items, including food and fuel, following the height of the coronavirus (COVID-19) pandemic (British Broadcasting Corporation [BBC], 2022).

**Critical realism:** A worldwide view that adopts a realist ontology and a constructivist epistemology. A critical realist accepts that an objective world exists separately from one's perceptions experiences *and* that one's subjective perceptions influence how the world is perceived (O'Mahoney & Vincent, 2014).

**Digital divide:** The gap between people who have and do not have access to the internet.

**Digital inequalities:** The differences *'…in material, cultural and cognitive resources required to make good use of ICT*' (Organisation for Economic Co-operation and Development [OECD], 2015, p.124).

**Digital literacy:** Having '*… the knowledge and skills needed to use (or decide not to use) ICTs in ways that help…to achieve beneficial, high-quality outcomes for themselves and others now and in the future'* (Helsper, 2021, p.77).

**Epistemology:** Theory of knowledge and focuses on '*how we know what we know*' (Guba & Lincoln, 1994).

**Sequential explanatory mixed method design:** A mixed method study design that involves a quantitative component followed by a qualitative line of inquiry (Schoonenboom & Johnson, 2017).

**Grey literature:** Information produced by a wide range of sources (e.g., governmental, academic and industry) outside of commercial publishers (Paez, 2017).

**Health inequalities**: Refers to disparities in health outcomes across individuals and social groups. The term is a dimensional concept, relating to measurable differences in health, and excludes the moral judgement relating to whether the differences are fair or just (Mariana et al., 2015; Kawachi et al., 2022).

**Health inequities:** Refers to differences in health that are avoidable and are deemed to be unjust of unfair (Whitehead, 1992).

**Index of Multiple Deprivation (IMD):** A relative measure of neighbourhood deprivation calculated by an amalgamation of multiple factors including income and health (Department for Communities and Local Government, 2015).

**Information Communication Technology (ICT):** A *'…diverse set of technological tools and resources used to transmit, store, create, share or exchange information. These technological tools and*

*resources include computers, the Internet (websites, blogs and emails), live broadcasting technologies (radio, television and webcasting), recorded broadcasting technologies (podcasting, audio and video players, and storage devices) and telephony (fixed or mobile, satellite, visio/videoconferencing, etc.)'* (United Nations Educational, Scientific and Cultural Organization [UNESCO] Institute for Statistics, 2009, p. 120). In my work, I conceptualised ICT as any technological tools employed as a medium to access post-diagnostic support.

**Instrumental activities of daily living (IADL):** Activities that enable an individual to live independently. Activities are more complex than activities of daily living (ADLs) and include cooking, cleaning, transport, laundry and managing finances (Guo & Spara, 2022).

**Integrated Care Systems (ICS):** Introduced in England in July 2022 following the Health and Care Act 2022. Integrated Care Systems accrue key stakeholders from NHS trusts, general practices, Local Authorities (LAs) and Third sector to, collaboratively, plan and organise the delivery of health and care services across areas (Health and Care Act, 2022).

**Living well with dementia:** *'The physical dimensions of living well are maintaining the ability to live their life and manage symptoms on a daily basis; the mental dimensions are being psychologically healthy and stable, maintaining identity and human dignity, and facilitating growth; and the social relationship dimensions are maintaining social relations and community connectivity, and ensuring government support'* (Kim & Shin, 2023, p. 7-8)

**Meeting centres:** Are '*…local resource, operating out of ordinary community buildings, that offers on-going warm and friendly expert support to people with mild to moderate dementia and their families.'* (University of Worcester, n.d.). While every meeting centre is different depending on the needs and interests of service recipients, they are implemented by the meeting centre model which is characterised by several essential features (University of Worcester, 2022).

**Mixed method research:** An approach to research that employs '*…rigorous quantitative research assessing magnitude and frequency of constructs and rigorous qualitative research exploring the meaning and understanding of constructs; utilising multiple methods (e.g., intervention trials and in-depth interviews); intentionally integrating or combining these methods to draw on the strengths of each; and framing the investigation within philosophical and theoretical positions*' (Creswell et al., 2011, p.4).

**Ontology:** Is the study of 'being' and focuses on the form and nature of reality (Guba & Lincoln, 1994).

**Person-centred care:** Person-centred care involves *'approaches and practices that see the person as a whole with many levels of needs and goals, with these needs coming from their own personal social determinants of health'* (World Health Organization [WHO], 2015, p.5).

**Post-diagnostic support:** A range of services delivered following a dementia diagnosis that seek to provide continuous support to meet the changing support and care needs throughout the disease trajectory, until the end of life (Prince et al., 2016). In The UK, post-diagnostic support is delivered by a mixture of sectors, providers and care settings.

**Public and Patient Involvement (PPI):** can be defined as *'...research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them'* (National Institute for Health and Care Research [NIHR], 2021a).

**Publication bias:** When the result of a study biases the decision to publish (Paez, 2017).

**Recall bias:** When participants do not remember past events accurately.

**Resilient health system:** A resilient health system has *'... the ability to prepare for, manage and learn from shocks, absorb information, adapt and transform*' (WHO, 2022, p.31).

**Social desirability bias:** Social desirability bias is the tendency of participants to answer questions in ways that they deem to be more favourable to others (Athubaiti, 2016).

**Social determinants of health:** Social determinants of health are '*non-medical factors that influence health outcomes'* (WHO, 2023b). Factors include conditions in which people are born, grow, work, live and age. Societal factors and systems which, at a macro level, influence the conditions of daily living are equally important, and include socioeconomic constructs and political systems.

**Subjective well-being:** An individual's assessment of their life, including fulfilment and/or satisfaction, and an evaluation of their experience of both negative and positive emotions (Diener and Chan, 2011).

**Telehealth:** Any communication at a distance with service recipients, including the delivery of health and care services (WHO 2012; 2016a).

**Telemedicine**: The delivery of remote medicine (WHO, 2012).

**Third sector:** Refers to organisations that are neither within the private or public sector and includes '*voluntary and community organisations (both registered charities and other organisations such as associations, self-help groups and community groups), social enterprises, mutuals and co-operatives*.' (National Audit Office [NAO], n.d).

**Universal Health Coverage:** When '*all people have access to the health services they need, when and where they need them, without financial hardship*' (WHO, 2023c).

**Unpaid carer:** An unpaid carer is *'someone who provides unpaid help to a friend or family member needing support, perhaps due to illness, older age, disability, a mental health condition or an addiction'* (Department of Health and Social Care [DHSC], 2018, p.4).

**Quality of Life:** An '*…individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*.' (WHO, 1995, p.11).

**Volunteers:** People '*…giving of time and energy… which can bring measurable benefits to the volunteer, individual beneficiaries, groups and organisations, communities, the environment and society at large. It is a choice undertaken of one's own free will and is not motivated primarily for financial gain or for a wage or salary.'* (Scottish Government, 2019, p.4-5).

# Dissemination from this Ph.D. project

## Publications

Caprioli, T., Mason, S., Tetlow, H., Reilly, S., & Giebel, C. (2023b). Exploring the views and the use of information and communication technologies to access post-diagnostic support by people with dementia and unpaid carers: a systematic review. *Aging and Mental Health*, *27*(12), 2329-2345. https://doi.org/10.1080/13607863.2023.2196246

Caprioli, T., Giebel, C., Reilly, S., Tetlow, H., Limbert, S., & Lloyd-Williams, M. (2023). Social support services for dementia during the COVID-19 pandemic: A longitudindinal survey exploring service adaptations in the United Kingdom. *Health Expectations*, *25*(4), 1726-1737. https://doi.org/10.111/hex.13784

Caprioli, T., Mason, S., Tetlow, H., Limbert, S., Reilly, S., Giebel, C. "Necessity is the mother of invention": lessons learnt from delivering and accessing dementia-related support services during the pandemic in the UK. Submitted to *Dementia*.

## Conference presentations

## Oral presentations

- 22nd July 2022. Manchester Institute for Collaborative Research on Ageing (MICRA), Ph.D. and Early Career Conference. Presentation entitled '*Social support services for Dementia during the COVID-19 pandemic: a longitudinal survey exploring service adaptations in the UK.*'

- 25th October 2023. 5th Annual Liverpool Dementia & Ageing Research Conference. Presentation entitled: *'"Necessity is the mother of invention": Lessons learned from delivering and accessing dementia-related support services during the pandemic in the UK'*.

## Poster presentations

- 16th-18th November 2022. British Geriatrics Society (BGS) Autumn Meeting. Poster entitled: '*The views and the use of Information Communication technologies to access dementia post-diagnostic support: A systematic review*'

- 5th July 2023. British Society of Gerontology (BSG) Annual Conference. Poster entitled: '"*Necessity is the mother of invention": Lessons learned from delivering and accessing dementia-related support services during the pandemic in the UK'*.

## Blogs

- 10th February 2021 I wrote a blog entitled *'My initial PhD plans'* for the Dementia Researcher platform (https://www.dementiaresearcher.nihr.ac.uk/guest-blog-my-initial-phd-plans/ )

- 10th November 2022 I wrote a blog entitled *'The benefits and drawbacks of accessing post-diagnostic support remotely'* for the Dementia Researcher platform https://www.dementiaresearcher.nihr.ac.uk/guest-blog-the-benefits-and-drawbacks-of-accessing-post-diagnostic-support-remotely/

- 21st September 2023 I wrote a blog as part of the University of Liverpool's 'Becoming an Expert' series. (https://news.liverpool.ac.uk/2023/09/21/becoming-an-expert-exploring-how-dementia-community-based-support-services-have-adapted-during-the-pandemic/)

# CHAPTER 1: INTRODUCTION

Dementia is a neurodegenerative disease resulting in the progressive decline in cognitive and everyday functioning and is a major cause of disability among older people worldwide (World Health Organization [WHO], 2023a). It is important that people with dementia and unpaid carers have access to post-diagnostic support to live fulfilling and meaningful lives. This chapter provides the background and rationale to undertaking my Ph.D. project, which explored how community-based social care and support services adapted during the coronavirus (COVID-19) pandemic, with a focus on the use of information communication technologies (ICT) within service delivery. I commence by providing a summary of dementia and the impact of symptoms on daily living. Secondly, I summarise what is important to living well with dementia and the involvement of unpaid carers, statutory and non-statutory services in the delivery of post-diagnostic support. Thirdly, I introduce the concept of social determinants of health and synthesis barriers in access to social care and support services prior to the pandemic. Fourthly, I define ICT in the context of my work, introduce the concept of, and possible factors influencing, digital inequalities and how the pandemic acted as a catalyst to the reliance of ICT to deliver social care and support services. The chapter concludes by providing the rationale to undertaking my Ph.D. project, stating the aim and objectives of my research and outlining the overarching structure of my thesis.

## 1.1Dementia: symptoms and living well

Dementia is a neurodegenerative disease that is associated with the progressive decline of cognitive and associated everyday functioning (WHO, 2023a). Currently, there are an estimated 55 million people living with dementia globally, and projections are anticipated to reach 78 million by 2030 (WHO, 2021a). However, the rising prevalence rates are far from homogenous across regions (Livingston et al., 2020), and rates are foreseen to increase the highest in Latin America, North Africa and in the Middle East (Ferri et al., 2005). Currently, over 900,000 people with dementia are living in the United Kingdom (UK), a number that is expected to increase to one million by 2024 (Wittenberg et al., 2019). The number of people with dementia who identify as coming from black, Asian and minority ethnic groups are expected to significantly increase, along with the number of people experiencing severe dementia symptomology (All Party Parliamentary Group [APPG] on Dementia, 2013).

Multiple aetiologies may cause dementia and an array of dementia subtypes exist. The range of dementia subtypes includes Alzheimer's disease, Lewy body disease, Frontotemporal lobar degeneration, Parkinson's disease, Mixed dementia and Huntington's disease (Grossman et al., 2006). Alzheimer's disease forms the most common aetiology and is responsible for an estimated 50-75% of dementias worldwide (Prince et al., 2015), and for 62% of diagnosed cases within the UK (Prince et al., 2014). Vascular dementia is the second leading cause and accounts to approximately 20-30% (Prince et al., 2015) of dementias worldwide, and 17% of diagnosed cases within the UK (Prince et al., 2014).

A deficit model forms the foundation of the diagnosis framework of dementia. For example, the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) states that substantial decline in at least one of the following domains: learning and memory, language, executive function, complex attention, perceptual-motor and social cognition, is a requisite to forming a dementia diagnosis (Sachdev et al., 2014). The cognitive impairments must occur in the absence of delirium, not due to other mental health conditions and be sufficiently severe to hinder the ability to independently complete instrumental activities of daily living (IADL) (Sachdev et al., 2014). IADLs are activities that relate to the ability to live independently and include tasks such as managing finances, shopping, medication regimes and preparing meals (Giebel et al., 2017a; Guo & Spara, 2022).

While each dementia subtype is associated with a cluster of symptoms, the changing clinical presentation throughout the disease trajectory is unique to the individual. Depending on the dementia subtype, cognitive symptoms may include impairments to memory, thinking and judgement skills, orientation and language abilities, and neuropsychiatric symptoms may include hallucinations, agitation, apathy, depression, and motor disturbances (Grossman et al., 2006). The symptoms experienced may result in functional decline, which significantly impacts daily living (Giebel et al., 2017a). During the earlier stages of dementia, people often exhibit a gradual decline in the ability to complete IADLs, such as experiencing difficulties while using the computer, managing finances and maintain an active social life (Giebel et al., 2017a). The ability to initiate and perform activities of daily living (ADLs), a group of basic self-care activities that are fundamental to manage one's physical needs, that includes personal hygiene and feeding (Edemekong et al., 2023), tends to be preserved more so until the later stages of dementia (Giebel et al., 2015).

In addition to functional decline, dementia can impact individuals' emotional wellbeing, and compared to people without dementia, people with dementia have a higher prevalence of depression (Enache et al., 2011). Furthermore, people with dementia often experience a loss of selfhood and a curtailment in social engagement (Hackett et al., 2019). However, living fulfilling and meaningful lives following a diagnosis is possible.

### 1.1.1 Living well with dementia

In recent years, focus (see section 1.3 for policies) has shifted from mainly addressing dementia symptoms, to facilitating living well with dementia (Quinn et al., 2021). Living well with a chronic disease is a multi-faceted construct that can be conceptualised as achieving '*the best possible state of health that includes physical, mental and social well-being*' (Living Well with Chronic Illness: A call for Public Health Action, 2015, p. 486). Recently, Kim and Shin (2023) sought to develop and analyse the concept of 'living well' with dementia. The authors conducted a literature review and in-depth interviews with people with dementia, unpaid carers and nurses, and proposed the following definition and dimensions to living well with dementia:

> *'The physical dimensions of living well are maintaining the ability to live their life and manage symptoms on a daily basis; the mental dimensions are being psychologically healthy and stable, maintaining identity and human dignity, and facilitating growth; and the social relationship dimensions are maintaining social relations and community connectivity, and ensuring government support'* (Kim & Shin, 2023, p. 7-8).

Within this broad definition, how the state of 'living well' is understood and evaluated is likely to differ across people with dementia (Quinn et al., 2021). No single measure to assess living well with dementia exists but the concept has frequently been explored through the lens of self-reported quality of life scales addressed to people with dementia and/or informants (Martyr et al., 2018). Quality of life can be defined as

> '*…individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*.' (WHO, 1995, p. 11).

While this definition reflects the wide-ranging concept and subjective assessment of living well with dementia, solely employing quality of life measurements may fail to include other factors at play when exploring what living well with dementia entails (Clare et al., 2019; Harding et al., 2019; Quinn et al., 2021). Although applied to a lesser extent (Martyr et al., 2018), the concept of subjective well-being may equally be important to consider while exploring living well with dementia. Subjective well-being can be understood as an individual's assessment of their life, including fulfilment and/or satisfaction, and an evaluation of their experience of both negative and positive emotions (Diener and Chan, 2011).

Living well with dementia, how it is understood, and how it can be facilitated, is subjective and will vary across individuals. Thus, it is critical to gain an understanding of what people with dementia and unpaid carers deem as important to live well and acknowledge that aspects are likely to change throughout the disease trajectory (Quinn et al., 2021). Exploring factors that positively and negatively affect the ability to live well, on an individual basis, is important, as some challenges may be mitigated by support.

The International Classification of Functioning, Disability and Health (ICF) model (WHO, 2013) can be conducive to exploring and promoting the concept of living well with dementia. The ICF model is a multi-dimensional framework that helps to describe and understand an individual's level of functioning, which is conceptualised as the interplay between their condition(s), personal and environmental factors (WHO, 2013). The ICF model is divided into two parts. The first part relates to an individual's functioning and disability. Functioning refers to an individual's body functions, activities and level of participation. Disability refers to impairments such as limitations to activities or participation. The second part of the ICF model relates to contextual factors, and is composed of personal (e.g., age, gender) and environmental factors (e.g., physical and social environment). Environmental factors

include barriers and facilitators to an individual's functioning (WHO, 2013). In the context of my work, the first part of the ICF model is concerned with the aetiology of dementia, symptoms experienced, and abilities to perform activities of daily living and within the social context (Hopper, 2007). Cognisant that experiencing difficulties while participating in activities are thought to hinder living well with dementia (Giebel et al., 2015; Reilly et al., 2020), the second part of the ICF model is important to identify facilitators and barriers to participation, and how the latter could be mitigated, often through appropriate and tailored support. This may include, for example, home adaptations, educational courses on dementia addressed to unpaid carers (Hopper, 2007) and adequate transportation available to access support.

However, it is important to acknowledge that the concept of living well with dementia may not resonate with all people with dementia and unpaid carers (Bartlett et al., 2017). While the focus on promoting and facilitating living well with dementia is key, it is equally important that more negative experiences are recognised and acknowledged (Bartlett et al., 2017).

Here, I conceptualise living well with dementia to encompass mental, social and physical well-being (Kim & Shin, 2023), a state of being which may be facilitated by accessing relevant forms of support. My work does not focus on how accessing support can facilitate living well with dementia. Rather, I acknowledge the importance of accessing support (see section 1.3.1) and the consequences non-access may engender (Giebel et al., 2022a; 2022b), and with the aim of reducing inequalities in access, my work explores the barriers and facilitators to engaging with post-diagnostic support.

Furthermore, an estimated 61% of people aged over 65 with dementia reside in the community, within their own homes (Social Care Institute of Excellence [SCIE], 2020a). Most people prefer to stay in their homes for as long as possible and, owing to the high expenditure associated with long-term care facilities, many policymakers advocate for the concept of 'ageing in place'. Ageing in place can be defined as the '*…ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level'* (Centres of Disease Control and Prevention [CDC], 2009). Older adults' perceived benefits of ageing in place are numerous and include instilling a sense of independence while upholding connections with community members (Wiles et al., 2012). It is important that people with dementia are empowered with the choice of where they age and have access to post-diagnostic support to remain independent for as long as possible.

My work focuses barriers and facilitators to engaging with community-based post-diagnostic support. Support to people with dementia can be provided by unpaid carers, statutory and non-statutory services. Thus, unpaid carers may simultaneously be providers and recipients of post-diagnostic support.

## 1.2Post-diagnostic support: unpaid carers

While not all people with dementia receive unpaid support, unpaid care is currently scaffolding the healthcare and social care system to provide post-diagnostic support. The Department of Health and Social Care (DHSC) defines an unpaid carer as *'someone who provides unpaid help to a friend or family member needing support, perhaps due to illness, older age, disability, a mental health condition or an addiction'* (DHSC, 2018, p. 4). Spouses, followed by adult children, form most unpaid carers, and some people with dementia rely on multiple unpaid carers (Alzheimer's Association, 2015). Akin to other chronic health conditions, the gender bias in dementia caregiving is known, and women tend to undertake most caregiving hours (Ory et al., 1999). Compared to other long-term conditions, dementia caregiving entails additional hours (Ory et al., 1999) that tend to increase when the caring dyad reside together and as the disease progresses (Angeles et al., 2021). Unpaid carers approximately provide six hours of care per person with dementia each day (Wimo et al., 2018), and across the UK, unpaid care is estimated to amount to 13.9 billion British Pound Sterling (GBP) worth of care annually (Wittenberg et al., 2019).

Unpaid carers play an important role in supporting people with dementia to live at home for as long as possible. The amount and type of support provided is likely to change throughout the disease trajectory. Caregiving in the earlier stages may include supporting the completion of IADLs and planning for future care. Thereafter, unpaid care may extend to full-time support with ADLs and constant supervision (Alzheimer's Association, 2022). Depending on the neuropsychiatric dementia symptoms experienced, unpaid carers may need to manage behavioural challenges, and if support form statutory or non-statutory services is sought, unpaid carers are often involved in coordinating the care (Alzheimer's Association, 2015).

While providing care may include positive aspects (Quinn & Toms, 2019), the hardships associated with caregiving are known. Following a review and concept analysis, Liu and colleagues (2020, p. 442) propose defining caregiving burden as '*the level of multifaceted strain perceived by the caregiver from caring for a family member and/or a loved one over time'*. Caregiving burden often leads to poorer physical and mental health, worsened quality of life, and a decrease in the amount of support provided (Liu et al., 2020). Compared to other long-term conditions, dementia caregiving instils a greater caregiving burden (Ory et al., 1999). The caregiving burden has been found to increase as the person with dementia becomes progressively dependent on receiving assistance to complete ADLs and/or if managing dementia-related behavioural difficulties is required (Sutcliffe et al., 2017).

Unpaid carers require adequate and tailored support. Post-diagnostic support can be provided from statutory and non-statutory services, and/or informally, from friends and family.

## 1.3 Post-diagnostic support: statutory and non-statutory services

Statutory and non-statutory services play a fundamental role in the provision of post-diagnostic support. Henceforth, unless specified, I employ the term 'services' to refer to both statutory and non-statutory services.

Living well throughout the disease trajectory is at the forefront of the WHO's Dementia Action Plan (2017) and is accentuated within several governmental documents from nations across the UK (Department of Health, Social Services and Public Safety, 2011; Scottish Government, 2023; Welsh Government, 2018; Department of Health, 2009, 2015, 2016). In England, the Prime Minister's Challenge on Dementia 2020 implementation plan has now expired (Department of Health, 2016). While the development of a ten-year dementia strategy plan was announced in 2022 (DHSC & The Rt Hon Sajid Javid MP, 2022), the decision is believed to be revised, and the 'Major Conditions Strategy' which includes dementia, intends to be published in 2024 (DHSC Media Team, 2023).

Developed by National Health Service (NHS) England, The Well Pathway to Dementia seeks to improve the delivery of healthcare and support for people with dementia and unpaid carers (National Collaborating Centre for Mental Health, 2018). As outlined in **Table 1** the pathway consists of five components, reducing risk (preventing well), improving and maintaining the diagnosis rates (diagnosis well) and greater access to post-diagnostic support (supporting well, living well and dying well) (National Collaborating Centre for Mental Health, 2018).

It is important to acknowledge that the Well Pathway was published in 2018, and the use of the term 'hard-to-reach groups' is contested and misleading (Cook, 2002). Broadly speaking, the term was often employed to refer to populations who are, from institutions' point of view (e.g., governmental entities, police, academia and health and social care sectors), difficult to engage with, including, but not limited to, people from minority ethnic groups, people with disabilities, people experiencing homelessness and the Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual community (Cook, 2002; Islam et al., 2021). In the context of social care and support services, 'hard-to-reach groups' was employed to refer to people with dementia and unpaid carers who experienced challenges in accessing services, resulting in unmet needs. The term placed the onus on people with dementia and unpaid carers to overcome their challenges to access services and diminished the responsibility of services to actively engage with potential service recipients, notably those who may face additional barriers to access (Healthwatch, 2020). The preferred term is 'underserved groups', from the point of view of people with dementia and unpaid carers receiving services and is the stance I adopt in my work.

**Table 1** The Well Pathway to Dementia (National Collaborating Centre for Mental Health, 2018)

| | **Preventing well** | **Diagnosis well** | **Supporting well** | **Living well** | **Dying well** |
|---|---|---|---|---|---|
| *Aim* | | | | | |
| | Risk of people developing dementia is minimised | Timely accurate diagnosis, care plan and review within first year | Access to safe high-quality health and social care for people with dementia and carers | People with dementia can live normally in safe and accepting communities | People with dementia die with dignity in the place of their choosing |
| *Standards* | | | | | |
| | Prevention; Risk reduction; Health information; Supporting research | Diagnosis; Memory assessment; Concerns discussed; Investigation; Provide information; Integrated and Advanced care planning | Choice; Liaison; Advocates; Housing; Hospital treatments; Technology; Health and Social Services; hard to reach Groups | Integrated services; Supporting carers; Carers respite; Co-ordinated care; Promote independence; Relationships; Leisure; Safe communities | Palliative care and pain; End of life; Preferred place of death |

Post-diagnostic support seeks to address people with dementia's physical and mental health needs, neuropsychiatric symptoms, social care needs and support, as well as supporting unpaid carers' needs (Livingston et al., 2020). Numerous services fall within the remit of post-diagnostic support, and these can be broadly categorised into health and social care and support services. Healthcare services address health needs, such as medical reviews, occupational therapy, and speech and language therapy, whereas social care and support services refer to services that assist living well with dementia, and may include day care centres, respite care, paid home care, peer support groups home care, organised social activities, and home adaptations. My work focuses on the access to community-based social care and support services.

Several components are integral to the delivery of good social care and support services. These include a timely identification and management of needs, understanding and managing dementia, emotional and psychological wellbeing, practical support and integrated care (Bamford et al., 2021). Moreover, the person-centredness of services is important to people with dementia (Arbalster & Brennan, 2022). The WHO (2015, p.5) defines person-centred care as *'care approaches and practices that see the person as a whole with many levels of needs and goals, with these needs coming from their own personal social determinants of health.'.* The National Institute for Health and Care Excellence [NICE] (2018) outlines principles and provides best-practice guidance on delivering person-centred care across the disease trajectory, which includes offering a range of activities that align with service recipients' preferences. Nevertheless, while best-practice guidelines are available, these may not be universally applied. Reasons why guidelines may not be (fully) applied may depend on organisations' adaptability and

available resources. The latter may include resources to execute recommendations, but equally to train staff and establish systems to monitor the implementation of guidelines (Feder et al., 1999). Thus, while standards of best practice are identified, these may not necessarily be comprehensively translated into practice.

### 1.3.1 Social care and support services: benefits offered

Accessing social care and support services may offer numerous benefits, many of which overlap with outcomes important to living well with dementia (Reilly et al., 2020). Accessing information, either by receiving tailored information or attending educational courses, empowers people with dementia with a greater understanding of the condition and may help to adjust to receiving a diagnosis (Kelly & Innes, 2016; Stamou et al., 2021). Furthermore, services that promote opportunities to engage in social and reactional activities are important to people with dementia (Chester et al., 2018). People with dementia often prefer services that encourage social participation (Stamou et al., 2021), and peer support groups (Willis et al., 2018), singing groups (Camic et al., 2013) and memory cafes (Kelly & Innes, 2016) may promote wellbeing and reduce feelings of loneliness.

Furthermore, accessing social care and support may reduce the number of appointments with general practitioners (Giebel et al., 2020a) and possibly decrease the length of hospital stays (Packer et al., 2019). Moreover, Lee and colleagues (2020) conducted a systematic review and a meta-analysis and found that interventions within the realm of community care coordination delayed the entry to long-term care facilities. Services included initial and ongoing assessments, individualised care plans, signposting to services and the provision of information and advice. While promising, caution ought to be applied when interpreting these findings, as the meta-analysis was only based on two studies (Lee et al., 2020).

Alongside addressing the needs of people with dementia, social care and support plays an important role in protecting and upholding the wellbeing of current and former unpaid carers. Preferences on the type of support accessed is likely to be temporal to reflect the changing needs experienced throughout the disease trajectory. During the early stages of dementia, unpaid carers' most preferred service attributes were accessing support to help with feelings and concerns and receiving information provision on coping with dementia (Chester et al., 2018). Vandepitte and colleagues (2016a) systematically reviewed randomised and non-randomised controlled trials to investigate the effectiveness of different approaches to support the wellbeing of unpaid carers. While findings were somewhat inconsistent, tailored supportive interventions often yielded the most favourable benefits. Overall, psychoeducational interventions, such as support groups, training, and counselling, generated a greater sense of self-efficacy and reduction in depressive symptoms (Vandepitte et al., 2016a). Furthermore, a systematic review by Clarkson and colleagues (2018) found evidence to suggest that interventions comprising of education/advice and behaviour management were effective in reducing

the caregiving burden, problem behaviours in people with dementia and increased unpaid carers' wellbeing. As the dementia progresses, unpaid carers' most preferred service attributes were accessing available respite care (Kampanellou et al., 2019). Day care centres were found to be the most researched type of respite, and while difficult to provide firm conclusions due to mixed outcomes, accessing day care may help decrease the caregiving burden and reduce problem behaviours in some people with dementia (Vandepitte et al., 2016b).

### 1.3.2 Social care and support services: unequal unmet needs

While ensuring equal access to good social care and support has received political traction (Department of Health 2009, 2015; DHSC, 2016), the shortcomings are known (Arbalster & Brennan, 2022), and substantial needs remain unmet (Giebel & Heath, 2023; Giebel et al., 2023a). Unmet needs are unequally distributed, and health inequalities refers to avoidable differences in health across individuals or social groups (Kawachi et al., 2002). Unlike the term 'health inequalities' which is conceptualised as a dimensional and measurable concept (Kawachi et al., 2002; Mariana et al., 2015), the term 'health inequities' embodies an ethical standpoint, which asserts commitment to social justice (Whitehead, 1992; Marmot et al., 2012). Thus, differences in health that are inequitable are avoidable *and* are deemed to be unjust or unfair (Whitehead, 1992). While the terms are often used interchangeably, depending on one's ethical perspective and definitions, not all differences in health may be considered unjust or unfair (Whitehead, 1992). My work seeks to identify the barriers and facilitators to engaging with community-based social care and support services. Assessing whether the identified barriers result inequitable access, use or outcomes, is beyond the scope of my research, and therefore, the term 'inequalities' shall henceforth be employed.

Access to health and social care is a complex concept, and many definitions exist. Some definitions conceptualise access to specifically relate to the actual use of services (Levesque et al., 2013) and other definitions include aspects relating to the availability and appropriateness of services (Rodgers et al., 1999; Levesque et al., 2013). Levesque and colleagues (2013) conducted a literature review and developed a revised conceptual framework to understand the complex notion of access. Access was defined as '*the opportunity to have health and care needs fulfilled*' (Levesque et al., 2013, p. 4), and was perceived to be influenced by factors stemming from the demand and supply side. Regarding the demand side, factors include service recipients' ability to perceive, seek, reach, pay and engage with services (Levesque et al., 2013). However, these factors are dependent on key attributes of the supply side, which include the approachability, acceptability, availability, affordability and appropriateness of services (Levesque et al., 2013). Spanning from identifying the need of support, to ensuring the availability of appropriate services, Levesque and colleagues' (2013) conceptual framework is conducive to thinking about possible barriers to access to social care and support services, both those relating to first-time access and those pertaining to continuous use (Carrillo et al., 2011). Barriers to accessing social care and support services are likely to be influenced by structural and individual led

factors, shaped by the social determinants of health (Gaugler et al., 2023). The WHO defines social determinants of health as '…*non-medical factors that influence health outcomes'* (2023b). Factors include conditions where people are born, grow, work, live and age, and include broader factors and systems, such as economic policies and social norms (WHO, 2023b). The following sections (see sections: 1.3.2.1; 1.3.2.2) synthesise the barriers people with dementia and unpaid carers may experience while accessing social care and support services, including those experienced prior to the actual use of services. While it is important to acknowledge the multitude of barriers hindering the ability to access services and fulfil social care and support needs (Levesque et al., 2013), my work focuses on the barriers and facilitators to engaging with, relating to the actual use of, social care and support services during the COVID-19 pandemic.

#### 1.3.2.1 Service availability

An adequate supply of social care and support services is required to allow the opportunity for service recipients to access services. Austerity measures have featured in the UK political agenda over the last two decades and are likely to have impacted the availability of social care and support services. Indeed, across England, the real term expenditure on adult social care has been considerably rationed (Alzheimer's Society, 2019; NHS, 2020), notably in areas of higher deprivation (Phillips & Simpson, 2018).

In England, the provision of post-diagnostic support involves multiple sectors, providers, and care settings. Sectors include primary care, secondary care, social care, private, and the Third sector. The Third sector refers to organisations that are neither within the private or public sector and includes '*voluntary and community organisations (both registered charities and other organisations such as associations, self-help groups and community groups), social enterprises, mutuals and co-operatives*.' (National Audit Office [NAO], n.d). Each sector differs in terms of expertise, priorities, and funding.

The commissioning process of post-diagnostic support is likely to engender discrepancies in the provision of social care and support across areas. Prior to the implementation of the 2022 Health and Care Act (Health and Care Act, 2022), post-diagnostic support was primarily commissioned by Clinical Commissioning Groups (CCGs) or Local Authorities (LAs). CCGs were statutory and clinically led entities, and LAs are local government structures. Entities commissioned different services. CCGs largely commissioned specialist memory services, whereas LAs commissioned services within the remit of social care, including home adaptations, day care centres and respite care. Services provided by the Third sector, such as telephone helplines, peer support groups and dementia friendly initiatives, were commissioned by both CCGs and LAs (Frost et al., 2021). Some services provided by the private sector or volunteer led initiatives were commissioned by neither (Frost et al., 2021).

Poor communication between stakeholders involved in the commissioning process frequently resulted in a fragmented service provision landscape (Wheatley et al., 2021), whereby some areas were

characterised by the duplicity or lack of services. Nevertheless, the 2022 Health and Care Act (Health and Care Act, 2022) created the formation of integrated care systems (ICS). ICS accrue key stakeholders from NHS trusts, general practices, LAs and the Third sector to, collaboratively, plan and organise the delivery of health and care services across areas. Although relatively new at the time of writing, it is hoped that this method of working will help to assimilate efforts amongst stakeholders involved in the commissioning process and promote the equal availability of comprehensive social care and support.

In addition to a lack of communication between stakeholders involved in the commissioning process, confusion as to what 'post-diagnostic support' entails persist (Wheatley et al., 2020). The lack of a shared understanding, alongside insufficient funding, is likely to contribute to the variation of social care and support services across areas. Whereas post-diagnostic support ought to encompass wide-ranging and continuous services throughout the disease trajectory (Prince et al., 2016), it was misconstrued by some stakeholders, as a singular meeting following a diagnosis, or meetings that solely focus on medication reviews (Wheatley et al., 2020). Unlike guidelines that outline care requirements and standards while forming a dementia diagnosis, the ambiguity as to what post-diagnostic support ought to entail, coupled with the absence of practical directives (Levin et al., 2018; Wheatley et al., 2020; 2021), is likely to contribute to the shared misunderstanding of which services to commission.

Lastly, the availability of social care and support services, across and within, countries, regions, and cities vary considerably (Moise et al., 2004; Frost et al., 2021; Giebel et al., 2021a). For example, geographically marginalised areas tend to have fewer social care and support services (Szymcynska et al., 2011), including peer support groups, respite care and day care centres (Morgan et al., 2015; Bayly et al., 2020).

#### 1.3.2.2 Barriers and facilitators in access and utilisation

Perceiving the need and overcoming attitudinal barriers towards accessing social care and support is cardinal (Stephan et al., 2018). During the initial stages following a diagnosis, some people with dementia experience difficulties accepting the diagnosis and may lack awareness of their presenting needs. Similarly, some unpaid carers do not perceive themselves as 'carers', nor do they identify their need for support. Accessing social care and support is frequently misperceived as hindering the person with dementia's independence (Kerpershoek et al., 2019) and as disempowering unpaid carers of their caring duties. Furthermore, people with dementia and unpaid carers from ethnic minority groups often experience additional barriers to identify and acknowledge the need for social care and support. Perceiving, acknowledging, and accepting the potential need for social care and support is often shaped by cultural influences, and is likely to differ among social groups and across ethnic groups. Service recipients from minority ethnic groups often misconceived the condition as a natural cause of ageing (Ketchum et al., 2022) and do not perceive the need to seek services (Kenning et al., 2017; Nielsen et al., 2021). Furthermore, cultural stigma, whereby participants reported that accessing support is

'shameful' or 'embarrassing', was found to be a widespread barrier to accessing support among people from minority ethnic groups in the UK (Parveen et al., 2017). The delay in accessing services often results in services being primarily used following a crisis (Bieber et al., 2019; Kerpershoek et al., 2019; Nielsen et al., 2021).

Furthermore, limited knowledge of the availability of services may thwart access (Shea et al., 2017; Parveen et al., 2017; Bieber et al., 2019; Giebel et al., 2021b; Nielsen et al., 2021). Some services have insufficient outreach which hinders awareness, and professionals completing referrals to social care and support services are often unaware of the availability of local services (Bieber et al., 2019). The information provided following a diagnosis appears to vary (Kerpershoek et al., 2019; Giebel et al., 2021b), and identifying services often relies on the proactiveness of unpaid carers (Giebel et al., 2021b). This is concerning, as some people with dementia do not receive support from unpaid carers, and receiving informal support should not form a gateway to accessing social care and support. The signposting of services from a key contact, such as Link workers or Admiral nurses, has shown to help overcome promote the awareness of available services (Shea et al., 2017; Kerpershoek et al., 2019; Hagan, 2020).

Spanning from finding time to attend social care and support services, to travelling to care settings, service recipients may experience practical barriers to accessing services. The high demands of dementia caregiving are known, and some unpaid carers may be providing unpaid care to more than one person, and/or are in employment. Many services fail to provide safe and reliable transportation (Shea et al., 2017), and are delivered at inconvenient times (Brodaty et al., 2005; Bauer et al., 2019). Furthermore, attending services in-person may disrupt routines, and unpaid carers are often required to remind and reassure people with dementia regarding their scheduled appointments (Gately et al., 2022).

Accessing social care and support services may incur direct and indirect costs. This is likely to be influenced by the structure and financing of the health and care structure across settings (Ketchum et al., 2022), and the ability to receive financial support. In England, while the costs of some services within the social care and Third sector are means-tested, financial barriers persist (Newbronner et al., 2013; Alzheimer's Society, 2018; Kerpershoek et al., 2019) and are likely to be exacerbated as the cost-of-living increases following the pandemic (Giebel & Heath, 2023). In 2021, the UK government proposed reforms to how service recipients pay for adult social care in England and sought to introduce a cap of 86,000 GBP that an individual would spend on personal care over their lifespan (Foster, 2023). While reforms were anticipated to be implemented in 2023, these have been delayed to 2025 (Foster, 2023). Therefore, at the time of writing, in England, the upper capital limit is set at 23,250 GBP, and service recipients with income and assets valued above the threshold self-fund their social care (NHS, 2022a). It is noteworthy to highlight that some dementia-specific social care services in England are more expensive than comparable services for service recipients without dementia (Alzheimer's Society,

2018). Furthermore, accessing services in-person may engender indirect expenses, such as forfeiting working hours or costs associated with travelling (Lima et al., 2022), notably when residing in geographically marginalised areas (Bayly et al., 2020).

Fostering a person-centred approach is important to people with dementia (Arbalster & Brennan, 2022). While unpaid carers, people with dementia and dementia charities are often involved in designing services (Frost et al., 2021), many service recipients find it difficult to identify services that align with their needs and preferences (Newbronner et al., 2013; Kerpershoek et al., 2019). People living with young onset dementia or with rarer dementia subtypes (Cations et al., 2017; Giebel et al., 2021b), and people from ethnic minority groups often find services poorly tailored to their presenting needs (Parveen et al., 2017; Ketchum et al., 2022). Moreover, people with dementia have reported an overall lack of services that address their mental health needs and those of their unpaid carers (Arbalster & Brennan, 2022), which is important, as good psychological health is important living well with dementia (Clare et al., 2019).

Furthermore, several structural barriers may hinder the ability to provide person-centred care, and previous negative experiences are likely to discourage future use (Kenning et al., 2017; Stephan et al., 2018). For example, people with dementia value engaging with home care providers. However, insufficient time is allocated per home visit, and home care providers prioritise attending to service recipients' physical needs (Dalgarno et al., 2021; APPG on dementia, 2022). Some service recipients prefer working with health and social care professionals who share a similar culture and/or have the same religious affiliation (Ketchum et al., 2022), nevertheless, this is difficult to achieve due the current scarcity of providers (Kenning et al., 2017). A consistent, approachable, and adequately trained workforce is important to foster personalised and meaningful connections (Innes et al., 2014; Bauer et al., 2019; Kerpershoek et al., 2019; Dalgarno et al., 2021). However, the workforce has a high turnover rate (Skills for Care, 2022; Chapman, 2022; Foster, 2023), and many providers lack training on dementia and/or standards of best practice (Bauer et al., 2019).

### 1.3.3 Social care and support services: characterising the providers and working conditions

Social care and support services cater an array of service recipients with differing needs, living with different conditions, and it is challenging to characterise the workforce who specifically deliver services to people with dementia and unpaid carers.

The adult social care workforce predominantly consists of people who identify as women and aged between 25-54. There is a slight increase in people who identify as men working in senior management, and across all job roles (Skills for Care, 2022). Overall, the ethnicity of the workforce is mainly White. Greater diversity is observed in London, where most of the workforce come from Black, Asian, and

minority ethnic groups. Since 2013, the proportion of providers coming from a Black, Asian, or minority ethnic group working in any job role has slowly increased (Skills for Care, 2022).

Akin to the adult social care workforce, people who work in the Third sector largely identify as women and White (The National Council for voluntary Organisations [NCVO], 2021). While the workforce largely consists of people aged above 50, the number of people under 34 years has increased in recent years. Volunteers are fundamental to organisations operating within the Third sector, including those delivering dementia-specific services (Sun et al., 2021). Often comprised of older adults identifying as women (NCVO, 2022), volunteers can be defined as people

> '*…giving of time and energy… which can bring measurable benefits to the volunteer, individual beneficiaries, groups and organisations, communities, the environment and society at large. It is a choice undertaken of one's own free will and is not motivated primarily for financial gain or for a wage or salary.'* (Scottish Government, 2019, p. 4-5)

The Third sector Trends Study is a large-scale longitudinal survey that explores the landscape of the Third sector across England and Wales (Chapman, 2022). The latest survey received over six thousand responses and found that over half of organisations surveyed 'strongly agreed' they would not be able to continue operating as an organisation without volunteers. When disaggregating findings by organisation size (defined by income level), almost all micro income organisations (below 10,000 GBP) surveyed 'agreed' or 'strongly agreed' that they would not be able to continue operating as an organisation without volunteers. Compared to organisations operating in deprived and/or urban areas, organisations serving more affluent and/or in rural areas were slightly more reliant on volunteers (Chapman, 2022).

Retaining staff is a longstanding issue within the adult social care and Third sector. Overall, the adult social care workforce has a high turnover rate, notably within job roles that involve providing direct care (Skills for Care, 2022). Concerningly, the high turnover rate is coupled with challenges in recruitment and increasing demand (Skills for Care, 2022; Bottery & Mallorie, 2023; Foster et al., 2023). Organisations across the Third sector operating within the Nort East and North West of England were found to experience the greatest challeneges in staff recruitment and retention (Chapman, 2022). Furthermore, over half of Third sector organisations with an income of 5 million - 25 million GBP, reported that staff recruitment and retention has become increasingly challenging since the pandemic (Chapman, 2022).

Several reasons are likely to underpin poor workforce retention rates. Firstly, working in adult social care, notably in job roles providing direct care, is associated with low pay and many providers are employed on zero-hour contracts. While the latter may provide flexibility, it can instil financial uncertainty (Foster, 2023). Domiciliary care work remains one of the lowest paid jobs, and acknowledging that travel time, including fuel, is not always reimbursed, some providers may be

working for less than minimum wage (Foster, 2023). Secondly, limited career progression opportunities within the adult social care are likely to contribute to the high workforce turnover rate, and greater training and career development pathways are needed to promote retention (Foster, 2023). Lastly, the morale and wellbeing level of the adult social care workforce is generally low, and many have reported being on the verge of burnout (House of Lords, 2017; Foster, 2023), which is likely to contribute to high staff turnover rate.

## 1.4 Post diagnostic support services: Information Communication Technologies

ICT can be defined as a

> *'…diverse set of technological tools and resources used to transmit, store, create, share or exchange information. These technological tools and resources include computers, the Internet (websites, blogs and emails), live broadcasting technologies (radio, television and webcasting), recorded broadcasting technologies (podcasting, audio and video players, and storage devices) and telephony (fixed or mobile, satellite, visio/videoconferencing, etc.)'* (United Nations Educational, Scientific and Cultural Organization [UNESCO] Institute for Statistics, 2009, p. 120)

Several terms exist to refer to the intersections between the use of ICT and health, and the terms telemedicine and telehealth are frequently used interchangeably (WHO, 2021b). Telemedicine is defined as the delivery of remote medicine, and telehealth is often conceptualised more broadly to include the remote delivery of health and care services (WHO 2012; 2016). My work focuses on the use of ICT within the delivery of social care and support services, and therefore, can be considered within the realm of telehealth.

ICT can be considered mainstream or assistive. The term 'mainstream ICT' has no standardised definition but can be understood as ICT planned for general use, as opposed to ICT mainly for the use by people with disabilities (Institute of Medicine (US) Committee on Disability in America, 2007). Instead, the term 'assistive technology' refers to *'…products or systems that support and assist individuals with disabilities, restricted mobility or other impairments to perform functions that might otherwise be difficult or impossible*' (Medicines & Healthcare products Regulatory Agency, 2023). Examples of assistive technologies within dementia care include reminders and safety systems such as sensors (SCIE, 2019). Within my work, I conceptualised ICT as a medium to access social care and support services.

Employing ICT within service delivery may present benefits and drawbacks. The role of ICT to leverage universal health coverage, defined as '*all people have access to the health services they need, when and where they need them, without financial hardship*' (WHO, 2023c), is recognised (World Health

Assembly [WHA], 2018). Nevertheless, the use of ICT within service delivery may disenfranchise service recipients who are digitally excluded. The term 'digital divide' refers to the gap between people who have and do not have access to the internet (Hargittai, 2003; Helsper, 2021). However, as the use of ICT and internet connectivity increased within the last two decades, a dichotomous grouping may mask inequalities. Instead, thinking about how ICT is used, and possible benefits garnered may be more appropriate (Hargittai, 2003; Helsper, 2021). The Organisation for Economic Co-operation and Development (OECD) defines digital inequalities as *'... differences in material, cultural and cognitive resources required to make good use of ICT*' (OECD, 2015, p. 124). The ability to make 'good use' of ICT is likely to depend on the skills one has at disposal. Digital literacy can be defined as having '*... the knowledge and skills needed to use (or decide not to use) ICTs in ways that help…to achieve beneficial, high-quality outcomes for themselves and others now and in the future'* (Helsper, 2021, p.77).

Progress to the digitalisation of social care and support services has been thwarted by cycles of innovations that largely remained within research settings (Meiland et al., 2017; Knapp et al., 2022). However, the repurposing of commercial-off-the-shelf technology, existing and available hardware and software (National Institute of Standards and Technology [NIST], n.d.), to be employed within the delivery of support has observed greater success than designing bespoke ICT formats (Knapp et al., 2022).

Prior to the pandemic, the use of ICT within the delivery of social care and support services was somewhat limited. While some studies reported on the use of ICT by people with dementia or both members of the dyad to access social care and support services (Hattink et al., 2016; Dekker-van Weering et al., 2019; Howe et al., 2020), research largely reported on the remote delivery of services addressing the needs of unpaid carers (e.g., Hopwood et al., 2018; Etxeberria et al., 2020; Leng et al., 2020). However, an umbrella review (Morgan et al., 2022) evaluating the effectiveness of internet-based interventions addressed to unpaid carers found considerable overlap among studies included within reviews, which suggests a limited number of empirical studies. Nevertheless, the available evidence suggests that using ICT to access support remotely may benefit some unpaid carers (Morgan et al., 2022). Two systematic reviews and metanalyses of randomised control trials (Leng et al., 2020) and/or studies with quasi-experimental designs (Etxeberria et al., 2020) suggest that internet-based interventions may positively impact unpaid carers' psychological wellbeing. Interventions included psychoeducation, training in managing psychological wellbeing, and receiving support from professional and/or other unpaid carers (Etxeberria et al., 2020). Overall, multicomponent interventions often yielded more favourable results (Etxeberria et al., 2020), and Leng and colleagues (2020) found evidence to suggest that benefits offered by internet-based interventions may extend beyond unpaid carers, to positively impact on the quality of life and neuropsychiatric symptoms of people with dementia. Nevertheless, these systematic reviews (Etxeberria et al., 2020; Leng et al., 2020) synthesised

available evidence relating to remotely delivered social care and support services that solely addressed unpaid carers' needs. Acknowledging the increased use of ICT within service delivery, it will be important to understand how social care and support services addressing the needs of people with dementia have been delivered remotely.

### 1.4.1 COVID-19 pandemic

The COVID-19 outbreak was characterised by an alarming transmission rate, severe symptomology, and mortality. The outbreak was declared a pandemic by the WHO (2020) on the 11th of March 2020, and countries within the UK established stringent public health measures (Institute for Governmental Analysis, 2021; Scottish Parliament Information Centre [SPICe], 2022; Welsh Parliament, 2021, 2022). Either directly due to an increased risk of acquiring a COVID-19 infection and experiencing worse outcomes (Wang et al., 2020), or indirectly, due to living under lockdown, people with dementia were disproportionally affected by the pandemic. The pandemic accelerated the deterioration of dementia symptoms, curtailed physical health levels, and negatively impacted the mental and social health of people with dementia (Giebel et al., 2022a). Likewise, unpaid carers were significantly impacted by the pandemic. Increased levels of feelings of social isolation, caregiving burden and worsening wellbeing levels were reported by unpaid carers (Giebel et al., 2022b). The lack of, or limited access, to social care and support services during the pandemic is thought to have contributed to people with dementia and unpaid carers' overall reduced wellbeing (Giebel et al., 2022a; 2022b), which is likely to engender long-term negative implications.

#### 1.4.1.1 Service availability

The COVID-19 public health measures invoked significant changes to how social care and support services operated, and catalysed, at least temporarily, the reliance on the use of ICT. The widespread withdrawal of social care and support services characterised the early stages of the pandemic (Cousins et al., 2021; Giebel et al., 2022a; 2022b). Although relatively few (Giebel et al., 2020b; Morton et al., 2023), some organisations adapted to deliver services remotely. These included establishing welfare calls (O'Rourke et al., 2021; Wheatley et al., 2022) and some services, such as cognitive stimulation therapy (Fisher et al., 2023; Peri et al., 2023), peer support groups (Masoud et al., 2021; Talbot & Briggs, 2022; Wheatley et al., 2022; Gerritzen et al., 2023a; 2023b; McLoughlin et al., 2023) and exercise health sessions (DiLorito et al., 2021; Park et al., 2022, 2023) reactively shifted to remote mediums, often by employing videoconferencing software. To my knowledge, no study has yet to longitudinally explore how an array of social care and support organisations delivered services at different timepoints across the pandemic. Mapping the availability of services and gaining an understanding of how service delivery adapted during the pandemic forms important considerations to assist the preparedness of service delivery to future public health crises.

Moreover, the availability and readiness of organisations' ICT infrastructure is likely to have influenced whether, and if so, how promptly, service delivery adapted to remote media, which may result in varied service provision across areas. While not restricted to dementia services, limited resources are likely to curtail the investment into organisations' ICT infrastructure (Blake et al., 2021; Charity Digital Skills, 2023), and are often felt more acutely by smaller organisations (Charity Digital Skills, 2023). Furthermore, while implementing a younger onset dementia telehealth service, Brown and colleagues (2023) found that, compared to organisations in urban areas, organisations in rural areas had access to lower quality and less reliable ICT devices. Whether the readiness and/or quality of ICT infrastructures differed across social care and support organisations, and if so, whether it influenced how service delivery adapted, would benefit from future investigation.

Furthermore, social care and support providers' digital skill sets are likely to vary (Meiland et al., 2017; Brown et al., 2023; Cowley et al., 2023; Fisher et al., 2023). Fischer and colleagues surveyed memory clinics across the UK to understand the provision of virtual cognitive stimulation therapy during the pandemic. Thirty-three memory clinics participated and almost half did not deliver cognitive stimulation therapy remotely. While reasons were numerous, some memory clinic providers reported that their limited ICT skills combined with insufficient opportunities to receive technological support resulted in the avoidance of the digital route. Digital skills may differ across job roles (Blake et al., 2021), influenced by the rurality of areas organisations serve (Brown et al., 2023) and the opportunity to receive digital training. The latter is likely to be influenced by the sector social care and support providers operate in. Although not restricted to dementia services, the provision of digital training within Third sector organisations is generally limited, especially within smaller organisations (Chapman, 2022). Little is known about social care and support providers' digital skillset and whether, if required, providers undertook measures to overcome their limited skills to deliver services remotely during the pandemic.

In addition to the reliance on an adequate digital skillset, delivering services remotely engendered significant changes to working approaches. This included the lengthy task of adapting the content of services to accommodate remote formats (Fischer et al., 2023) and identifying how to facilitate engagement with service recipients remotely (DiLorito et al., 2021; Cowley et al., 2023). Therapists in Cowley and colleagues' (2023) study reported that creativity was indispensable while tailoring the remote delivery of an exercise health intervention to different service recipients. Documenting and disseminating the lessons learned while adapting the delivery a breadth of social care and support services remotely may help to identify how to optimise the use of ICT within future service delivery.

Lastly, acknowledging the extent to which people with dementia and unpaid carers were impacted by the pandemic (Giebel et al., 2022a; 2022b), the content of social care and support services may have adapted to reflect service recipients' presenting needs. For example, post-diagnostic support providers

in Wheatley and colleagues' (2022) study and exercise therapists in Cowley and colleagues' (2023) study reported that service recipients presented with increased emotional support needs. Exploring wheather, and if so, how the content of an array of social care and support services adapted during the pandemic will be invaluable to assist the preparedness of service delivery amidst future public health crises.

#### 1.4.1.2 Barriers and facilitators in access and utilisation

Access to suitable ICT devices forms a prerequisite to access remote social care and support services. Over the past decade, the proportion of people older than 65 years who have access to digital technologies has significantly increased (Pew Research, 2022) and the number of people over 75 years using the internet has almost doubled (Office for National Statistics [ONS], 2021). However, older adults are vulnerable to digital exclusion (Ofcom, 2022), and many do not have access to adequate ICT devices and/or internet connectivity. Indeed, while appointments by videoconferencing software were offered during the pandemic, the main reason for attending a memory clinic appointments in-person during the pandemic was due to service recipients' lacking a suitable ICT device and/or internet connectivity (Collins et al., 2021). Of the service recipients who attended a memory clinic appointment in person, 67% did not own a smartphone, laptop or tablet device (Collins et al., 2021).

A recent systematic review (Yi et al., 2021) synthesised studies reporting on dementia-related telemedicine visits prior to the pandemic, and found that, to bridge service recipients' limited access to ICT devices, many studies provided the required equipment to participate. Understanding how possible barriers in access to ICT devices have been, or attempted to be, addressed during the pandemic may help to identify sustainable approaches to avoid leaving behind digitally excluded people with dementia and unpaid carers amidst future public health crises. Furthermore, Yi and colleagues' (2021) systematic review synthesised studies reporting on telemedicine visits, which included performing cognitive capacity tests and forming a diagnosis at a distance. My work focuses on social care and support services accessed following a diagnosis. In addition, the systematic review included studies that reported on people on mild cognitive impairments and solely focused on interventions delivered synchronously by videoconferencing software (Yi et al., 2021). A diagnosis of mild cognitive impairment and dementia is different, and, compared to people with mild Alzheimer's Disease, people with mild cognitive impairment were found to experience fewer challenges while navigating everyday technology (Malinowsky et al., 2010). Thus, to complement Yi and colleagues' (2021) systematic review, it will be important to synthesise studies reporting on how ICT has been used, in any format, to access social care and support services addressing the needs of people living with dementia.

Furthermore, access to suitable ICT devices needs to be complemented by sufficient digital skills. Some people with dementia were able to access online support by videoconferencing software (Tablot & Briggs, 2022; Gerritzen et al., 2023a; 2023b) and participate in exercise health interventions remotely

(DiLorito, 2021; Park et al., 2022; 2023). Nevertheless, not everyone disposed of adequate digital skills, and the inability to use ICT devices formed a reason to declining memory clinics appointments by videoconferencing software (Collins et al., 2021). The likelihood to experiencing challenges while navigating videoconferencing software was found to be increased in people with dementia with a lower educational attainment (Yook & Paek, 2023) and the severity of dementia symptoms is likely to engender additional problems while using ICT (Gerritzen et al., 2023a; 2023b).

However, the opportunity to receive technological support by unpaid carers facilitated the access of people with dementia to remote social care and support services (Vellani et al., 2022; 2023; Peri et al., 2023). Nevertheless, not all unpaid carers may be able to provide technological assistance, and age is likely to be an important factor. Indeed, successful medical appointments by videoconferencing software frequently occurred while people with cognitive impairments were accompanied by younger unpaid carers, including children and grandchildren (Arighi et al., 2021). Nonetheless, ongoing technological support and training provided by social care and support providers bridged some unpaid carers' limited skillset, which consequently, increased people with dementia access to virtual cognitive stimulation therapy (Peri et al., 2023).

Furthermore, accessing services remotely, notably by videoconferencing software, compelled substantial changes in how service recipients engaged with social care and support services. While the shift was welcomed by some people with dementia and unpaid carers, the use of ICT was not suitable for everyone (Cousins et al., 2021; Evans et al., 2021; Giebel et al., 2021d; Masoud et al., 2021; Talbot & Briggs, 2022; Gerritzen et al., 2023a; 2023b). Accessing services remotely may offer convenience (McLoughlin et al., 2023), notably for service recipients residing is geographically marginalised areas (Bayly et al., 2020). However, some dementia-related symptoms, including behavioural problems (Masoud et al., 2021) and short attention spans (Park et al., 2023), were found to hamper the ability of some people to optimally engage with social care and support services remotely. Furthermore, the presence of comorbidities, including visual impairments, which are common in people with dementia (Zhang et al., 2023), formed additional barriers to engaging with social care and support services remotely (Giebel et al., 2021d; Gerritzen et al., 2023a). Cognisant that access to social care and support prior the pandemic was hamstrung by unequal and persisting barriers (see section 1.4.3), the use of ICT within service delivery has the potential to help overcome some barriers for some service recipients. Nevertheless, the use of ICT may equally hinder access and widen inequalities. Thus, to identify types of remote services that are acceptable and for whom, it will be important to systematically synthesise the evidence relating to people with dementia and unpaid carers' views on accessing support remotely.

### 1.4.2 Rationale for the current Ph.D. project

The current evidence-base has largely focused on how service delivery adapted from the service recipients' perspective (e.g., Masoud et al., 2021; Giebel et al., 2021c; 2021d; Cousins et al., 2022;

Gerritzen et al., 2023a; 2023b; Park et al., 2022; 2023; Vellani et al., 2022; 2023) and studies reporting on the use of ICT by people with dementia or both members of the dyad to access support, and their views on accessing support remotely, has yet to be systematically reviewed. Nevertheless, some studies explored how service delivery adapted from the service providers' perspective. While some focused on the delivery of post-diagnostic support services (e.g., Chueng & Peri, 2020; DiLorito et al., 2021; Cowley et al., 2023; Fischer et al., 2023), to my knowledge, few report on the delivery of social care and support services (Evans et al., 2021; Wheatley et al., 2022; Dai & Moffatt, 2023; Morton et al., 2023). These are briefly summarised below.

Firstly, to gain an understanding into how services adapted during the pandemic, Wheatley and colleagues (2022) interviewed post-diagnostic support providers. While some participants worked within the Third sector and provide insights into the delivery of social care and support services, most participants worked within the primary or secondary health care. Although the study provides valuable insights, the differences in sectors, in terms of priorities, scope of service delivered and available resources, need to be acknowledged, and evidence focusing on the delivery of social care and support services adaptation is merited. Secondly, a study by Dai and Moffatt (2023) reports on the transition of a social programme from in-person to remote by videoconferencing software during the pandemic. However, only two facilitators were interviewed regarding the remote delivery of the programme. Thirdly, a study (Evans et al., 2021; Morton et al., 2023) explored how meeting centres in four case study sites in the UK adapted at different timepoints during the pandemic. Meeting centres are '*…local resource, operating out of ordinary community buildings, that offers on-going warm and friendly expert support to people with mild to moderate dementia and their families.'* (University of Worcester, n.d.). While meeting centres deliver different services including social activities and peer support, these are implemented according to the Meeting Centre Model (University of Worcester, 2022). While some social care and support services are likely to embody elements integral to the Meeting Centre Model (University of Worcester, 2022), the model may not be reflective of all social care and support services, notably those established more informally, by people with dementia or unpaid carers, or those operating within the social care sector.

Therefore, to complement and expand the existing evidence base, further empirical research is required to understand how a breadth of social care and support services adapted during the pandemic from the providers' perspective. Exploring social care and support providers' experiences of delivering services during the pandemic may help to reduce inequalities in access during current and future service delivery.

As the pandemic wanes, it is likely that the use of ICT within the delivery of social care and support services will continue to feature, in some form. Innovations to service delivery are important to the sustainability of services and digitalising aspects of service delivery aligns with governmental initiatives (DHSC 2021b; 2023). Understanding how social care and support providers delivered services during

the pandemic may help to identify how to capitalise on possible benefits offered by ICT, while avoiding widening inequalities in access.

Moreover, the occurrence of pandemics (UNESCO, 2020) and other public health crisis such as extreme weather conditions (European Environment Agency [EEA], 2023) are expected to increase, it is important that service delivery builds resiliency to future emergency situations. Resilience is a multi-factorial concept, and the WHO defines resilient health systems as *'... the ability to prepare for, manage and learn from shocks, absorb information, adapt and transform*' (WHO, 2022, p.31). As part of preparing for future public health crises, it is important to develop capacities to promptly adapt delivery methods to reduce service disruption. Exploring and documenting lessons learned while adapting the delivery of social care and support services during the COVID-19 pandemic may help the preparedness of service delivery amidst future public health crises.

## 1.5 Research Aims and Outline

Employing a mixed-methods approach, my Ph.D. project sought to explore the barriers and facilitators to engaging with community-based dementia-related social care and support services during the pandemic. My research aim was guided by the following objectives:

1. To understand how the delivery of community-based social care and support services adapted, and to map out the availability of services across the UK during the pandemic.
2. To explore the facilitators and barriers to delivering and utilising community-based social care and support services during the pandemic.
3. To recommend strategies to possibly overcome barriers that lead to inequalities in access and utilisation.

### 1.5.1 Overview of my Ph.D. structure

To address my Ph.D. project's aim and objectives, I conducted a systematic review, a quantitative longitudinal survey, and qualitative semi-structured interviews. My thesis consists of six chapters and is prepared in a 'thesis by publication' format, with two chapters published and one submitted to a journal. The format was chosen as my research topic is timely and is relevant to the current delivery of social care and support services.

The **first** chapter outlines the background and rationale to undertaking my research. The **second** chapter presents the findings from my systematic review that sought to understand how ICT has been used to access post-diagnostic support and explored service recipients' views on accessing support remotely. The **third** chapter details the philosophical stance adopted, the mixed method study design undertaken and patient and public involvement. The **fourth** chapter presents the findings of the quantitative longitudinal survey that compared the service delivery methods and ICT formats used to deliver community-based social care and support services prior to and during the pandemic in the UK. The

**fifth** chapter reports on the findings of the qualitative semi-structured interviews that explored the experiences of delivering and accessing community-based social care and support services during the pandemic in the UK. The **sixth** chapter critically discusses findings from all my studies, and highlights implications for policy, practice, and future research.

# CHAPTER 2: EXPLORING THE VIEWS AND THE USE OF INFORMATION COMMUNICATION TECHNOLOGIES TO ACCESS POST-DIAGNOSTIC SUPPORT BY PEOPLE LIVING WITH DEMENTIA AND UNPAID CARERS: A SYSTEMATIC REVIEW

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This chapter presents the findings of my systematic review, which was published in *Aging and Mental Health* in 2023 as listed below:

Caprioli, T., Mason, S., Tetlow, H., Reilly, S., & Giebel, C. (2023b). Exploring the views and the use of information and communication technologies to access post-diagnostic support by people with dementia and unpaid carers: a systematic review. *Aging and Mental Health*, *27*(12), 2329-2345. https://doi.org/10.1080/13607863.2023.2196246

**Author contributions:** TC: Conception, generated the search strategy, screening of the citations (stage 1 and 2), extracted the data and appraised the methodological quality of included studies, interpretation of results, drafting and writing the manuscript. CG and SR: Offered contributions to the conception of the study design, interpretation of results, editing and reviewing the manuscript. SM: Offered contributions to the interpretation of results, editing and reviewing the manuscript. HT: Offered contributions to the interpretation of results, editing and reviewing the manuscript.

The searches were updated in July 2023 prior to thesis submission, and the findings are reported separately.

## 2.1 Abstract

**Objectives:** This systematic review examined how information communication technologies (ICT) has been used to access remote post-diagnostic support that address the needs people with dementia, or those of dyad, and explored service recipients' views on accessing support remotely.

**Method:** Concepts relating to dementia and ICT were searched across six databases (PsychInfo, PubMed, Cochrane Library, CINAHL, Social Care Online, and Web of Science) in March 2021 and updated in March 2022. Studies published from 1990 and written in English, German or French were considered for inclusion. Methodological quality was appraised using the Hawker quality assessment tool and reporting structured according to PRISMA guidelines.

**Results:** The search yielded 8,485 citations. Following the removal of duplicates and screening processes, 18 papers reporting on 17 studies were included. Studies described a range of post-diagnostic support, including medical follow-ups and therapeutic sessions, and were often delivered on a one-to-one basis via videoconferencing software. Whilst often relying on assistance from unpaid carers, people with dementia directly engaged with ICT to access post-diagnostic support in 13 studies. Accessing post-diagnostic support remotely appears feasible, nevertheless, service recipients' views were mixed. Access was frequently facilitated by supplying devices and providing ongoing technological support.

**Conclusions:** Accessing post-diagnostic support remotely is likely to benefit some service recipients, however, to prevent widening inequalities in access, services within the current hybrid landscape need to accommodate people who are digitally excluded. Future research should capture the support provided by unpaid carers to facilitate the engagement of people with dementia to remote post-diagnostic support.

**Keywords:** dementia; post-diagnostic support; ICT; remote service delivery

## 2.2 Background

Globally, an estimated 55 million people are currently living with dementia and projections suggest this will increase to 139 million by 2050 (WHO, 2021a). Accessing support is paramount to living well with dementia, nevertheless, challenged with increasing demand and coupled with finite resources, the ability of strained health and care systems to sustainably provide equitable, responsive, and timely post-diagnostic support, is of mounting concern.

Following a dementia diagnosis, post-diagnostic support can be defined as services delivered to cater for the changing care and support needs experienced by people with dementia and unpaid carers throughout the disease trajectory (Prince et al., 2016). The prompt identification and the holistic management of needs are key components to good post-diagnostic support (Bamford et al., 2021). Dementia care pathways differ across regions and countries. In the UK, the provision of post-diagnostic support services often involves a mixture of providers (private, public and voluntary) operating within three sectors (primary and secondary healthcare, social care and Third sector), across various care settings. Sectors differ in funding and priorities. Post-diagnostic support within the healthcare sector may encompass services such as dementia medical reviews and psychological support, the social care sector may provide day care centres, respite care and carer's assessments, and the Third sector may include centres, befriending services, and peer support groups (Frost et al., 2021).

Post-diagnostic support offers many potential benefits which extend from facilitating the initial adjustment phase, to dying well with dementia. Benefits include encouraging independence and positively impacting the social health of people with dementia (Kelly & Innes, 2016; Willis et al., 2018; Giebel et al., 2020a).

Post-diagnostic support may alleviate the caregiving burden and help to address feelings of depression and anxiety within unpaid carers (Vandpeitte et al., 2016a; Carter et al., 2020). The usage of post-diagnostic support services should align with individual preferences whilst reflecting service recipients' evolving needs. Nevertheless, the service provision landscape is fragmented and access remains inequitably laden with potential hurdles. Factors contributing to the unmet needs include poor signposting of services, rural residency, and financial and/or time constraints (Bieber et al., 2019; Bayly et al., 2020; Giebel et al., 2021a; Watson et al., 2021). Whilst some barriers to accessing post-diagnostic support may span different contexts (Giebel et al., 2022a; Ketchum et al., 2022) many are likely to require setting-specific approaches.

The potential role of information communication technology (ICT) in achieving universal health coverage is recognised, and may, for example, increase service recipients' access to services by overcoming barriers associated with rural residency (Bayly et al., 2020; Sekhon et al., 2021). Nevertheless, the adoption of ICT in practice has remained somewhat limited until the COVID-19 pandemic provoked, at least temporarily, a shift to remote service delivery.

Overall, research has largely focused on accessing remote services involved in forming a dementia diagnosis (Barth et al., 2018; Haralambous et al., 2021), assistive technology (Pappada et al., 2021), and post-diagnostic support which solely addresses the needs of unpaid carers (Etxeberria et al., 2020; Leng et al., 2020). Prior to the pandemic, some studies reported on remote post-diagnostic support that addressed the needs of people with dementia or those of the dyad. These included medical follow-ups (Azad et al., 2012), and non-pharmacological services such as exercise health (Alonso et al., 2020; Dekker-van Weering et al., 2019) and information provision (Hattink et al., 2016; Howe et al., 2020). Whilst the support accessed was valued by both members of the dyad, unpaid carers often became the primary users and navigated the technology (Hattink et al., 2016; Howe et al., 2020). The impact following the curtailment of post-diagnostic support provision during the pandemic is concerning (Giebel et al., 2020b; 2020c; 2022a) and is likely to entail long-term implications. As some services shifted to remote service provision, studies reported on post-diagnostic support accessed through innovative mediums, including remote memory clinics (Benaque et al., 2020) exercise health interventions (DiLorito et al., 2021) and singing groups (Lee et al., 2020). Although many service recipients valued accessing post-diagnostic support remotely during the pandemic, the support was sometimes delivered at inconvenient times, and was perceived as being unable to replicate the benefits offered by face-to-face contact.

Despite a growing evidence base exploring the feasibility and acceptability of accessing post-diagnostic support remotely, both prior to and during the ongoing pandemic, these studies have yet to be systematically reviewed. Thus, this systematic review sought to explore the use of ICT to access post-diagnostic support services that address the needs of people with dementia or those of the dyad and their accompanying views on accessing dementia-related post-diagnostic support services remotely. Specifically, this systematic review addressed the following interlinked review questions; '*How has ICT been used to access post-diagnostic support that address the needs of people with dementia and unpaid carers? What are the views of people with dementia and unpaid carers on accessing dementia-related post-diagnostic support services remotely*?' Findings may provide insights and assist policymakers or service providers when planning and designing prospective remote dementia-related post-diagnostic support services.

## 2.3 Methods

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed when conducting and reporting this systematic review (Liberati et al., 2009). The review protocol was registered on PROSPERO International prospective register of systematic reviews (ID = CRD42021233776). The completed PRISMA checklist (Page et al., 2021) can be found in **Appendix V.**

### 2.3.1 Search strategy

#### 2.3.1.1 Development of search strategy

The sensitivity of a search relates to the number of potentially relevant references and the precision refers to the number of definitively relevant references obtained (University of Michigan Library, 2023) Balancing the sensitivity and precision ensures a comprehensive yet manageable number of references. The Setting, Population, Intervention, Comparison and Evaluation (SPICE) tool (Booth, 2006) was employed as it was deemed most suitable to my review questions. To identify search terms, terms employed within the titles or abstracts of potentially relevant studies were recorded, and the use of a thesaurus maximised the number of synonyms obtained. **Table 2** depicts the initial search terms. Suitable databases were identified by identifying databases searched in previous relevant systematic reviews (e.g., Vandepitte et al., 2016a; Hopwood et al., 2018; Leng et al., 2020) and by using the University of Liverpool's 'Discovery' tool. Six databases were selected (APA Psych Info, PubMed, Cochrane Library, CINHAL Plus, Social Care Online and Web of Science). Some databases allowed for controlled searches, and the most suitable subject headings were identified in each database.

**Table 2** Initial search terms

| SPICE category | Definition | Search terms |
|---|---|---|
| Population | People with dementia and unpaid carers | Dement*; Alzheimer*; "mild cognitive impairment" MCI |
| Intervention | Use of ICT to access remote post-diagnostic support | Tele*; Technolog*; Online; Internet; Electronic; Computer*; Digital*; "E Health"; Ehealth; App*; Mobile; Videoconference*; Web*; ICT; "Information Communication Technologies"; Gerontechnology; Virtual; Remote |
| Evaluation | Access and views on accessing support remotely | "Post diagnostic support"; "social support"; "social care"; Communit*; Outreach; "day cent*"; "day service"; Outpatient; Ambulatory; "home based"; Befriending; "peer support"; Respite; Psychoeducational; Psychosocial |

Using Boolean operators, the initial search terms (**Table 2**) were piloted and searched within titles and abstracts across references within PubMed and APA PsychInfo. The databases were selected for the pilot as it was anticipated that these would hold a sizeable number of relevant references. A controlled search was conducted where available, and subject headings were adjusted accordingly. A search restriction was applied to exclude studies published prior to 1990 and to include studies written in German, French and English. The number of references obtained in the first pilot can found in **Appendix A**. The references retrieved were not overly relevant to the review questions, and a University of Liverpool librarian was consulted to consolidate the search strategy.

At the time of conducting the first pilot, few studies employed the term 'post-diagnostic support' within their titles or abstracts. Due to the broad array of services included within the term post-diagnostic

support, and to avoid biasing the references retrieved, the ‘evaluation’ SPICE category of the search strategy was removed. To refine the search strategy, the search terms within the ‘intervention’ SPICE category were individually searched with terms within the ‘population’ category. Several changes to the search strategy were made. For example, while the search terms ‘App*’ and ‘technolog*’ resulted in a substantial number of references, these were beyond the scope of my review questions. Furthermore, the key term ‘tele*’ was employed to capture the terms ‘telehealth’ and ‘telemedicine’, however, it retrieved a considerable number of non-relevant references. Thus, the search terms ‘telehealth’ and ‘telemedicine’ were written in full.

The search terms were amended and piloted across the titles and abstracts of references within the six databases. The second pilot ensured that the search strategy was sensitive and sufficiently precise to answer my review questions. **Table 3** depicts the final search terms used.

**Table 3** Final search terms

| SPICE category | Definition | Search terms |
|---|---|---|
| Population | People with dementia and unpaid carers | Dement*; Alzheimer*; “mild cognitive impairment” MCI |
| Intervention | Use of ICT to access remote post-diagnostic support | "e health"; "information technology"; "technology based"; "web based"; eHealth; internet; online; telehealth; telemedicine |

#### 2.3.1.2 Searches conducted

The six databases were searched (APA Psych Info, PubMed, Cochrane Library, CINHAL Plus, Social Care Online and Web of Science) in March 2021 and updated in March 2022. Furthermore, the searches were updated prior to thesis submission, in July 2023. To complement the data-base searches, additional searches were conducted. References of included studies were screened and, Google scholar was used to track the citations of included studies (Aveyard et al., 2016).

### 2.3.2 Eligibility criteria

Post-diagnostic support was defined as all services delivered following a dementia diagnosis to cater for the changing care and support needs of people with dementia and unpaid carers and informal carers during the disease trajectory, until end of life (Prince et al., 2016). **Table 4** details the inclusion and exclusion criteria. Eligible studies reported on the use of ICT access dementia-related remote post-diagnostic support that addressed the needs of people with dementia and/or the dyad. Studies focusing on community dwelling people with dementia and/or unpaid carers and satisfying the inclusion criteria outlined in were included. Studies reporting on individuals not living with dementia or people with dementia not residing in community were excluded. Studies frequently report, notably during the pandemic, on participants who identify or self-report as living or caring for someone with dementia, without confirming the diagnosis (e.g., Giebel et al., 2020b; Talbot & Briggs, 2022). Thus, to draw

conclusions from a wider pool of evidence, confirming the dementia diagnosis of the participants did not form a requirement to be considered for inclusion in our review.

**Table 4** Inclusion and exclusion criteria

| | **Inclusion criteria** | **Exclusion criteria** |
|---|---|---|
| 1 | Empirical studies with either qualitative, quantitative or mixed-method study designs. | Service proposals, study protocols, guidelines, opinion pieces or case studies / reports that are based on anecdotal evidence |
| 2 | Studies written in English, German or French and published between 1990-2022. | Studies written in a language other than English, German or French. Published prior 1990. |
| 3 | Studies describing at least one type of ICT used as a medium to access post-diagnostic support that either address the needs of people with dementia or those of the dyad, and reporting on one or both of the following, (1) characteristics of the post-diagnosis support service accessed; (2) the views of people with dementia (or those reported by a proxy) and unpaid carers on accessing dementia-related post-diagnostic support services remotely | Studies investigating the use of ICT as a medium to access non-dementia related post-diagnostic support, or post-diagnostic support that solely address the needs of the unpaid carers or studies that do not report on one of the following criteria: a) characteristics of the post-diagnosis support intervention accessed; b) the views of people with dementia (or those reported by a proxy) and unpaid carers on accessing dementia-related post-diagnostic support services remotely |
| 4 | Participant lives with dementia and resides in the community (includes supportive / assistive living accommodation). Study participants with a dementia diagnosis, probable diagnosis and those identifying as living with dementia will be included. Participant is an unpaid carer to someone living with dementia. Studies involving participants from one or both study population will be considered. Participants living with dementia and unpaid carers did not have to be living together. | Participant does not live with dementia (e.g., mild cognitive impairment diagnosis/ subjective cognitive impairment) or does not reside in the community (e.g., nursing / care home). |
| 6 | If a study has mixed study samples or is multicomponent, it will only be considered for inclusion if the findings relating to the information of interest are reported separately in the result section. | Studies which do not report on the information of interest separately in the result section |

### 2.3.3 Selection procedure

I conducted all database searches. The PRISMA guidelines (Liberati et al., 2009) were followed when reporting this systematic review. I read all titles and abstracts of relevant titles and studies were excluded if they did not satisfy the inclusion criteria. For studies that appeared to satisfy the inclusion criteria, the study was read in full. If there was any uncertainty relating to the suitability of a study for inclusion, it was discussed amongst the review team members and included if in unanimous agreement.

### 2.3.4 Quality appraisal

Critical appraisal can be defined as *'... the process of carefully and systematically examining research to judge its trustworthiness, and its value and relevance in a particular context*' (Burls, 2009, p.1). Studies were not excluded based on their methodological quality. Instead, the process assisted me to identify and assess any methodological biases that may influence findings of included studies, and, subsequently, conclusions drawn by my systematic review (Petticrew & Roberts, 2005). Evidence

included in my systematic review stemmed from quantitative, qualitative or mixed method empirical studies. Multiple critical appraisal tools exist for different study designs (Crowe & Sheppard, 2011). I decided to use a tool that accommodates to different study designs rather than using different tools for each study design. Pragmatism and time efficiency largely underpinned the decision (Pluye, 2015). Available tools to appraise the methodological quality of disparate research paradigms include the checklist developed by Hawker and colleagues (Hawker et al., 2002) and the Mixed Method Appraisal Tool (MMAT) (Pluye et al., 2009; Hong et al., 2018).

The Hawker et al., tool (Hawker et al., 2002) consists of nine components to appraise the methodology quality of studies by examining the introduction and aims; methodology; sampling; data analysis; ethics and bias; results; transferability and generalisability of findings; and the implications and usefulness of findings to policy and practice. Each component is rated according to a four-point Likert scale (good, fair, poor and very poor) and numerical value can be attributed to each scale (overall score range: 9-36). An overall score of 36 indicating studies with rigorous methodologies. The MMAT (Pluye et al., 2009; Hong et al., 2018) consists of two screening questions (clarity of research questions and whether the data collection methods enable the research questions to be answered) and five questions tailored to each study design. Questions include the relevance of study design, sampling and sample sizes and adequate interpretation of findings. Each question is rated 'yes', 'no' and 'don't know'. Scoring each study with a numerical value is discouraged.

To decide which tool to use, I identified three studies with differing study designs (qualitative, quantitative and mixed method) that were likely of being included in my systematic review, and critically appraised their methodological quality using both tools. Overall, I found the Hawker et al., (Hawker et al., 2002) tool easier to use. Specifically, I found the questions relating to mixed method study designs within the MMAT (Pluye et al., 2009; Hong et al., 2018) challenging to answer. Following discussions with my supervisory team, I decided to employ the Hawker et al., tool (Hawker et al., 2002). Once studies included in the review were identified, I appraised the methodological quality of all included studies, and any uncertainties were discussed amongst the supervisory team.

### 2.3.5 Data extraction and analysis

A bespoke data extraction form was devised to collect information on the following elements: country of origin, year of publication, study objectives, design, sample, data collection, type of ICT used, characteristics of the post-diagnostic support accessed and/or the views of accessing remote dementia-related post-diagnostic support. I piloted the data extraction form by extracting the data from two studies that were likely to be included in the systematic review. Piloting the form ensured that it extracted the data required to answer my review questions. The form was subsequently amended and shared amongst the supervisory team. Following the completion of the searches and screening, I extracted the data from all included studies.

A meta-analysis was not feasible due to the heterogeneity of the included studies in terms of study designs employed and types of post-diagnostic support described. Therefore, following the guidance developed by the Economic and Social Research Council (ESRC) (Popay et al., 2006), the results were narratively synthesised and presented in a tabular format. A narrative synthesis is an *'... approach to the systematic review and synthesis of findings from multiple studies that relies primarily on the use of words and text to summarise and explain the findings of the synthesis*' (Popay et al., 2006, p.5). Data was presented in textual descriptions, tables and clustered within groups.

## 2.4 Results

This section discusses the findings from the initial searches (March 2021 and March 2022). The results of the included studies retrieved following the updated searches (July 2023) can be found in **Appendix B.**

The initial search yielded 8,485 citations. Following the removal of duplicates and screening the titles and abstracts (Stage 1), a total of 56 studies were retrieved. Subsequent to full-text screening (Stage 2), a total of 18 papers reporting on 17 studies were included (**Figure 6**).

### 2.4.1 Study characteristics

Nine studies employed a quantitative study design (Chodosh et al., 2015; Kim et al., 2017; Dial et al., 2019; Possin et al., 2019; Ptomey et al., 2019; Capozzo et al., 2020; Laver et al., 2020; Moo et al., 2020; Panerai et al., 2021), five employed a qualitative study design (Killin et al., 2018; Giebel et al., 2021d; Masoud et al., 2021; O'Rourke et al., 2021; Cousins et al., 2022) and three employed a mixed-methods approach (Dal Bello-Haas, 2014; Rogalski et al., 2016; Gately et al., 2020a) (**Table 5**). Research emerged from six countries, including the USA, UK and Italy, and six studies included a comparative or control element (Chodosh et al., 2015; Kim et al., 2017; Possin et al., 2019; Laver et al., 2020; Moo et al., 2020). Accessing remote post-diagnostic support during the COVID-19 pandemic was explored in six studies (Capozzo et al., 2020; Giebel et al., 2021d; Masoud et al., 2021; O'Rourke et al., 2021; Panerai et al., 2021; Cousins et al., 2022;) and one study explored accessing remote post-diagnostic support in people from marginalised groups (Chodosh et al., 2015).

A dementia diagnosis formed a requirement in twelve studies (Dal Bello-Haas., et al., 2014; Chodosh et al., 2015; Rogalski et al., 2016; Killin et al., 2018; Dial et al., 2019; Possin et al., 2019; Ptomey et al., 2019; Capozzo et al., 2020; Moo et al., 2020; O'Rourke et al., 2021; Panerai et al., 2021; Cousins et al., 2022). Participants with a dementia diagnoses, a probable diagnosis or a Mini-Mental State Examination score below 24 was eligible to participate in Laver et al., 2019's study. The participation or presence of unpaid carers, alongside the person with dementia, formed a requirement in four studies (Killin et al., 2018; Possin et al., 2019; Ptomey et al., 2019; Laver et al., 2020) and encouraged in two (Rogalski et al., 2016; O'Rourke et al., 2021). Access to wireless internet was a requirement in one

study (Ptomey et al., 2019) and basic computer skills was a prerequisite in another (Gately et al., 2020a). Whilst not explicitly part of the inclusion criteria, Rogalski et al (2016) briefly screened participants' technology skills. People visual and/or hearing impairments were excluded from Dial et al (2019)'s study.

All included studies were of good methodological quality, with scores ranging between 33-36 points, from a possible maximum of 36 points (**Table 6**).

### 2.4.2 Types of remote post-diagnostic support accessed

Studies described a range of remote post-diagnostic support which addressed the needs of people with dementia or of the dyad. People with dementia or both members of the dyad directly engaged with the ICT to access remote post-diagnostic support in thirteen studies (Dal Bello-Haas et al., 2014; Kim et al., 2017; Killin et al., 2018; Rogalski et al., 2016; Dial et al., 2019; Ptomey et al., 2019; Giebel et al., 2021d; Moo et al., 2020; Capozzo et al., 2020; Masoud et al., 2021; O'Rourke et al., 2021; Panerai et al., 2021; Cousins et al., 2022) and four studies reported on support accessed by the unpaid carer (Chodosh et al., 2015; Possin et al., 2019; Laver et al., 2020; Gately et al., 2020a) (**Table 7**).

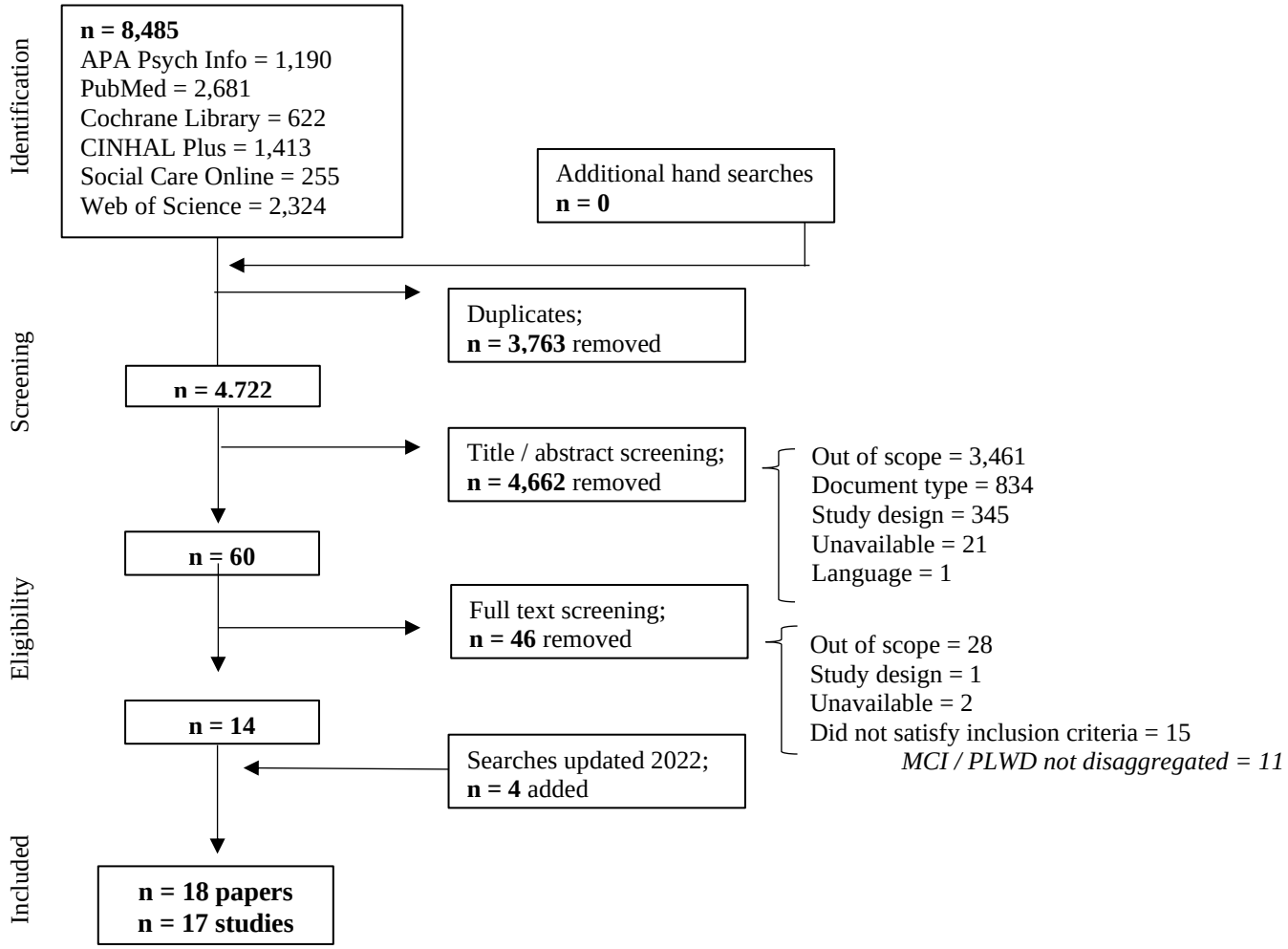


**Figure 1** PRISMA flowchart

**Table 5** Study Characteristics

| Authors | Country | Aims | Design | Participants | Method | Results |
|---|---|---|---|---|---|---|
| Dal Bello-Haas et al., (2014) | Canada | To examine the demand, acceptability, practicality, and implementation of telehealth-delivered exercise for rural dwelling people living PLWD and informal carers. | Mixed-methods exploratory approach | - Phase 1: PLWD: n=42. UNPAID CARERS: n=35.<br>- Phase 2: n=2 dyads. PLWD: n=1AD; n=1 FTD | - Phase 1: Semi-structured interviews, quantitative survey, Older Persons Attitudes Towards Physical Activity and Exercise.<br>- Phase 2: Intervention: revised version Menorah Park Engagement Scale, attendance.<br>- Post-intervention (4 weeks): dyadic interview and questionnaire. | - PLWD and unpaid carers interested in remote exercise.<br>- High attendance rate, dyads enjoyed the intervention. |
| Chodosh et al., (2015) | USA | To compare the effectiveness and costs of telephone only approach to in person plus telephone for delivering an evidence-based coordinated care management program for dementia | Quantitative | - n=144 dyads.<br>- PLWD: Average of 73.1 years; 62.5% female.<br>- UNPAID CARERS: Average of 50 years; 65.3% female. n=77 adult child; n=33 unrelated; n= 25 spouse. | - Random allocation to in-person and telephone format, or only through telephone calls.<br>- Baseline, 6 and 12-month follow-up: ZBI; PHQ-9; CG-QOL; HUI; Blessed Roth Dementia Scale; BAS.<br>-Unpaid carer questionnaire: dementia care quality, PLWD health care utilization, hospitalisation, nursing home placement. | - Improvement in care quality in both groups<br>- Similar unpaid carer burden, PLWD problem behaviours, retention and health care utilization across both groups<br>- Greater costs when delivering intervention in-person |
| Rogaliski et al., (2016) | USA | To determine if internet-based delivery of speech and language therapy was feasible for individuals with progressive aphasia symptoms. | Mixed methods | - n=34 dyads enrolled, n=31 dyads completed.<br>- PLWD: average of 67.2 years; 52.9% female. n=28 PPA; n=3 other dementia.<br>- UNPAID CARERS: n= 27 spouses | - Baseline, 2- and 6-month follow-up: ASHS-FCM; CCRSA.<br>- 2 and 6-month follow up: Evaluation of target words. 6-moths follow-up: treatment compliance.<br>- Post-intervention: dyadic semi-structured interview | - Increase in functional gains and confidence in communication at 2-months follow-up, maintain at 6-month follow up. |

| | | | | | | |
|---|---|---|---|---|---|---|
| Kim et al., (2017) | South Korea | To assess the feasibility of telemedicine in the long-term management of patients with dementia based on cognitive function as the primary outcome | Quantitative | - PLWD: n=188.<br>- In-person: n=90; average of 78.0 years; 67% female. 88.9% AD; 8.9% VaD and 2.2% other dementia.<br>-Remote: n=98; average of 78.2 years; 69% female. 91.9% AD; 8.1% VaD. | - CDR; Korean version of MMSE scale | - No statistically significant difference in MMSE scores between PLWD accessing medical follow-ups remotely and in-person.<br>- Telemedicine may be useful to service recipients to reside in rural areas. |
| Killin et al., (2018) | UK, Scotland | To determine the feasibility of improving the quality of life of PLWD and informal carers with the Digital Support Platform (DSP). | Qualitative | - n=10 dyads.<br>- PLWD: average of 74.5 years, 80% male. n=4 AD; n=6 mixed dementia. | - Dyadic semi-structured interviews | - Valued post-diagnostic support, but less suitable during early stages of dementia.<br>- Challenging to navigate DSP. |
| Dial et al., (2019) | USA | To evaluate the feasibility and utility of treatment delivered through teletherapy compared to in-person treatment with people with PPA | Quantitative | - PLWD: n=31; n=17 in-person; n=14 teletherapy.<br>- In person: n=5 nfvPPA; n=6 svPPA; n=6 1vPPA. LRT treatment: n= 12; 66.7% female; average of 68.9 years, MMSE: 23.8. VISTA treatment: n =5; 60% female; average of 67.6 years, MMSE 26.0.<br>- Teletherapy: n=5 ngvPPA; n=4 svPPA; n=5 1vPPA. LRT treatment: n=9; 55.6% male; average of 61.0 years MMSE: 24.8. VISTA treatment: VISTA n=5; 60% female; average of 67.8 years, 27.6 MMSE. | - 3, 6 and 12-month follow up. LRT treatment: pre-post change score on trained items, untrained items and changes score on the BNT and WAB AQ. VISTA treatment: change score of the percent of correct intelligible scripted words and NAT. | - Both treatment types resulted in significant improvements which were maintained regardless if accessed in-person or remotely |
| Possin et al., (2019) | USA | To determine whether the Care Ecosystem is effective in improving outcomes important to PLWD, unpaid carers, and payers beyond those achieved with usual care | Quantitative, single group pragmatic randomised clinical trial | - n=780 dyads.<br>- PLWD: Care Ecosystem: n=512; average of 78.7 years; 58.2% female;49.8% mild; 28.7 moderate †; 21.5% advanced. Control: n=268; average of 77.6 years; | - Baseline, 6 months and post-intervention (12 months): QoL-AD, PHQ-9, ZBI, Caregiver Self Efficacy and hospitalisation / use of emergency services.<br>- Post-intervention: questionnaire | - Care management successfully delivered via centralised hubs.<br>- Compared to usual care, the Eco System increased PLWD's quality of life, reduced emergency department visits, reduced unpaid carers' |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | 52.6% female; 50.4% mild, 29.1% moderate; 2.6% advanced †<br>- UNPAID CARERS: Care Ecosystem: n=512; average of 65.3 years; 69.9% female. Control: n=268; average of 64.0 years; 73.1% female | | depression and caregiving burden. |
| Ptomey et al., (2019) | USA | To evaluate the feasibility of a group video conference approach to increase moderate physical activity (MPA) in adults with AD and informal carers. | Quantitative | - n=9 dyads enrolled, n=7 completed.<br>- PLWD: n=AD. average of 74 years. 56% female.<br>- UNPAID CARERS: average of 67 years. 67% female. | - Baseline and post-intervention (12 weeks): QOL-AD, SF-36.<br>- During the intervention: attendance, minutes of MPA.<br>- Post-intervention: questionnaires for PLWD and unpaid carers | - Good attendance rate<br>- Increase in weekly MPA in both members of the dyad |
| Capozzo et al., (2020) | Italy | To evaluate whether the assessment of people with FTD using telemedicine is feasible and acceptable during the COVID-19 pandemic | Quantitative | - PLWD: n=32; 56.3% male; average of 66.3 years. n=2 PPA; n=3 PPA-Parkinsonism; n=12 bvFTD; n=9 bvFTD-Parkinsonism; n=2 bvFTD-PSP; n=2 bvFTD-MSA; n=2 bvFTD-ALS.<br>- UNPAID CARERS: n=15; 100% spouses | - Questionnaire (including changes in cognitive, behaviour, personality, language, sleep disturbances, nutritional status, swallowing capacity, respiratory function, access to rehab, SALT, pharma therapy); CDR-FTD; COVID-19 symptoms. Unpaid carer distress evaluated with 5-point Likert scale, question from Neuropsychiatric Inventory.<br>- Post-intervention: questionnaire one week after | - Most were satisfied with the remote neurological consultation.<br>- Compared to the last in-person consultation, half of PLWD experienced worsening of clinical symptoms (behaviour and language functions) and quality of life. |
| Gately et al., (2020a) | USA | To examine the feasibility of using videoconferencing software for an occupational therapy home safety evaluation | Mixed methods | - UNPAID CARERS: n=10; average of 62.8 years, 80% women. n=6 spouse; n=4 adult child | - Field notes (technical glitches, audio and video problems, number of unpaid carers present, difficulties logging on, device ownership, formal support requirement and use of a second device) | - Remote home safety evaluations are feasible<br>- Technical difficulties experienced during most evaluations. |
| Gately et al., (2020b) | USA | To examine caregiver satisfaction with the video telehealth home safety evaluation, through in-depth | Mixed methods | - PLWD: n=10; average age of 82.5 years; 90% male; 60% in the mild-to-moderate stages (MMSE score > 12.2). | - Post-intervention: questionnaire (ability to see, hear, communicate, understand the provider, comfort of technology use, sufficient technical | - Overall positive experience.<br>- Lower satisfaction related to technological glitches and the |

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| | | examination of caregiver satisfaction relative to person, environment, and occupation factors | | - UNPAID CARERS: n=10; average of 62.8 years, 80% women. n=6 spouse; n=4 adult child | assistance, privacy, time, format preference).<br>- Risky Behaviour Questionnaire; Confidence in Caregiving Scale.<br>- Field notes | presence of PLWD during the home safety evaluation. |
| Laver et al., (2020) | Australia | To determine whether delivery of a dyadic intervention using telehealth was noninferior to delivery of the same program using in person delivery through home visits | Quantitative, Non-inferiority randomised control trial | - n=63 dyads.<br>- PLWD: In person: n=32; average of 80.5 years; 72% male. Telehealth: n=31; average of 79.5 years; 52% female.<br>- UNPAID CARERS: In person: n=32; n=25 spouse; 81% female; average of 70.7 years. Telehealth: n=31; n=23 spouse; 71% female; average of 69.5 years | - Baseline and post-intervention (4 months): CMI, PCI, CAFU, Caregiver Behavioural Occurrence and Upset Scale.<br>- Post-intervention: unpaid carer questionnaire.<br>- Therapists recorded time travelling and spent with participants. | - Improvements in CMI and PCI in both intervention arms.<br>- Same time to deliver the intervention, remote delivery significantly reduced therapists' travel time. |
| Moo et al., (2020) | USA | To evaluate efforts to recruit patients affiliated with an outpatient dementia management programme into Home Clinical Video Telemedicine | Quantitative, retrospective programme evaluation study | - n=222 dyads.<br>- In person: n=184 dyads. PLWD: 96.7% male; 76.6% White; average of 84 years. -UNPAID CARERS: 91.8% female; 56% spouses; 33.2% adult child.<br>- Telemedicine: n=38 dyads. PLWD: 97.4% male' 73.7% White; average of 79 years. UNPAID CARERS: 78.9% female; 84.2% spouses; 13.2% adult child | - Post-intervention: five-point Likert scale questionnaire (miss work to attend and impact on PLWD's daily routine). Open-ended questions on experience and logistics.<br>- Ranked reasons for participating in telemedicine intervention | - Follow-up visits delivered as successfully through telemedicine as in in-person format.<br>- Telemedicine may offer benefits (reduce travel distance and PLWD routine), but may not be suitable for all dyads. |
| Masoud et al., (2021) | USA | To provide insight into the experiences of PLWD and informal carers who regularly attend Memory Cafes. To explore how these gatherings, affect perceptions of social connectedness. | Qualitative exploratory study | - PLWD: n=5 self-identified as living with dementia.<br>- UNPAID CARERS: n=12. n=8 spouses; n=4 adult children. | - Individual and dyadic semi-structured interviews | - Highlights benefits offered by attending Memory Cafes.<br>- Virtual Memory Cafes may offer similar benefits to some PLWD and informal carers. |
| O'Rourke et al., (2021) | UK, England | To explore the impact of the COVID-19 pandemic on PLWD and informal carers | Qualitative | - PLWD: n=11 interviewed, data provided for n=19. Average of 76.5 years; 52.6% female, 68.4% living | - Individual and dyadic semi-structured interviews | - Some PLWD were coping well, whereas some experiences negative impacts. |

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| | | and how negative effects could be mitigated | | with others, 89.4% White British.<br>n=6 AD; n=4VaD; n=3 FTD; n=3 mixed; n=2 Lewy Body; n=1 addition PCA diagnosis.<br>- UNPAID carers: n=10 interviewed, data provided for n=13. 84.6% female; 61.5% spouse | | - Value of personalised COVID-19 information and regular 'checking in' calls. |
| Panerai et al., (2021) | Italy, Sicily | To determine whether telephone-based reality orientation therapy (T-ROT) can improve cognition, mood, and neuropsychiatric symptoms among patients with major neurocognitive disorders who are forced to isolate, and whether T-ROT can relieve the burden of distress among their informal carers. | Quantitative non-randomised interventional comparison | - n=27 dyads. n=14 dyads experimental and n=13 dyads in control group.<br>- PLWD: average of 65 years. n=3 AD; n=5 vascular dementia; n=1 FTD; n=1 mixed dementia; n=4 other.<br>- UNPAID CARERS: Average 61 years. | - Baseline and post intervention (4 weeks): CIRS, Katz Index of Independence in Activities of Daily Living, Lawton Instrumental Activities of Daily Living Scale. HAM-D, CSDD, NPI-Q, CBI. | - Compared to non-treatment, T-ROT significantly improved PLWD depression, behaviour, cognition and burden on unpaid carers. |
| Cousins et al., (2022) | UK, England | To gain an understanding of the experiences, impact and implications of the COVID-19 pandemic on PLWD and informal carers. | Qualitative | - PLWD: n=5. n=1 YOD; n=2 FTD; n=1 vascular dementia with Lewy bodies; n=1 unknown. 100% male.<br>- UNPAID CARERS: n=7. n=5 spouse; n=2 adult children. 100% female. | - Individual and dyadic semi-structured interviews | - Both positive (opportunities for quality time) and negative experiences (feelings of loss and isolation) during the COVID-19 pandemic. |
| Giebel et al., (2021b) | UK | To explore how community services and institutional care settings have adapted during the pandemic in the UK and are providing care to people living with dementia and carers | Qualitative | - PLWD: n=8 AD; n=2 VD; n=3 YOD.<br>- UNPAID CARERS: n=10 adult child; n=6 spouse; average of 55.3 ± 6.2 years; 93.8% female | - Semi-structured interviews with unpaid carers | - Lack of support available during the COVID-19 pandemic.<br>- Whilst remote services were helpful to some, did not replace in-person services. |

Acronyms: AD: Alzheimer's Disease; ALS: Amyotrophic Lateral Sclerosis; ASHS-FCM: American Speech-Language-Hearing Association functional communication measures; BAS: Bi-Dimensional Acculturation Scale; BNT: Boston Naming Test; CAFU: Caregiver Assessment of Functional Upset; CBI: Caregiver Burden Inventory; CCRSA: Communication Confidence Rating Scale for Aphasia; CDR: Clinical Dementia Rating Scale; CIRS: Cumulative Illness Rating Scale, CG-QOL: Caregiver Quality of Life; CMI: Caregiver Mastery Index; CSDD: Cornell Scale for Depression in Dementia; FTD: Frontotemporal dementia; HAM-D: Hamilton Rating Scale for Depression;

HUI: Health Utilities Index; LRT: Lexical Retrieval Treatment MMSE: Mini-Mental State Examination; MSA: Multiple System Atrophy; NAT: North Western Anagram Test; NPI-Q: Neuropsychiatric Inventory Questionnaire; PCA: Posterior Cortical Atrophy; PCS: Perceived Change Scale; PHQ-9; Patient Health Questionnaire-9 items; PLWD: People living with dementia; PPA: Primary Progressive Aphasia; PSP: Progressive Supranuclear Palsy; QOL-AD: Quality of Life for the adult with Alzheimer's Disease; RMBPC: Revised Memory and Behaviour Problem Checklist; SF-36: Short Form Health Questionnaire; T-MMSE: Telephone Mini-Mental State Examination; VaD: Vascular Dementia; VISTA: Video-implemented script training for aphasia; WAB-AQ: Western Aphasia Battery Aphasia Quotient; YOD: Young Onset Dementia; ZBI: Zarit Burden Interview. †Baseline dementia severity data missing for 15 of the 780 dyads.

**Table 6** Methodological appraisal of included studies (Hawker et al., 2002)

| Reference | Abstract | Introduction and aims | Methods and data | Sampling | Data analysis | Ethics and bias | Results | Transferability and generalizability | Implications and usefulness | Overall Score[α] |
|---|---|---|---|---|---|---|---|---|---|---|
| Dal Bello-Haas et al., | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Chodosh et al., | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Rogalski et al., | Good | Good | Fair | Good | Fair | Fair | Good | Good | Good | 33 |
| Kim et al., | Fair | Good | Good | Good | Good | Fair | Good | Good | Good | 34 |
| Killin et al., | Fair | Good | Good | Good | Good | Fair | Good | Good | Good | 34 |
| Dial et al., | Good | Good | Good | Good | Good | Fair | Good | Good | Good | 35 |
| Possin et al., | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Ptomey et al., | Good | Good | Good | Good | Good | Fair | Good | Good | Good | 35 |
| Capozzo et al., | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Gately et al., | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Gately et al., | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Laver et al., | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Moo et al., | Fair | Fair | Good | Good | Good | Good | Good | Good | Good | 34 |
| Masoud et al. | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| O'Rourke et al., | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Panerai et al., | Good | Good | Good | Good | Good | Fair | Good | Good | Good | 35 |
| Cousins et al., | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Giebel et al., | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |

[α] Very Poor =1; Poor =2; Fair=3; Good =4 points. Score range = 9-36 (minimum- maximum)

**Table 7** Summary of post-diagnostic support accessed, service recipients' views and ICT formats employed

| Reference | ICT format (s) employed | ICT support provided | Post-diagnostic support accessed | Views on accessing remote post-diagnostic support |
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| ***Post-diagnostic support accessed by people with dementia or both members of the dyad*** | | | | |
| Dal Bello-Haas et al., (2014) | -Video-conferencing software.<br>- Accessed in a telehealth suite. | - One investigator attended the first two sessions and provided on-site training and evaluate participants' ability to set-up equipment and exercise safely. | - 40-45minutes sessions, twice a week for four weeks.<br>- warm-up, aerobic exercise using an upper extremity cycle ergometer, and a cool down.<br>- Led by a research assistant in a telehealth suite in the Saskatoon Regional Health Authority, another research assistant attended the sessions with the participants in the telehealth suite in the rural regional health authority. | - PLWD observed laughing and smiling during some sessions.<br>- Overall intervention rated as good-to-excellent; good voice quality, good-to-excellent visual quality, the ability to engage with the facilitator and with the group was excellent.<br>- Participants enjoyed the intervention, being able to exercise with people and easy to use ICT.<br>- One participant mentioned the lack of variety between sessions.<br>-*Everyone knows TV nowadays, it's just like being there'* (Unpaid carer) |
| Rogalski et al., (2016) | - Communication bridge web application.<br>- Included 'to do lists', pre-recorded strategy videos and embedded video-conferencing software function. | - In-person training on ICT use.<br>- Account set up for each participant. | - Initial evaluation, eight one-hour video-conferencing treatment sessions and two evaluations (two- and six-months post-enrolment).<br>- Treatment followed impairment-based approaches, activity and/or participation approaches.<br>- Individualised home exercise program<br>- Provided ongoing disease education, counselling and support. | - 16/31 dyads reported that the intervention 'exceeded' their expectations.<br>- Out of 30 dyads, several stated that the pre-recorded videos were helpful, 37% would not change anything and 20% would like more sessions. |
| Kim et al., (2017) | - Videoconferencing software (Tandberg 990 system), a personal computer and monitors.<br>- Accessed remotely from rural health centre. | None reported. | - Medical follow-up with specialist in Kangwon National University Hospital.<br>- Medications review, disease education, supportive psychotherapy.<br>- Between April 2007 and December 2012. | None reported. |
| Killin et al., (2018) | - Digital Support Platform (DSP) consisted of three | - Provided tablets, PCs, mobile with data depending on need and preference. | -Living it up: a wellbeing portal. Provides information, advice and community networks. | - Lack of a perceived current need for the DSP.<br>- Understood as suitable for people at latter stages of disease trajectory. |

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| | tools: living it up, jointly and click and go. | - DSP pre-installed on devices.<br>- In-person demonstration of DSP. | - Jointly: a care coordination services that enables all unpaid carers to communicate and access shared tools.<br>- Click and go: a support appointment scheduling interface for families with statutory package of care in place.<br>- Participants had accessed the DSP for at least two months. | - Carers were the primary users, and some carers and PLWD found the DSP too difficult to use.<br>- '*But she's not a teacher – she finds it very difficult… And it can be a bit upsetting as well. She's much better than me but she's not very happy trying to take me by the hand and leading me through the procedure and she gets very frustrated as well'* (PLWD)<br>- '*As I say, if-if somebody had gone through it with me at the beginning, that would have been helpful. Just sat down and said now, you know, this is what you can do with it and that's what you can do with it. I think that would have been helpful'* (Unpaid carer)<br>- *'I'm not here feeling sorry for myself, I can get into (the tablet) and the day goes quicker… I dunno what to say to be honest. I love it. I love it.'* (PLWD) |
| Dial et al., (2019) | - Videoconferencing software (Adobe connect or Fuze).<br>- Telephone or Team Viewer for trouble shooting. | - Document which included written instructions and screenshots to install the videoconferencing software.<br>- Additional support provided by telephone or Team Viewer.<br>- An iPad Air with pre-installed software was provided to participants who did not own a computer or webcam. | - LRT treatment: trained to use word finding strategies capitalizing on the retrieval of residual semantic, phonological, orthographic and autobiographical or episodic knowledge. Cueing hierarchy.<br>- VISTA treatment: facilitate grammaticality, intelligibility and fluency of connected speech. Script training. | None reported. |
| Ptomey et al., (2019) | -Video conferencing software (Zoom).<br>- iPad mini tablet and Fitbits. | - Provided iPads, Fitbits and HDMI adaptor.<br>- iPad pre-installed software and videos explaining how to use the ICT.<br>- In-person raining on ICT use. | - 30-minute exercise sessions via video-conferencing, three times per week, over 12 weeks.<br>- Groups of 5-8 dyads, each in their own home. - A warm up, MPA and a cooldown. MPA included walking, sit to stand, dance movement and resistance exercises.<br>- Context of sessions varied, led by a health coach<br>- Each dyad attended a monthly 15 minutes education / support session with the health coach. | - PLWD and unpaid carers enjoyed the program.<br>- 28.6% of unpaid carers experienced difficulties when connecting the iPad to the internet and, 14.3% reported difficulties connecting the Fitbit to the iPad.<br>- All unpaid carers reported it was easy to navigate the iPad and the Zoom app. |

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| Capozzo et al., (2020) | - Videoconferencing software option, but all participant chose telephone calls | None reported. | - Consultation with neurologist and lasted between 60-90 minutes.<br>- Assessment based on a structured question to identify significant changes since last evaluation (behaviour, personality, language, sleep disturbances, nutritional status, swallowing capacity, respiratory function, access to rehab, SALT, pharma therapy) | - Satisfied with voice quality: 81% very satisfied; 19% fairly satisfied; not satisfied at all: 0%.<br>- Satisfied with the neurologist's skills to understand problems: 88% very satisfied; 12% fairly satisfied; 0% not satisfied.<br>- Satisfied with experience: 81% very satisfied; 19% fairly satisfied; 0% not satisfied.<br>- Able to talk as during in person consultation: yes: 82% and No: 18%. |
| Moo et al., (2020) | -Videoconferencing software (CISCO Jabber)<br>- Telephone for trouble shooting | - Provided videoconferencing software access and, if required, a webcam.<br>- Technician called unpaid carers to identify home computer and internet capabilities.<br>- Provided support to download and install videoconferencing software over the telephone.<br>- Conducted a test run before intervention.<br>- Participants received an email with appointment time and log in details. | - Telemedicine visits complimented in-person follow-up visits.<br>- Conducted by a behavioural neurologist and lasted 45 minutes.<br>-Topics covered included: changes in cognition, behaviour, mood, sleep, appetite, continence, mobility issues, safety concerns, independent activities of daily living and activities of daily living.<br>- Recommendations communicated with unpaid carers and medication changes or referrals inputted into the medical record.<br>- Next visit scheduled depending on need (ranged from 2 weeks – 9 months).<br>- Between March 2013 to October 2014. | - Convenience regarding travel and to maintain PLWD's routine<br>-Similar satisfaction regardless if accessed remotely and in-person or in-person only.<br>- Decreased in travel distance when service accessed remotely<br>- Participants reported being at least as satisfied with remote visits as when accessed in-person. |
| Masoud et al., (2021) | - Video conferencing software (Two memory cafes used Zoom and one used Microsoft Teams) | None reported | - Held at least once a month.<br>- Included different activities (trivia, jam making, bingo) and invited guest facilitators. | - Engaging with remote Memory Cafes was different and not the same as in person format, but was appreciated during the COVID-19 pandemic.<br>- Some unpaid carers reported the convenience offered by remote service delivery.<br>- *'I don't feel like I do about the support group, which I've been to for much longer and, also, in person and done some socializing with some of them. It'll take a while, I think, to feel that we're part of a group'* (Unpaid carer)<br>- *'We've enjoyed the [virtual] memory cafe as is. I do know that mom and dad - it is more likely that will attend via zoom* |

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| | | | | *then if it was in person... because to get mom out of the house, it becomes an ordeal...'* (Unpaid carer) |
| O'Rourke et al., (2021) | - Telephone | None reported | - Check-up calls, weekly, fortnightly or monthly.<br>- Calls mostly by voluntary organisations, sometimes by NHS staff.<br>- Asked how the person / dyad were managing, engage in conversation (social or identifying support needs). | - Valued during the COVID-19 pandemic.<br>- *'one of them will ring you, and say 'how's things going?' and all of the rest of it, you know, and then if you've got any problems that come up during the conversation, you'll find someone will follow it up, and then ring you back, which all makes you feel good*' (Unpaid carer).<br>- *'Age concern in (town), you know, we are... every... certainly every month we'll have a phone call from them saying, you know, are you okay, Mr (surname), is there anything we can do for you and whatever'* (PLWD) |
| Panerai et al., (2021) | - Telephone | None reported | - Ten sessions lasting 50-60 minutes over four weeks, three sessions a week.<br>- Each session focused on a theme (me and the calendar, holidays and anniversaries, my story, my family, my home, my daily life, my character, my appearance, my preferred food and my leisure time). | None reported. |
| Cousins et al., (2022) | - Video conferencing software | None reported | - Remote peer support groups.<br>- Different activities (e.g., games and crafts). | - Source of positivity during lockdown. Valued and helpful.<br>- *'Yeah, and he's really enjoyed that... it was the other members that we've got to know since we've been on the Zoom. And we've made real friends with them, haven't we? Through Zoom.'* (Unpaid carer)<br>- *'The thing is, that if we didn't have these (the groups) it would be a bit bleak. I think all the online things they do at least give you a feeling, you known, that you are still part of a community'* (PLWD) |
| Giebel et al., (2021b) | - Video conferencing software (Zoom), telephone, Facetime | None reported | - Telephone calls from memory clinic and care navigators.<br>- Facetime and videoconferencing software to access groups. | - Limited provision of remote support, telephone calls were sometimes at inconvenient times. Did not replace in-person support<br>- Hearing impairments impaired engagement with remote services.<br>- *'…but it's not quite the same as in person is it, and I know you can see somebody on a screen but it's not quite the same* |

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| | | | | *as sitting down and having a cup of coffee and a good chat is it really'* (Unpaid carer)<br>- *'he [PLWD] also struggles we've noticed with understanding using like a zoom, my brother will set up zoom and we can zoom and I've noticed he has certain faces he uses when he's finding a way to answer a question he doesn't understand'* (Unpaid carer)<br>- *'there has been no outside support at all erm other than we did have 1 phone call from the Care Navigators… so maybe about 3 or 4 weeks ago just to see how my mother in law was getting on and whether she needed anything which was really lovely but possibly a little late'* (Carer) |
| ***Post-diagnostic support accessed by unpaid carers*** | | | | |
| Chodosh et al., (2015) | - Telephone | - Some unpaid carers not engaging with care managers due to limited minutes included in phone plan.<br>- Provided phones with unlimited minutes for eight unpaid carers. | - 12 months intervention delivered by social workers.<br>- Initial and 6-months assessment guided intervention and assessed unmet needs for assistance; lack of social support; educational needs; difficulty with managing dementia related behavioural issue and safety concerns; need for respite; depression of the PLWD and carer; management of other chronic medical issues; need for diagnostic information and assistance with acute medical issues.<br>- Complimented with counselling, education and self-management skills, referrals for community services and medical care.<br>- Minimum of seven contacts with participants, either in-person or telephone calls. | None reported. |
| Possin et al., (2019) | - Telephone, email | None reported. | - Delivered by care team from two hubs – University of California and University of Nebraska.<br>- Care team navigators telephoned dyads on average 15 times during the 12-month | - 97% reported that they would recommend the care ecosystem to another unpaid carers<br>- 45.4% were very satisfied; 32.9% were satisfied; 17.5% were neutral; 2.8% were unsatisfied and 1.2% were very unsatisfied with the intervention |

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| | | | intervention. Responded to unpaid carer's initial needs, screened for problems and provided personalised support and standardised support.<br>- Additional contact by email and mail. Care team navigators<br>- Lighter version offered, included educational materials though the post, possibly to contact care team navigators if required. | |
| Gately et al., (2020a; b) | - Videoconferencing software.<br>- Telephone used during two evaluations due to audio loss during videoconferencing call. | - Remote assistance to download videoconferencing software for unpaid carers owned a laptop with a camera, microphone and access to broadband internet.<br>-Tablets / laptop with pre-installed videoconferencing software was provided if needed.<br>- 15-minute 'test call'<br>- Remote support from technician during two home visits.<br>-Research assistant often remotely assisted to log in and during the home visit. | - A home safety evaluation (40-45 minutes) | - Scale 1 (strongly disagree) – 5 (strongly agree). Median scores: able to hear = 4.5; able to see = 4; easy to communicate = 4; understood providers = 5; comfort using tech =5; sufficient technical assistance = 4; time efficiency: = 5; Prefer video to in-person = 3. |
| Laver et al., (2020) | - Videoconferencing software (Cisco Webex) | - Able to use own laptop, tablet or smartphone.<br>- Opportunity to loan a tablet with pre-installed software.<br>- In person videoconferencing demonstration. | - Up to eight consultation (60 minutes) over 16 weeks.<br>- Participants in telehealth group received two sessions in person, six over telehealth.<br>- Theory-based intervention delivered by an occupational therapist, consisted of an assessment of PLWD, unpaid carer and environment.<br>- Works with unpaid carer to solve, educate, build skills and stress management. Works with the dyad to promote activity engagement | - Moderate-high levels of satisfaction with programme.<br>- In-person intervention yielded more favourable satisfaction scores. |

Acronyms: COVID-19: coronavirus; DSP: Digital Support Platform; HDMI: High-Definition Multimedia Interface; ICT: information communication technology; LRT: Lexical Retrieval Treatment; NHS: National Health Service; PC: Personal Computer; PLWD: People living with dementia; SALT: Speech and Language Therapy; VISTA: Video-implemented script training for aphasia.

#### 2.4.2.1 Post-diagnostic support access by people with dementia or both members of the dyad

Studies described exercise classes (Dal Bello-Haas et al., 2014; Ptomey et al., 2019; Giebel et al., 2021d), therapeutic interventions, including speech and language (Rogalski et al., 2016; Dial et al., 2019) and reality orientation (Panerai et al., 2021) therapy, supportive interventions, including support groups and memory cafés, (Giebel et al., 2021d; Masoud et al., 2021; Cousins et al., 2022), medical follow-ups (Kim et al., 2017; Capozzo et al., 2020; Moo et al., 2020), 'check-up' calls (Giebel et al., 2021d; O'Rourke et al., 2021) and information provision (Killin et al., 2018). Some people with dementia had previously accessed support groups and memory cafes (Masoud et al., 2021; Cousins et al., 2022), reality orientation therapy (Panerai et al., 2021) and medical follow-ups (Capozzo et al., 2020; Moo et al., 2020) when delivered in in-person formats. Some unpaid carers provided support to facilitate the engagement of the person with dementia when exercising (Dal Bello-Haas et al., 2014), and their presence was beneficial during speech and language therapy sessions (Rogalski et al., 2016). Most remote post-diagnostic support was mainly accessed on a one-to-one basis (Rogalski et al., 2016; Killin et al., 2018; Dial et al., 2019; Capozzo et al., 2020; Moo et al., 2020; Giebel et al., 2021d; O'Rourke et al., 2021; Panerai et al., 2021) and accessible from participants' home. Support accessed ranged from a single medical follow-up visit (Capozzo et al., 2020) to a long-term medical management spanning five years (Kim et al., 2017). Two studies reported on follow-up with time frames of six (Rogalski et al., 2016) and 12 (Dial et al., 2019) months, and three studies reported on ongoing support accessed throughout the COVID-19 pandemic (Masoud et al., 2021; O'Rourke et al., 2021; Cousins et al., 2022).

*Outcomes*

Overall, adherence to remote post-diagnostic support was high (Dal Bello-Haas et al., 2014; Rogalski et al., 2016; Ptomey et al., 2019). Moderate physical activity levels increased in service recipients participating in Ptomey et al. (2019)'s exercise classes, and people with dementia improved in speech and language outcomes (Rogalski et al., 2016; Dial et al., 2019). Increased gains and confidence were maintained six months following the interventions (Rogalski et al., 2016) and long-term improvements were comparable to benefits received from accessing speech and language treatment in-person (Dial et al., 2019). Compared to the control group, increased Mini–Mental State Examination (MMSE) scores, decreased behavioural and psychological symptoms, notably depression, was found in people living with dementia who had accessed telephone orientation therapy, and outcomes positively impacted unpaid carers' levels of distress (Panerai et al., 2021). The MMSE scores of people with dementia who attended long-term medical management through telemedicine and in-person were comparable. The MMSE score of people with dementia with less severe initial impairments decreased less in the

telemedicine group than the in-person group (Kim et al., 2017). Following the implementation of social distancing, people with dementia were found to have a lower quality of life, worsening symptoms and language abilities (Capozzo et al., 2020).

#### 2.4.2.2 Post-diagnostic support access by unpaid carers

Studies described care management interventions (Chodosh et al., 2015; Possin et al., 2019), a home safety evaluation (Gately et al., 2020a) and a supportive intervention (Laver et al., 2020), which were delivered on a one-to-one basis and accessible from participants' home. Support accessed ranged from a single home safety evaluation (Gately et al., 2020a) to a care management intervention lasting a year (Possin et al., 2019). Two studies reported on follow-ups with time frames of six months (Chodosh et al., 2015; Possin et al., 2019).

*Outcomes*

The care management intervention decreased the caregiving burden, behavioural problems and health care utilisation, regardless of whether unpaid carers accessed the support remotely or in-person (Chodosh et al., 2015). Compared to unpaid carers who had accessed care management remotely, a greater decline in the quality of life of people with dementia and more visits to the emergency department were found in the control group from baseline to 12 months (Possin et al., 2019). The depression scores of unpaid carers who accessed the care management declined more than the control group at 23 months (Possin et al., 2019). The supportive intervention, when accessed remotely or in-person, increased caregiving mastery and perceptions of caregiving. People with dementia in the remote group experienced greater a functional decline, but experienced greater improvements in behavioural problems compared to the in-person group (Laver et al., 2020). Delivering a care management and supportive intervention in an in-person format required greater expenditures (Chodosh et al., 2015) and travelling (Laver et al., 2020).

### 2.4.3 ICT formats employed, issues encountered and technological support

Video-conferencing software was the most employed ICT format (Dal Bello-Haas et al., 2014; Rogalski et al., 2016; Kim et al., 2017; Dial et al., 2019; Ptomey et al., 2019; Gately et al., 2020a; Laver et al., 2020; Moo et al., 2020; Giebel et al., 2021d; Masoud et al., 202; Cousins et al., 2022) followed by the telephone (Chodosh et al., 2015; Possin et al., 2019; Capozzo et al., 2020; Giebel et al., 2021d; O'Rourke et al., 2021; Panerai et al., 2021). In Capozzo et al (2020)'s study, people with dementia chose to access medical follow-ups through telephone calls, rather than via videoconferencing software. Six studies reported on ICT issues experienced. This included difficulties connecting devices to access exercise classes (Ptomey et al., 2019), accessing and using the information portal (Killin et al., 2018) and poor audio and visual quality during speech and language therapy sessions (Rogalski et al., 2016) and home

safety evaluations (Gately et al., 2020a). Insufficient minutes on unpaid carers' personal phone plans formed a barrier to engaging with a care management intervention (Chodosh et al., 2015) and two people with dementia ceased attending speech and language therapy sessions due to dementia severity or limited ICT literacy (Rogalski et al., 2016).

If required, devices were provided in seven studies (Chodosh et al., 2015; Killin et al., 2018; Ptomey et al., 2019; Gately et al., 2020a;; Laver et al., 2020; Moo et al., 2020). These included tablets and/or mobile phones, often pre-installed with the required software, or mobile phones with unlimited call minutes (Chodosh et al., 2015). Two studies (Killin et al., 2018; Moo et al., 2020) contacted participants beforehand to identify devices participants owned or engaged with. Sessions explaining the technology was delivered in-person (Killin et al., 2018; Ptomey et al., 2019; Laver et al., 2020) and remotely (Killin et al., 2018; Dial et al., 2019; Gately et al., 2020a;; Moo et al., 2020). Two studies (Gately et al., 2020a; Moo et al., 2020) conducted a test-run with the participants beforehand. Some unpaid carers assisted people with dementia by setting up the technology (Ptomey et al., 2019; Giebel et al., 2021d) and liaising with the study team regarding the technology setup (Moo et al., 2020).

### 2.4.4 Views on accessing post-diagnostic support remotely

Thirteen studies explored the views of people with dementia and unpaid carers when accessing post-diagnostic support remotely (**Table 7**). Service recipients' views were largely obtained via individual or dyadic interviews (Dal Bello-Haas et al., 2014; Killin et al., 2018; Giebel et al., 2021d;; Masoud et al., 2021; O'Rourke et al., 2021; Cousins et al., 2022) or quantitative surveys (Dal Bello-Haas et al., 2014; Possin et al., 2019; Ptomey et al., 2019; Capozzo et al., 2020; Laver et al., 2020; Gately et al., 2020b). Ptomey et al (2019) devised a simplified questionnaire, which was administered verbally and accessible to people with dementia. Dal Bello-Haas et al (2014) observed the engagement of the dyad during the exercise class. Four studies (Killin et al., 2018; Moo et al., 2020; Giebel et al., 2021d; Cousins et al., 2022) studies included views of people with dementia reported by proxy.

Overall, views were mixed. People with dementia and unpaid carers enjoyed participating in exercise classes (Dal Bello-Haas et al., 2014; Ptomey et al., 2019), willing to continue accessing the intervention, and unpaid carers reported an increase in exercising independently (Ptomey et al., 2019). During the exercise class, Service recipients were able to focus without distraction, privacy was respected and able to engage with the facilitator (Dal Bello-Haas et al., 2014). People with dementia enjoyed accessing speech language treatment remotely, would have liked to receive more sessions, and found the pre-recorded videos helpful (Rogalski et al., 2016). Service recipients chose to access medical follow-ups remotely due to convenience, increased contact with service providers and to maintain the routine of the person with dementia (Moo et al., 2020). Accessing remote medical follow-ups yielded high

satisfaction (Capozzo et al., 2020; Moo et al., 2020), service recipients were at least as satisfied when remotely accessing medical follow-ups as when attending visits in-person (Moo et al., 2020), and many would like to continue access appointments remotely (Capozzo et al., 2020). During the medical follow-ups, service recipients felt able to talk as when during in-person follow-ups, comfortable accessing care remotely (Capozzo et al., 2020) and staff answered their questions satisfactorily (Moo et al., 2020). Unpaid carers were satisfied with remotely accessing home safety evaluations (Gately et al., 2020b), supportive (Laver et al., 2020) and care management interventions (Possin et al., 2019). The remote safety evaluation was perceived as being time efficient and unpaid carers felt comfortable using the technology (Gately et al., 2020b). Nevertheless, when comparing in-person to remote service delivery, unpaid carers were slightly more favourable towards accessing home safety evaluations (Gately et al., 2020b) and supportive interventions (Laver et al., 2020) in an in-person format. Whilst some people with dementia and unpaid carers valued the information provided on the information portal (Killin et al., 2018), it did not align with their perceived present needs and many experienced difficulties whilst navigating the technology, which contributed to the underuse of the service.

During the COVID-19 pandemic, check-up calls (Giebel et al., 2021d; O'Rourke et al., 2021), memory cafes (Masoud et al., 2021) and peer support group (Giebel et al., 2021b; Cousins et al., 2022;) provided valuable support, an opportunity to engage in activities and to connect with others. Whilst some people with dementia recognised their friends remotely, some were unable to (Giebel et al., 2021d; Masoud et al., 2021). Some unpaid carers reported that due to behavioural problems and general disinterest in technology, remote memory cafes were unsuitable for people with dementia (Masoud et al., 2021). Remote memory cafes rendered it difficult to meaningfully connect with others (Masoud et al., 2021) and remote memory cafes and support groups were ‘not the same’ as when meeting people in-person (Giebel et al., 2021d; Masoud et al., 2021). Furthermore, these were perceived to provide fewer benefits (Masoud et al., 2021), and may be unsuitable for people with visual impairments (Giebel et al., 2021d) or dementia-related behavioural problems (Masoud et al., 2021). Two studies reported reasons for declining remote post-diagnostic support. These included being unable to access or being unacquainted with the technology (Moo et al., 2020; Masoud et al., 2021), difficulties in engaging with the remote format and being unable to form meaningful connections with others remotely (Masoud et al., 2021).

## 2.5 Discussion

Findings from this systematic review suggest that, whilst remote post-diagnostic support may help to address some of the needs presented by people with dementia, or the dyad, service recipients’ views on accessing services remotely remained mixed. The increased reliance on remote service delivery during the COVID-19 pandemic has shed light on the duality of the use of ICT in service delivery (Wheatley et al., 2022), and lessons learnt are invaluable to construct future resilient services. As some elements

of remote service delivery are likely to endure as part of routine delivery, the use of ICT in service provision needs to be carefully considered, as to avoid further widening inequalities in access.

Remote post-diagnostic support may offer several benefits, nevertheless, these are likely to be limited to people with dementia and unpaid carers who can access and engage with ICT. Benefits include positively impacting on service recipients' quality of life, behavioural problems, caregiving burden, speech and language abilities and level of physical activity (Rogalski et al., 2016; Ptomey et al., 2019; Panerai et al., 2021). Some studies found benefits to be comparable to those offered through in-person service delivery (Chodosh et al., 2015; Kim et al., 2017; Dial et al., 2019; Possin et al., 2019; Laver et al., 2020). However, remote formats may be unable to replicate some benefits relating to social health, such as meaningfully engaging with others (Giebel et al., 2021d; Lee et al., 2021; Masoud et al., 2021), which is important to living well with dementia (Reilly et al., 2020). Accessing remote post-diagnostic support may not be suitable for people with advanced dementia (Rogalski et al., 2016) or sensory impairments (Giebel et al., 2021d), conditions which often form part of the exclusion criteria of studies exploring remote interventions (Yi et al., 2021). This highlights the importance of identifying when along the disease trajectory remote post-diagnostic support is suitable, and that the presence of comorbidities may hinder the ability to optimally engage with remote services.

A person-centred approach is integral to the delivery of dementia care pathways (NICE, 2018). People with dementia and unpaid carers should be offered a range of tailored post-diagnostic support services that cater to their changing needs and be presented with choices on how to access them. Prior to the COVID-19 pandemic, some service recipients preferred to access post-diagnostic support remotely, and the shift to remote service delivery during the pandemic was welcomed by some. Remote services may offer practical benefits such as reduced travel and associated costs, preservation of the person with dementia's routine, and help to circumvent mobility and caring constraints (Lee et al., 2021; Masoud et al., 2021; Sekhon et al., 2021). People with dementia and unpaid carers were satisfied with accessing some forms of post-diagnostic support remotely (Dal Bello-Haas et al., 2014; Rogalski et al., 2016; Ptomey et al., 2019), which aligns with findings of previous research (Hattink et al., 2016; Howe et al., 2020b; Sekhon et al., 2021). During the COVID-19 pandemic, remote post-diagnostic support was greatly valued, helped to scaffold much needed routines and to reduce loneliness (Capozzo et al., 2020; O'Rourke et al., 2021; Masoud et al., 2021; Cousins et al., 2022). Nevertheless, when comparing remote to in-person service delivery, service recipients' views were mixed (Gately et al., 2020b; Laver et al., 2020; Moo et al., 2020) and unpaid carers felt that remote memory cafes were overall less beneficial, and unsuitable to people with dementia with behavioural problems (Masoud et al., 2021). When interpreting the views on accessing post-diagnostic support remotely during the COVID-19 pandemic, it is important to acknowledge that in-person service delivery was either unavailable or undesirable at

that time. Thus, the hybrid delivery landscape needs to accommodate to presenting needs whilst empowering service recipients to access post-diagnostic support in their preferred format.

Many people with dementia and unpaid carers received ICT devices and ongoing technology support from the study team, which aligns with the findings of previous reviews (Gately et al., 2019; Sekhon et al., 2021). Nevertheless, after receiving devices and in-person orientation session, some service recipients continued to experience difficulties whilst engaging with ICT to access post-diagnostic support remotely (Killin et al., 2018). This queries the capacity of the current health and social care system to sustainably adopt similar delivery models without increasing the digital divide. Accessing services remotely is likely to require a suitable device, adequate digital literacy, which are likely to be intrinsically related to socio-demographic factors (Hargittai et al., 2019). People with dementia often relied on assistance from unpaid carers to access remote post-diagnostic support by installing the technology or facilitating their engagement with the service (Rogalski et al., 2016; Ptomey et al., 2019; Giebel et al., 2021d). Whilst the participation or presence of unpaid carers, alongside the person with dementia, formed a requirement to satisfy the inclusion criteria of several studies included in this review, the support provided by unpaid carers was not systematically captured. Understanding the degree of reliance on unpaid carers, and characterising the support provided is important, as some people with dementia live alone, and the ability of unpaid carers to provide technological support, is likely to be related to socio-demographic factors, notably age (Arighi et al., 2021). Additionally, unpaid carers may benefit from respite when people with dementia attend or engage with post-diagnostic support (Giebel et al., 2021e). Thus, if unpaid carers are required to provide support to facilitate the access or engagement of people with dementia with remote post-diagnostic support, this may limit the downtime they receive. Although beyond the scope of this systematic review, the assistance provided by service providers to promote meaningful engagement with people with dementia remotely is likewise fundamental (DiLorito et al., 2021; Yi et al., 2021), and ensuring service providers are adequately supported is key to the sustainable delivery of quality of support.

## 2.6 Strengths and limitations

To my knowledge, this systematic review is the first to synthesise evidence relating to accessing remote post-diagnostic support that address the needs of people with dementia or those of the dyad, and the explore service recipients' on accessing services remotely. Searches were conducted across six databases and studies written in English, German and French were considered for inclusion. Whilst included studies were of good methodological quality, some limitations ought to be acknowledged when interpreting the results. Firstly, due to a lack of resources, only one study team member screened the citations, appraised the methodological quality of studies and extracted the relevant data. Although any uncertainties were discussed and agreed upon with all study team members, the lack of a second

reviewer independently screening the citations may have led to some citations being missed. Grey literature was not searched, and studies that did not confirm the self-reported dementia diagnosis of participants were included. Evidence synthesised came from six countries (mainly the US and UK) and only one study explored the access to remote post-diagnostic support with people from minority groups (Chodosh et al. 2015). Cognisant that digital access and literacy is likely to be influenced by several socio-economic factors, my findings may not be representative nor generalisable to settings which are less economically developed, or populations coming from minority groups. Furthermore, several included studies lacked long follow-up time frames, control groups and the support provided by unpaid carers was not systematically captured. The study designs and tools employed in future studies would benefit from including longer follow-up time frames, control groups, capturing the support provided by unpaid carers, as well as investigating the feasibility and acceptability of remotely accessing different types of post-diagnostic support, notably those relating to social health, to reflect the diverse range of post-diagnostic important to living well with dementia.

## 2.7 Conclusions

This systematic review suggests that accessing post-diagnostic support remotely is likely to benefit some service recipients, nevertheless, views towards accessing services remotely remained mixed. Access to remote post-diagnostic support was frequently facilitated by providing ICT devices and ongoing technological support. These are important factors to consider whilst employing ICT within service delivery, and to avoid widening inequalities in access, it is important that services operating within the current hybrid service delivery landscape remain accessible to service recipients who are digitally excluded or who prefer to access services in-person.


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## 2.9 Disclosure statement

The authors report there are no competing interests to declare.

## 2.10 Comparing the findings from the original and updated search

The following paragraphs compare the findings from the original and updated search. The updated search was conducted in July 2023, and the results are reported in **Appendix B**. Similar to studies retrieved from the original search, studies from the updated search employed heterogenous study

designs and were of good methodological quality. Findings from the updated search align with, and expand upon, the results retrieved from the original search.

Firstly, akin to studies retrieved from the original search, several studies from the updated search report on evidence from higher income countries. However, the updated search identified three studies that report on evidence from Turkey, Indonesia and Brazil, which are classified as upper middle-income countries (The World Bank, 2022). This is important as using ICT is likely to be associated with socio-economic factors (Robinson et al., 2015; 2020). Expanding the evidence-base to include studies reporting on different contexts furthers our understanding of the feasibility and acceptability of accessing post-diagnostic support remotely.

Secondly, the types of post-diagnostic support accessed, and ICT formats employed, were similar across the studies retrieved from the original and updated search. The most frequently reported post-diagnostic support included exercise health sessions, peer support and medical follow-up consultations and videoconferencing software remained the most employed ICT format. However, retrieved from the update search, one study reported on an additional type of post-diagnostic support, an advanced care plan intervention (Vellani et al., 2022; 2023) and two studies reported on the use of WhatsApp (Lima et al., 2022; Gerritzen et al., 2023a). Expanding the evidence base to report on multiple ICT formats and types of post-diagnostic support is important to help identify the best format(s) to access different types of support remotely.

Thirdly, akin to studies retrieved from the original search, several studies from the updated search provided (if required) orientation or training sessions on how to use the ICT and relevant software, however, no studies from the updated search lent ICT devices to service recipients. This could be due to data collection occurring during the COVID-19 pandemic, which may have engendered additional logistical challenges to deliver ICT devices, and service recipients' increased ownership of ICT devices. Several studies retrieved from the original and updated search required people with dementia to have an unpaid carer to satisfy the inclusion criteria. Nevertheless, the support provided by unpaid carers, either to navigate the ICT and/or to engage with post-diagnostic support, was not systematically captured. Characterising the support provided by unpaid carers is important as some people with dementia live alone, and not all unpaid carers may be able to provide support (Arighi et al., 2021).

Lastly, similar to studies retrived from the original search, studies from the updated search suggest that accessing some forms of post-diagnostic support remotely may benefit some service recipients. Nevertheless, service recipients' views towards acccessing post-diagnostic support remotely were mixed, which aligns with findings of the original search. However, the updated search expands our understanding of service recipients' views by providing evidence that remote service provision may

help to deliver inclusive services, whereby people with dementia can commuicate in their preferred format (text and/or verbally). Furthermore, the updated search retrieved studies that reported on why people with dementia stopped accessing support remotely, and suggestions offered by service recipients to improve remote services.

## 2.11 Research developments from this chapter

This chapter presented the findings of my systematic review that sought to understand how ICT has been employed to access post-diagnostic support and service recipients' views on accessing support remotely. Several types of post-diagnostic support, including exercise health sessions, dementia-related medical follow-up sessions and speech and language therapy, were accessed remotely, often by videoconferencing software. Overall, my findings suggest that accessing some types of post-diagnostic support remotely may benefit some service recipients, however, people with dementia and unpaid carers views towards accessing support remotely were mixed.

My Ph.D. project focuses on the engagement with social care and support services, which form part of post-diagnostic support, during the pandemic. In my systematic review, I identified four studies reporting on different types of social care and support services accessed during the pandemic (Masoud et al., 2021; Cousins et al., 2022; O'Rourke et al., 2022; Giebel et al., 2021d). All studies adopted qualitative lines of inquiries. Cognisant that a breadth of services that form part of social care and support, it is important to understand how the delivery of an array of services adapted throughout the pandemic and service recipients' views on accessing services remotely. Thus, I sought to devise a quantitative survey to understand how different types of social care and support services were delivered at different timepoints during the pandemic (**fourth** chapter). Findings from my systematic review, notably the types of ICT formats employed to access post-diagnostic support, informed the development of some aspects of the measuring tool. Furthermore, to expand on service recipients' views on accessing social are and support services remotely from my systematic review, I sought to conduct semi-structured interviews with people with dementia and unpaid carers (**fifth** chapter). The following chapter describes the methodology of the empirical studies I conducted.

# CHAPTER 3: METHODS AND MATERIALS

My Ph.D. project sought to explore the barriers and facilitators to engaging with social care and support services during the pandemic. Specifically, my aim was guided by the following objectives:

1. To understand how the delivery of community-based social care and support services adapted, and to map out the availability of services across the UK during the pandemic.
2. To explore the facilitators and barriers to delivering and utilising community-based social care and support services in the during the pandemic.
3. To recommend strategies to possibly overcome barriers that lead to inequalities in access and utilisation.

To address the objectives, I conducted explanatory sequential mixed method study that consisted of a quantitative longitudinal survey and semi-structured interviews. My thesis is prepared in a journal format with published or submitted papers forming the **fourth** and **fifth** chapter. While the specific methodologies and methods employed are provided in their respective chapters, this chapter provides additional detail and justification to employing a mixed methods approach. The chapter commences by explaining the research philosophy, explanatory sequential mixed-method study design and introduces the study populations and sampling strategies. Data collection and analysis procedures are explained, and the chapter concludes by outlining the involvement of the public advisors and the use of the Health Inequality Assessment Toolkit (Porroche-Escudero & Popay, 2020).

## 3.1 Research philosophy

Lincoln and Guba state that paradigms *'represent a distillation of what we think about the world (but cannot prove)'* (1985, p.15). The beliefs are dependent on the research philosophy, the ontological and epistemological positionings, which successively, shape the methodology and methods employed. Ontology is *the study of being*, which focuses on the nature of reality, and epistemology, is concerned with *how we know what we know* (Guba & Lincoln, 1994). A continuum of research philosophies, ranging from positivism to constructivism, exist. The ontology and epistemology associated with positivism and constructivism are briefly described below.

Positivism adopts a realist ontology that acknowledges a single and observable reality (Guba & Lincoln, 1994). The epistemology underpinning positivism is objectivism. Objectivism perceives truth to exist within objects, and objective truth can be researched (Crotty, 1998). A dualistic epistemological position is assumed, whereby the researcher and phenomenon, remain independent (Guba & Lincoln, 1994). Positivist research is often associated with quantitative methods and employs a deterministic

cause-and-effect approach that seeks to generate general laws regarding variables through controlled experiments.

In contrast, a constructivist ontology rejects the notion of an objective reality, or that is can be objectively researched. Instead, multiple realities exist as it is constructed within one's perceptions, experiences and language (Guba & Lincoln, 1994). A constructivist epistemology contends that while fallible, knowledge on reality can be obtained through human perspectives and experiences. Knowledge is contextual (Crotty, 1998) and is a '*…an expression of the language, values, and beliefs of particular groups and communities*' (Bantjes & Swartz, 2017 p.7). A constructivist epistemology is transactional, whereby the researcher is unable to be separated from the knowledge created (Guba & Lincoln, 1994). This worldwide view is often associated with qualitative methods and seeks to explore and interpret subjective perceptions through discourse (O'Mahoney & Vincent, 2013). Unlike positivist thinking, constructivism research does not conceptualise causality as linear, but constructed within human perception.

My work is grounded in the philosophy of science of critical realism, a relatively new school of thought which adopts elements of positivist and constructivist thinking. The development of critical realism is attributed to the work of Roy Bhaskar, who critiqued that reducing reality to what can be known about reality is limiting our understanding of reality (Bhaskar, 1975). For example, the ontological position held by positivism limits our knowledge to things that are observable, and thus measurable. Positivist research can yield numerical and statistical relationships between variables in a controlled environment (e.g. laboratory environment). However, positivist research may have limits in explaining why things happen, do not happen, or sometimes happen (Bhaskar, 1975; O'Mahoney & Vincent, 2014), and does not convey the phenomenological. With regards to constructivist approaches, as the philosophical stance holds that an external world beyond human perception does not exist, knowledge on reality must be viewed at face-value and claims that 'better' explanations of reality that may exist must be rejected (Bhaskar, 1975; O'Mahoney & Vincent, 2014). Bhaskar argued that the dichotomy between objectivism and subjectivism creates a false illusion of two different realities. By posing '*What must the world be like for science to be possible?*' (Bhaskar, 1975, p.13), Bhaskar contends that epistemology must be separated from ontology and argues that while a real world exists beyond human perception (realist ontology), knowledge concerning the real world is conceptually mediated (constructivist epistemology) (Bhaskar, 1975). Therefore, the implausibility of acquiring objective knowledge is accepted, and the production of knowledge is deemed fallible (Maxwell & Mittapalli, 2010). Critical realism holds several assumptions on reality, which are briefly expanded upon below.

Critical realism perceives reality as a '*stratified, open system of emergent entities*' (O'Mahoney & Vincent, 2014, p. 7). An open system refers to the complex interactions between mechanisms causing observable events to occur, which, unlike a laboratory environment, are context specific and cannot be controlled (O'Mahoney & Vincent, 2014). Entities are defined as 'things', including people, organisations and policies, that can cause change (O'Mahoney & Vincent, 2014). Entities possess powers, which they may or may not exert, and interact with other entities to result in change(s). The interplay between entities that may result or trigger observable events can be referred to as 'generative mechanisms' (Mukumbang, 2023).

Moreover, critical realism divides reality into three domains, and distinguishes the real from the observable (Bhaskar, 1975; O'Mahoney & Vincent, 2014; Critical Realism Network, 2021[1]). The *empirical* domain is concerned with the human experiences and observations of a phenomenon. The *actual* domain relates to a phenomenon, both observable and non-observable, that has occurred. The *real* domain refers to the mechanisms or structures that generate the actual world. **Table 8** shows the three domains of reality applied to my Ph.D. project. The distinctions between the domains of reality are important as it encourages the processes explaining how things are and how they act in certain contexts, to be explored (Burson et al., 2023).

**Table 8** Definition of the three dimensions of reality and how they apply to my Ph.D. project (Critical Realism Network, 2021[2])

| **Definition** | **Applied to Ph.D. project** |
|---|---|
| *Domain of empirical* | |
| The experiences we can capture through our senses and perceptions | - Experiences of delivering and accessing social care and support services during the pandemic<br>- Adaptations to the delivery of social care and support services during the pandemic |
| *Domain of actual* | |
| The events that happen but are not necessarily observable | - Access or non-access to social care and support services during the pandemic |
| *Domain of real* | |
| Mechanisms that are responsible of the outcome that is observed | - Factors influencing inequalities in access to social care and support services during the pandemic |

By studying events within the *actual* domain, such as the access or non-access to social care and support services, through human perception and senses (the *empirical* domain), information relating to the mechanisms (the domain of *real*) can be explored. Critical realism accepts the multiplicity of generative mechanisms and that the interplay between mechanisms may not always yield with the same outcome(s)

[1] Resource accessed: Introducing Critical Realism Workshop 1: Ontology

[2] Resource accessed: Introducing Critical Realism Workshop 1: Ontology

(Bhaskar, 1975; Maxwell & Mittapalli, 2010; Koopmans & Schiller, 2022). Furthermore, the philosophical stance acknowledges that mechanisms may be influenced by contextual structures (both physical and social) and/or by entities exerting (or not) powers, which enables a nuanced exploration (O'Mahoney & Vincent, 2014) of factors related to the access or non-access to social care and support services during the pandemic.

Transitioning from the domain of the *empirical* to the domain of the *real* often involves a mixture of abduction and retroduction reasoning (O'Mahoney & Vincent, 2014). Abduction involves connecting observations to propose possible explanations of generative mechanisms, and retroduction involves thinking about what '*the world (e.g., broader context) must be like in order for the mechanisms we observe to be as they are and not otherwise*' (O'Mahoney & Vincent, 2014, p. 18). In the context of my Ph.D. project, abduction reasoning involves observing how the delivery of social care and support services adapted during the pandemic and exploring possible reasons influencing access or non-access to services. Retroduction reasoning involves thinking about the broader context, the social determinants of health, which factors may facilitate and hinder access, where and for whom. Providing an exhaustive account of mechanisms influencing access or non-access to social care and support services during the pandemic is beyond the scope of my research. Instead, I aim to document how service delivery adapted and provide meaning to delivering and accessing services during the pandemic.

Owing to critical realism's realist ontology and constructivist epistemology, the metatheory can provide a helpful orientation to research, notably studies with aims seeking to describe and explain things, while considering the context in which they occur. Although focused on studying organisations, the chapter by O'Mahoney & Vincent (2014) provides a practical and accessible introduction to understanding how critical realism informed research can produce nuanced, context-dependent, accounts and explanations of events. My work focuses on access to social care and support services during the pandemic. I chose to adopt a critical realist lens of inquiry as I sought to describe and explain access to social care and support services during the pandemic. This involved describing how service delivery adapted, and gaining an understanding of why services adapted as they did. Furthermore, I sought to explore who had access to social care and support services, and possible barriers and facilitators experienced. Causal mechanisms influencing access to remote social care and support services are likely to be related to the social determinants of health (see section 3.2), which enabled me to explore my work in the context of inequalities in access. Nevertheless, providing an exhaustive account of causal mechanisms influencing access to social care and support services during the pandemic is beyond the scope of my research. Instead, I aim to document how service delivery adapted and provide meaning to delivering and accessing services during the pandemic.

## 3.2Dahlgren-Whitehead model

The Dahlgren-Whitehead model (Dahlgren & Whitehead, 2021) offers a framework to think about how social determinants of health may result in inequalities in health outcomes across individuals and populations. The model consists of five layers. Within each layer there are factors that are positive to health outcomes, protective against adverse outcomes, and risks to health problems (Dahlgren & Whitehead, 2006). The model depicts how factors can interact with one another to influence and result in different health outcomes (Dahlgren & Whitehead, 2021).

Recently, Jahnel and colleagues (2022) suggested that the model is conducive to thinking about how the use of ICT may influence health and health inequalities. As shown in **Figure 2**, the authors have included examples of 'entry points' where the reliance on ICT may result in health inequalities (Jahnel et al., 2022). The adapted model was used to shape and guide my thinking while discussing my findings and the possible factors influencing access and non-access to social care and support services.

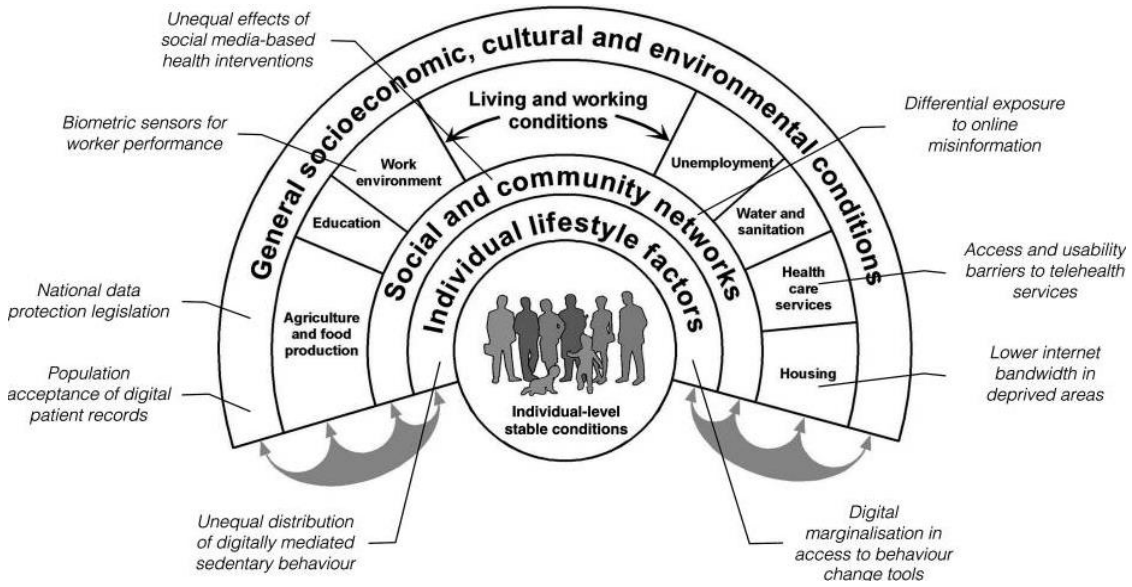


**Figure 2** Developed by Jahnel and colleagues (2022), the figure is based on the Dahlgren-Whitehead model (Dahlgren & Whitehead, 2021) and includes examples of ICT entry points of health inequalities

## 3.3 Mixed method study design

Critical realism is compatible to quantitative and qualitative lines of inquiries and lends itself well with mixed-method approaches (Maxwell & Mittapalli, 2010; O'Mahoney & Vincent, 2014).

### 3.3.1 Overview of mixed method study designs

The use of mixed methods approaches, whereby one or more research methods are mixed in a single study, has become a widespread methodological choice, notably within the realm of health service research (O'Cathain et al., 2007). Creswell and colleagues (2011a) proposed the following definition that encapsulates the heterogeneity among mixed method study designs.

> [Mixed methods approaches focuses] '… *on research questions that call for real-life contextual understandings, multi-level perspectives, and cultural influences; employing rigorous quantitative research assessing magnitude and frequency of constructs and rigorous qualitative research exploring the meaning and understanding of constructs; utilising multiple methods (e.g., intervention trials and in-depth interviews); intentionally integrating or combining these methods to draw on the strengths of each; and framing the investigation within philosophical and theoretical positions*' (Creswell et al., 2011a, p.4)

Elements contributing to the variance of mixed method study designs include the purposes to mixing research methods, timing of components, and when components meet (Morse & Niehaus, 2009; Schoonenboom & Johnson, 2017). These elements are briefly expanded upon below.

Research methods may be mixed to achieve different purposes, that include triangulation of findings, complementarity (use the findings from the latter study to elaborate on the results of the former), development (findings of the former study are used to help the sampling, tool development or inform the analysis of the latter study), initiation (combine both lines of inquiry to uncover contradiction) and expansion (increase scope, breath or width of the former study with the latter) (Greene et al., 1989).

The timing of the components may differ. Data collection and analysis of each component can be undertaken concurrently or sequentially (Schoonenboom & Johnson, 2017). Morse and Niehaus employ the term 'point of interface' to refer to the '*… the position in the research process in which the two components meet'* (Morse & Niehaus, 2009, p.55). Some authors recognise one point of interface within a study (Morse & Niehaus, 2009), whereas others argue that one study may have multiple points (Fetters et al., 2013; Schoonenboom & Johnson, 2017). Furthermore, depending on the research aim(s), components may be attributed priority. Priority denotes '*…the relative importance or weighting of the quantitative and qualitative methods for answering the study's questions…*' (Creswell, 2011b, p. 65). Morse and Niehaus (2009) argue that study components are unable to be granted equal weighting, however, other authors (e.g., Creswell et al., 2011b) recognise and argue that components can be granted equal weighting.

### 3.3.2 Sequential explanatory study design

I employed a sequential explanatory mixed-methods study design, which involves a quantitative component followed by a qualitative line of inquiry (Schoonenboom & Johnson, 2017). This enabled me to quantitatively document, in real time, how the delivery of social care and support services adapted, and to complement and expand my findings through qualitative exploration. Components were granted equal weighting as both studies were important to provide a holistic account of the delivery and access to social care and support services during the pandemic.

Based on a figure devised by Ivankova and colleagues (2006), **Figure 3** outlines the points of interface. Connecting data is a form of integration, which involves applying the findings of the former study, to inform the initial phases of the following study (Creswell et al., 2011a; 2011b; Fetters et al., 2013). Integration also occurred at the interpretation and reporting level. A narrative staged approach was adopted (Fetters et al., 2013) whereby the findings from the survey and interviews were analysed and interpreted separately and reported in two distinct published or submitted papers (**fourth** and **fifth** chapters). The **sixth** chapter forms an overall critical discussion, and findings from my survey and interviews are presented together.

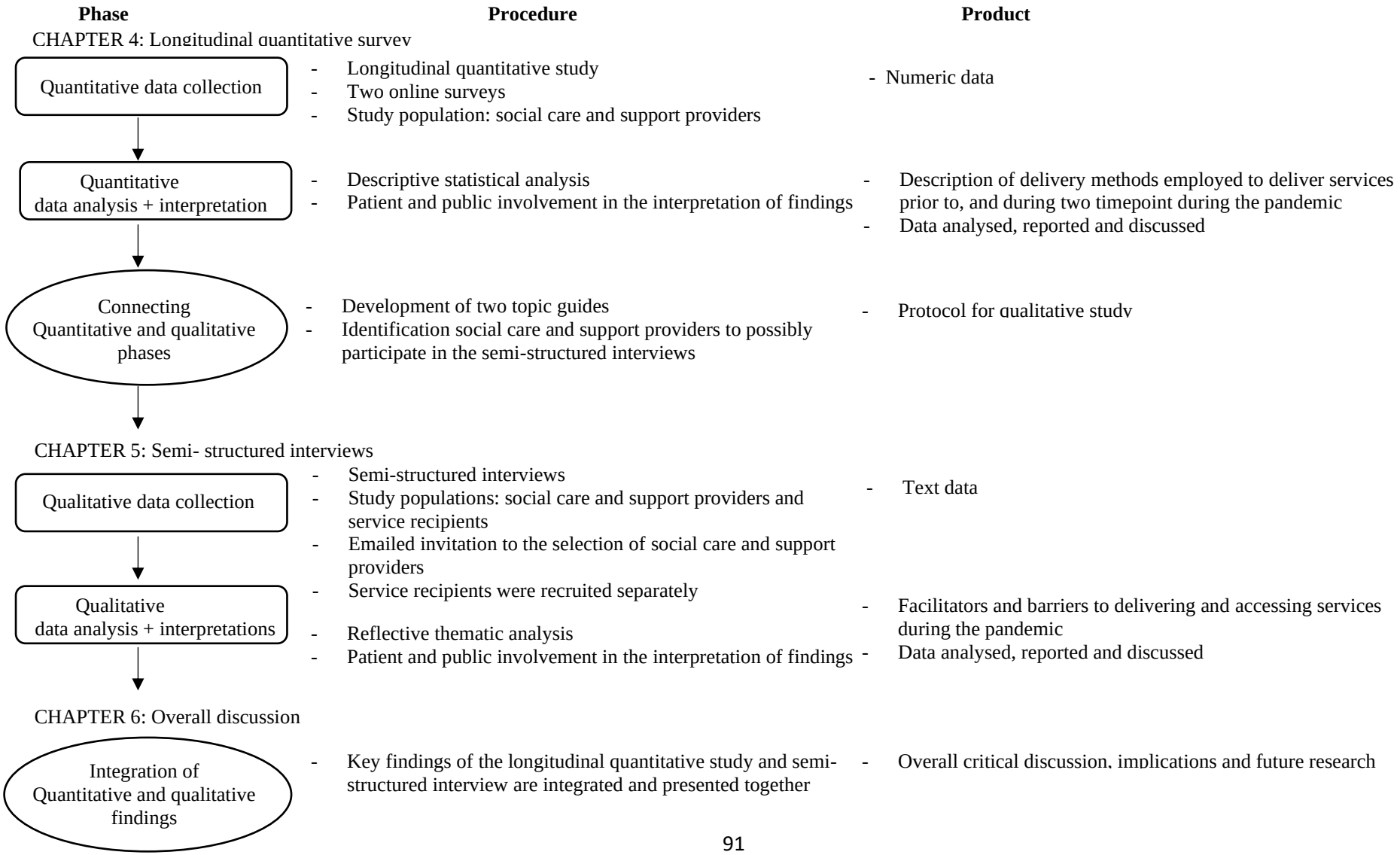




**Figure 3** Overview of the sequential explanatory study design employed. (Figure based on a figure devised by Ivankova et al., 2006)

#### 3.4.2.1 Mapping the objectives of the thesis and studies

The aim of my Ph.D. project was to explore the barriers and facilitators to engaging with community-based social care and support services during the pandemic, and was guided by the following objectives:

1. To understand how the delivery of community-based social care and support services adapted, and to map out the availability of services across the UK during the pandemic.
2. To explore the facilitators and barriers to delivering and utilising community-based social care and support services in the during the pandemic.
3. To recommend strategies to possibly overcome barriers that lead to inequalities in access and utilisation.

The survey compared (1) the types of community-based social care and support services delivered; and (2) the delivery methods employed prior to and at two timepoints during the pandemic. The findings from the survey addressed the first and third thesis objectives.

The interview study sought to (1) understand how the delivery of community-based social care and support services adapted during the pandemic; (2) explore the experiences of delivering and accessing community-based social care and support services during the pandemic; and (3) to understand the challenges and opportunities presented by using ICT within service delivery. Findings from the interview study addressed all three thesis objectives.

## 3.4 Study populations

### 3.4.1 Longitudinal quantitative survey

The survey was addressed to social care and support providers, defined as someone who delivers non-clinical community-based social care and support services to people with dementia and/or to unpaid carers in a paid or unpaid (volunteer) capacity. The delivery of social care and support services is likely to rely upon a mixture of people who are formally employed and volunteers (McCall et al., 2020; Sun et al., 2021). Volunteers were defined as people

> '*…giving of time and energy… which can bring measurable benefits to the volunteer, individual beneficiaries, groups and organisations, communities, the environment and society at large. It is a choice undertaken of one's own free will and is not motivated primarily for financial gain or for a wage or salary.'* (Scottish Government, 2019, p.4-5).

Eligible social care and support providers satisfied the following criteria: (1) currently working (paid capacity) or helping / volunteering (unpaid capacity) to deliver social care and support services within the public, private of voluntary sector in the UK; (2) delivering social care and support services to

people with dementia and/or to unpaid carers living in the community; (3) either directly involved in delivering social care and support services or involved in the management / organisation of the delivery of social care and support services and (4) at least 18 years of age.

### 3.4.2 Semi-structured interviews

Interviews were conducted with social care and support providers, people with dementia and unpaid carers. Eligible social care and support providers satisfied the following criteria: (1) currently working (paid capacity) or helping / volunteering (unpaid capacity) to deliver social care and support services within the public, private of voluntary sector in the UK; (2) delivering social care and support services to people with dementia and/or to unpaid carers living in the community; (3) either directly involved in delivering social care and support services or involved in the management / organisation of the delivery of social care and support services and (4) at least 18 years of age.

Individuals with dementia were eligible to participate if they: (1) lived in the community; (2) accessed social support services in the UK both prior to and during the COVID-19 pandemic; (3) able to provide informed consent; and (4) at least 18 years of age. The inability to provide informed consent formed part of the exclusion criteria. All dementia subtypes were included, and akin to other studies conducted during the pandemic, participants' dementia diagnosis was not confirmed (e.g., Giebel et al., 2021c; Talbot & Briggs, 2022; Gerritzen et al., 2023a; 2023b)

The DHSC defines an unpaid carer as '*…someone who provides unpaid help to a friend or family member needing support, perhaps due to illness, older age, disability, a mental health condition or an addiction'* (2018, p.4). Based on the DHSC's definition, this study defined an unpaid carer as '*someone who self-identifies as an unpaid carer, which includes providing unpaid help to a friend or family member needing support due to their dementia'.* Current and former unpaid carers who have or are supporting a community-dwelling person with dementia and met the following criteria were eligible to participate: (1) have accessed social care and support services prior to and during the COVID-19 pandemic in the UK that either addresses their needs, the needs of the person with dementia or the dyad's needs; and (2) at least 18 years of age.

## 3.5 Sampling strategies

### 3.5.1 Longitudinal quantitative survey

Convenience sampling is a non-probability technique whereby a sample is drawn from a population that is most readily available (Green & Thorogood, 2018). Cognisant of the changing COVID-19 public health measures (Institute for Governmental Analysis, 2021; SPICe, 2022; Welsh Parliament, 2021, 2022), a convenience approach to sampling was employed to enable as many social care and support

providers to participate in a short-time frame. While convenience sampling reduces the generalisability of the findings and is subject to selection bias (Althubaiti, 2016; Andrade, 2021), it has been employed by several studies, notably during the pandemic (e.g., Giebel 2021c; McLoughlin et al., 2023; Neill et al., 2023).

Publicly available email addresses and telephone numbers of social care and support organisations across the UK were contacted. A flyer (**Appendix C**) was devised, shared on social media (X, formerly Twitter), in University of Liverpool Newsletters and advertised within dementia sub-group of the Contacts, Help, Advice and Information Network (CHAIN). CHAIN is a support group network for people working within health and social care (CHAIN, 2023). Furthermore, I engaged with social prescribing routes and attended and shared the research opportunity at a Link worker meeting.

### 3.5.2 Semi-structured interviews

#### 3.5.2.1 The concept of saturation and information power

The concept of 'saturation', often understood as information redundancy, stems from the notion of theoretical saturation in grounded theory (Braun and Clarke, 2021). To assist with sample size estimation ahead of data collection, several authors (e.g., Guest et al., 2006) have operationalised the concept of saturation, and identified a minimum range of participants needed to achieve saturation. In a recent commentary, Braun and Clarke (2021) argued that the concept of saturation, and operationalising it ahead of data collection, is unsuitable for some types of thematic analysis (TA), including reflexive TA, which I employed (see section 3.8.2.1). In reflexive TA, Braun and Clarke (2021) state that analysis is dependent on researchers' iterative engagement with the data and argue that concept of saturation is problematic. Instead, the authors (Braun and Clarke, 2021) suggest that the concept of information power (Malterud et al., 2016) may help in guiding estimation of sample sizes ahead of recruitment.

Thus, to determine appropriate sample sizes, Malterud and colleagues' (2016) concept of 'information power' encourages researchers to reflect on the study aim, sample specificity, use of established theory, quality of dialogue and analysis strategy. The dimensions related to the concept of 'information power' and their implications to sample sizes are summarised in **Table 9**, and the following paragraph explains how I established a provisional sample size ahead of data collection.

**Table 9** Dimensions related to the concept of 'information power' and sample size requirement (Malterud et al., 2016)

| Dimensions | Sample size | |
|---|---|---|
| | **Smaller** ◄——► | **Larger** |
| *Study aims* | Narrow | Broad |
| *Sample specificity* | Dense | Sparse |
| *Established theory* | Applied | Not applied |
| *Quality of dialogue* | Strong | Weak |
| *Analysis strategy* | Case | Cross case |

Firstly, a broader study aim is likely to require a greater sample size. The aims of my interview study were relatively narrow, and a smaller sample size was deemed sufficient. Secondly, the specificity of the sample relates to participants' '*experiences, knowledge, or properties*' (Malterud et al., 2016, p.1755). While several recruitment strategies were planned (see section 3.5.2.2), challenges in recruiting participants (notably people with dementia) with heterogenous experiences was anticipated, and therefore, a larger sample size would be required. Thirdly, information power relates to the degree of theoretical background underpinning the study. While my study was conducted through the lens of critical realism, limited theoretical background was applied, requiring a larger sample size. Fourthly, a smaller sample size is likely to be required if the interviews yield rich dialogue. In part, rich dialogue may be facilitated by the researcher's interviewing skills and the rapport built between the interviewer and participant. While my background in physiotherapy may facilitate rapport building, my experience in qualitative research is limited, and a larger sample size is likely to be required. Lastly, information power relates to the data analysis method employed. I sought to explore and compare participants' experiences of delivering and accessing services, which is likely to require a larger sample size than would occur in an in-depth analysis due to the critical lens through which the data are examined.

Based on the elements described above and cognisant of resource constraints, a provisional sample size of 15 participants from each study population was established (n=15 social care and support providers and n= 15 service recipients).

### 3.5.2.2 Recruitment avenues

Social care and support providers were recruited from participants who participated in my survey and who expressed interest in taking part in further qualitative research. To increase the diversity of experiences captured, potential participants were purposefully sampled. Purposeful sampling can be defined as '*a sample in which cases are selected 'purposefully' in order to include a predetermined*

*range or information -rich cases*' (Green & Thorogood, 2018, p.387). Maximum variation sampling is a form of purposive sampling that involves selecting potential participants to ensure that the experiences garnered '*…cover(s) the widest range of 'types' that would be found in the larger population, although not necessarily in the proportions that would be found in the population*' (Green & Thorogood, 2018, p.76). The following elements, previously collected within the survey, guided the invitation of social care and support providers:

- Socio-demographic factors (ethnic group, gender and age group)
- Index of Multiple Deprivation (IMD) quintile of service provision area
- Geographical location within the UK
- Sector (public, private and Third sector)
- Types of services delivered during the pandemic
- Technological and non-technological formats employed to deliver services during the pandemic

The elements were selected due to the following reasons. Firstly, while most of social care and support providers in the public and Third sector consist of people identifying as White and female (Skills for Care, 2022; NCVO, 2021), it is important to explore the experiences of providers from diverse backgrounds. Secondly, access to social care and support services may differ across geographical areas and levels of deprivation (Bieber et al., 2019; Giebel et al., 2021d). The IMD is a relative measure of neighbourhood deprivation calculated by an amalgamation of multiple factors including income and health (Department for Communities and Local Government, 2015). Areas are classified into quintiles, the first being the most deprived and fifth the least deprived. Thirdly, to depict the heterogeneity of social care and support services and providers involved in delivering services, potential participants were selected depending on the types of services delivered, sector and contractual arrangement (paid / volunteering). Lastly, to explore experiences of using a breadth of technological and non-technological formats to deliver services during the pandemic, selection was also guided by the formats employed.

Potential participants were invited by emailing the study information sheet (**Appendix G**), and if required, were sent a follow-up email one week after. However, challenges were faced while recruiting, and the research opportunity was shared with all eligible participants (n=43).

People living with dementia and unpaid carer participants were recruited by convenience sampling (Green & Thorogood, 2018). A flyer was devised (**Appendix D**). The research opportunity was shared on social media (X, formerly Twitter), amongst known dementia social care and support organisations and social prescribing routes. Dementia specific recruitment avenues were explored. The research opportunity was advertised on Join Dementia Research (n.d), at a remote dementia peer support group and at in-person dementia information day. Join Dementia Research is a free service that connects

interested people with dementia and unpaid carers with studies advertised on the platform by inclusion criteria and postcodes. Further information regarding postcode selection is provided in **Appendix U**. If potential participants expressed interest, respective study information sheets (**Appendix G**) were shared. Potential participants' eligibility (except for mental capacity of people with dementia, see section 3.6.2.1) was confirmed by email prior to scheduling an interview date.

## 3.6 Ethical considerations

The research undertaken adhered to the ethical principles outlined in the declaration of Helsinki (World Health Assembly [WHA], 2013).

### 3.6.1 Longitudinal quantitative survey

Ethical approval was granted by the University of Liverpool (reference 9817) prior to the commencement of the study. A study information sheet was devised (**Appendix E**). The consent form (**Appendix F**) was uploaded onto Jisc Online Surveys, and written informed consent was obtained. Only prospective participants agreeing to all statements outlined in the consent form were able to participate. For participants who participated by telephone, I read out the consent form and recorded their answers on the electronic version of the survey.

The survey was piloted with my public advisor and wider supervisory team and was not deemed to cause distress (see sections 3.7.1.2 and 3.10.2). However, the contact details of the research team members and ethics committee were included in the information sheet. Participants were encouraged to contact members of the research team or ethics committee should they have questions regarding the survey or how the study was conducted. The data management plan can be found in **Appendix L**.

### 3.6.2 Semi-structured interviews

Ethical approval was granted by the University of Liverpool (reference 1036) prior to the commencement of the study. Study information sheets (**Appendix G**) and consent forms (**Appendix H**) were devised for each study population and shared ahead of the interview. Verbal informed consent was obtained prior to interviewing. I read out each statement outlined in the consent form, and if prospective participants agreed, they were asked to state so while the recording device was on. Only prospective participants who agreed to all the statements were eligible to participate.

The topic guides were piloted with my public advisor (see sections 3.7.2.1 and 3.10.2) and were not deemed to cause distress. Nevertheless, owing to the nature of the topic, two debrief forms were devised (**Appendix O**). The distress protocol and the data management plan can be found in appendices (**Appendix N** and **Appendix M**).

### 3.6.2.1Mental Capacity Act

The Mental Capacity Act (2005) (MCA) regulates the eligibility of people with dementia to participate in research in England and Wales by providing a framework to assess the ability of prospective participants to provide an informed decision regarding their participation. The MCA details a two-stage process to assess the mental capacity of an individual. The initial step involves identifying if an individual has an impairment to the brain or mind. If so, the second step compromises of assessing whether the identified impairment results in the inability of an individual to make a decision under consideration at a given time. An individual is deemed to have the mental capacity to make a specific decision if they can: understand the relevant information; retain the information; weigh up the decision as part of the decision-making process and to communicate their decision (Mental Capacity Act, 2005).

All prospective participants with dementia were sent the study information sheet and consent form, by email, at least one week prior to the scheduled interview date. To ensure that the study documents were accessible, dementia-friendly writing recommendations were followed (Dementia Engagement and Empowerment Project [DEEP], 2013) and documents were reviewed by public advisors working on the project (see section 3.10.2). People with dementia may require additional time (Alzheimer's Society, 2023) to consider the information and to decide whether they would like to participate, and the information sheet was sent at least one week before the interview. Prior to the interview, I exchanged several emails with prospective participants with dementia, which gave me an informal indication of their ability to provide informed consent. On the day of the interview, I ensured they had read the study information sheet, discussed the study and, outlined what participating entailed. Time was allocated for questions or clarifications. Thereafter, using open-ended questions, I asked individuals to tell me about the study in their own words, and why they would like to participate (Alzheimer's Society, 2023). The discussion was summarised in the field notes. If prospective participants were deemed to not have the mental capacity to provide informed consent regarding their participation, they were thanked for their interest and explained the reason why, on this occasion, they were unable to participate. If prospective participants were deemed able to provide informed consent, verbal informed consent was obtained as detailed above (see section 3.6.2). During the interview, I considered any visual cues (if interviewed by videoconferencing software with video icon enabled) and how participants with dementia were responding (Alzheimer's Society, 2023). If any signs of tiredness or disinterest were observed, participants were offered to continue the interview another day. Should participants elect to continue the interview later, verbal informed consent was gained prior to the interview, following the same procedure as outlined above (see section 3.6.2).

My primary supervisor, who has extensive experience with working with people with dementia in a research context, was present and observed me conduct all mental capacity assessments. Prior to the

commencement of the study, I completed the NHS Health Research Authority (2022) e-learning training on the 2005 MCA Act.

## 3.7 Data collection methods

### 3.7.1 Longitudinal quantitative survey

Cognisant of the changing COVID-19 public health measures, a longitudinal descriptive study design was deemed suitable to compare service delivery methods employed prior to, and at two timepoints during the pandemic.

#### 3.7.1.1. Study design

I employed a panel study, a type of longitudinal study design that measures the same variables on the same subjects over time (Ruspini, 2002), to describe the delivery of social care and support services prior to and during the pandemic. The first survey elicited information on service delivery prior to the pandemic (retrospectively) and at the first timepoint (T1). The second survey solely obtained information regarding service delivery at the second timepoint (T2). The study was conducted as COVID-19 public health measures were easing. Cognisant of the changing COVID-19 public health measures, and following discussions with the supervisory team, it was decided to implement a period of three months between the surveys. A summary of the public health measures across the survey timepoints are found in **Appendix I.** Due to the ongoing COVID-19 public health measures, all surveys were conducted remotely, either by telephone or Jisc Online surveys. Jisc online surveys is a commercial cloud-based software designed for academic research that disseminates surveys and instantly collates the results on a password-controlled cloud and is used as it was freely available by the University of Liverpool.

#### 3.7.1.2. Tool development

The measuring tool was devised based on discussions with the supervisory team, public advisors and previous literature, including my systematic review. To place minimal demand on social care and support providers, the tool was developed to be quick and easy to complete. Composed of a mixture of closed-ended dichotomous, listed multiple responses and additional free text options, the tool (**Appendix J**) collected information on variables detailed below.

*Characteristics of participants (age range, gender, ethnicity, years of full-time education completed and years of working or volunteering as a social care and support provider)*

Age was collected in ranges, and the options in the first part of the questions recommended by the Office for National Statistics (ONS) (n.d.) was used to collect information on participants' ethnic group.

Years of full-time education and years of working / volunteering was used as a proxy for educational attainment and experience in the field. All questions included the options 'prefer not to say' and 'other'.

*Characteristics of providers (sector, current contractual arrangement (paid / unpaid), postcode of service provision area)*

It was important to collect information regarding the sector, as it is likely that service delivery adapted differently across sectors. The postcode of service provision areas (if services mainly involved home visits, organisations' local office postcode was collected) enabled the IMD index (Department for Communities and Local Government, 2015) to be generated. All questions included the option 'prefer not to say'. The number of hours worked / volunteered per week was collected across survey timepoints as it may provide valuable insight how service delivery adapted. Furthermore, the COVID-19 public health measures resulted in the, at least temporary, closures of services (e.g., Giebel et al., 2020b). Thus, if applicable, the number of weeks service delivery was paused was collected.

*Services delivered (types of services delivered, identification of primary service)*

A closed-ended question elicited the types of services participants delivered across survey timepoints. Participants were able to select multiple options. Previous literature (Giebel et al., 2021c) and discussions with the supervisory team and public advisor assisted in identifying different types of services to include as options. An 'other' option allowed participants to report services not included within the options. To compare the delivery methods and use per service type, participants were asked to identify their primary service. The primary service was defined as the service most delivered at each survey timepoint. The same close-ended question employed to ascertain all types of services delivered was used, however, participants could only select one option. Service recipients of the primary service were collected (people with dementia, current / former unpaid carers or both) as the delivery of services may adapt differently depending on the intended recipient.

*Delivery methods employed (in-person, hybrid or remote, use of digital and non-digital formats)*

A closed-ended question elicited the delivery method employed to deliver primary services across survey timepoints. Participants could select multiple of the following options: in-person - one-to-one; in-person - group format; remote - one-to-one; remote - group and other. The options sought to characterise the possible transitions of service delivery models, notably as COVID-19 public health measures were easing. A closed-ended question elicited technological and non-technological formats employed to deliver primary services across survey timepoints. Participants could select multiple options, and options were drawn from previous studies, notably those identified in my systematic

review. A four-point scale (never, sometimes, often and all the time) was employed to compare how often primary services were delivered remotely per regular month across survey timepoints. Following discussions with the supervisory team and with my public advisor, the timeframe of one month was chosen as some organisations only deliver services monthly. A closed-ended question elicited COVID-19 mitigation measures employed when delivering in-person primary services. Participants could select multiple options, and options were devised from publicly available guidelines (e.g., UK Health Security Agency, 2022) and through discussions with my public advisor. An 'other' option was included to enable participants to report on additional COVID-19 mitigation measures. A three-point scale (very satisfied, fairly satisfied, not satisfied) collected participants' satisfaction with service delivery across survey timepoints. While satisfaction is likely to depend on numerous factors, the question sought to obtain an overall insight regarding the level of satisfaction with primary service delivery.

*Usage of primary service (service recipients; number of service recipients accessing service during a regular month)*

During a regular month, participants were asked how often primary services were delivered, how many service recipients attended primary services, and the size of in-person and remote groups.

I set-up the survey onto Jisc Online Surveys and to test out the user-friendliness of the electronic survey, I piloted the layout on a phone and computer screen. Instructions were included throughout. The electronic survey was piloted with a public advisor (see section 3.10.2) and the supervisory team. One public advisor and one member of the supervisory team have experience in delivering social care and support services prior to and during the pandemic. The wording and sequence of some questions was amended following the pilot, and the survey tool was not deemed to cause distress.

#### 3.7.1.3. Administering the survey

The data collection period for the survey at T1 lasted from the 25th of March to 4th of June 2021. Participants were re-invited, by email, to complete the survey at T2 three months after they had completed the survey at T1. Three weeks were allocated to complete the survey at T2, with, if required, reminders sent to participants every six days after the initial invitation to complete the survey at T2. Data collection for the survey at T2 took place between 25th of June and 22nd of September 2021. Participants could choose to complete surveys online (Jisc Online Surveys) or by telephone. Where these were undertaken by telephone, I scheduled a call and entered participants' answers on the online version of the survey on their behalf. Completing the survey should not have taken longer than twenty minutes, and participants were made aware that they did not have to answer any questions they preferred not to.

Following the completion of each survey, three participants were randomly drawn to receive a shopping voucher, either by post or online (two of 25 GBP and one 50 GBP). All participants were given the opportunity to receive a lay summary of the findings by post or email.

### 3.7.2 Semi-structured interviews

A semi-structured approach to interviewing was undertaken as the pre-determined topics enabled comparison across participants (Stuckey, 2013) and the study design provides the flexibility to elaborate on aspects that were not necessarily identified while devising the topic guides (Gill et al., 2008).

#### 3.7.2.1. Topic guide development

Two topics guides (one for social care and support providers, one for service recipients) were devised. Based on discussions with my public advisors, wider supervisory team, findings from my survey and previous literature, topics were identified to structure the topic guides and address study aims (Alan, 2015). As shown in **Figure 4**, topics focused on the delivery and access to social care and support services prior to and during the pandemic, and the use of ICT in current and future service delivery. Topic guides commenced with questions to establish rapport. Thereafter, questions were ordered chronologically, starting with service delivery and access prior to the pandemic and concluding on future service delivery. Topic guides were piloted with a public advisor, who has experience in delivering and accessing social care and support services prior to and/or during the pandemic. The topic guides can be found in **Appendix K**.

To characterise the sample of service recipients, information relating to age, gender, ethnic group, and if applicable, the type of dementia and time (years) since diagnosis, was collected. It was important to collect participants' ethnic group as individuals coming from ethnic minorities often have reduced access to services (e.g., Bieber et al., 2019; Nielsen et al., 2021). Dementia subtypes may impact individuals' experience of ICT use and engagement to access services, and years living with dementia was used as a proxy to condition severity.

The topic guides were piloted with a public advisor. Following the pilot, the ordering of some questions changed. The questions were not deemed to cause distress and were answerable within 45 minutes.

#### 3.7.2.2. Conducting interviews

Prior to data collection, I completed a training course on remote interviewing. Interviews were conducted by videoconferencing software (Zoom) or telephone between May and December 2022. Pre-interview discussions ensured that participants understood what the study entailed, and that participation was voluntary. Verbal informed consent was obtained and recorded prior to interviewing (see section 3.6.2). Interviews were scheduled at a time convenient to participants. If conducted by

videoconferencing software, participants chose whether to enable the video-camera and received the meeting log-in details in advance. All interviews were audio recorded by using the Zoom audio-recording function or with a recording device (Philips Voice Tracer). Interviews with social care and support providers were conducted on a one-to-one basis, and, depending on service recipients' preferences, individual or dyadic interviews were offered

Time was allocated for questions following the interview. As a reimbursement for their time, participants were given a 10 GBP worth shopping voucher (by post or online). All participants were offered to receive a lay summary of the findings by post or email. Field notes were recorded following each interview. Information recorded included any overarching non-verbal behaviours, interesting comments or thoughts during the interview that I felt were relevant.

Following each interview, I reflected on my field notes which helped to improve my interview technique. For example, a question on my topic guide asked service recipient participants the positive aspects and drawbacks of accessing social care and support services during the pandemic. While interviewing my first participant with dementia, I realised that asking a question with two concepts (positive aspects and drawbacks) caused confusion. Thus, while interviewing subsequent participants with dementia, I ensured that I asked questions pertaining to one concept at a time.

I transcribed verbatim a third of the audio-recordings and the remaining were transcribed by a professional transcription agency through the University of Liverpool.

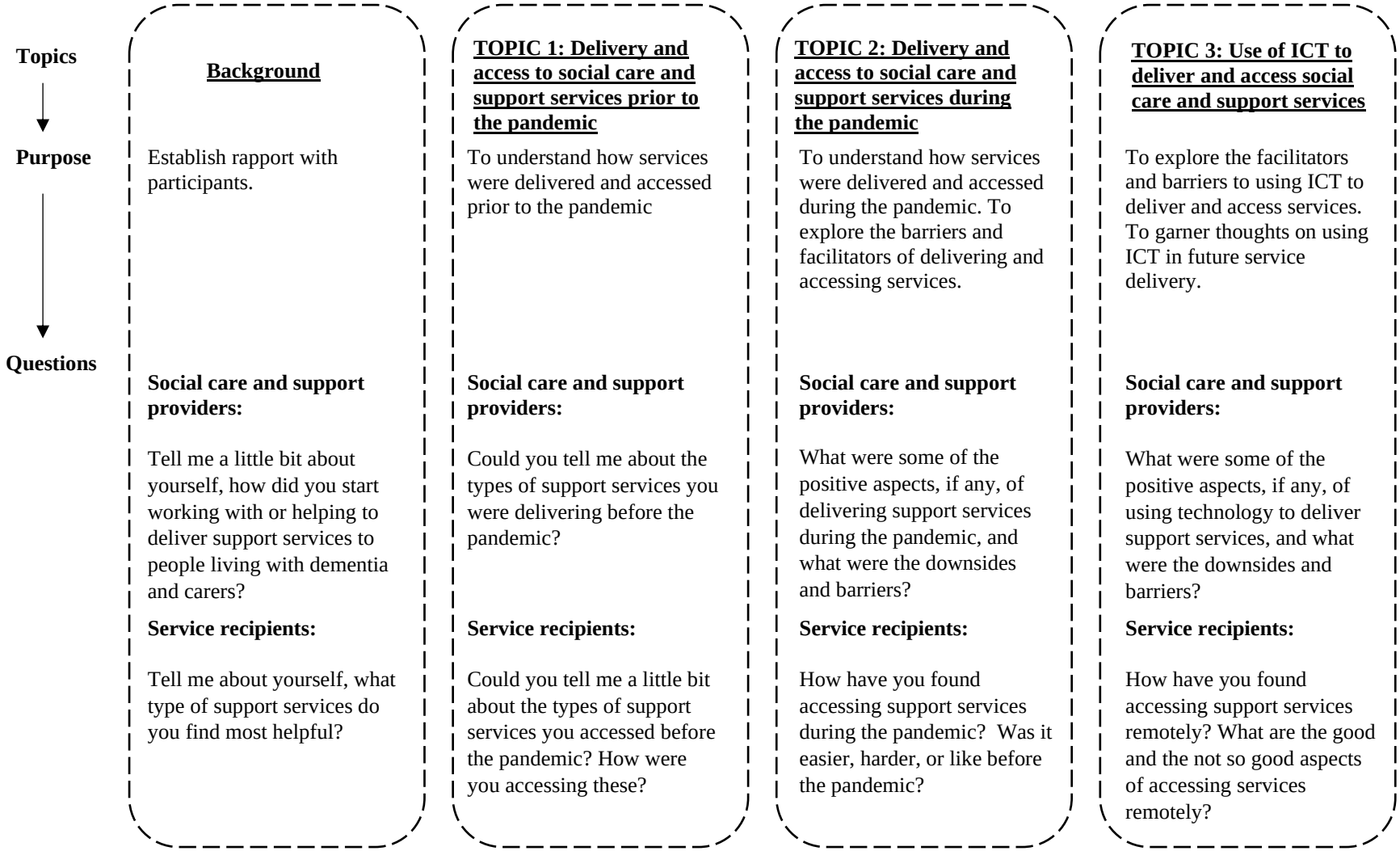




**Figure 4** Topic guide development process

## 3.8 Data analysis

### 3.8.1 Longitudinal quantitative survey

Data was cleaned in Microsoft Excel (version 2308). Email addresses (collected to re-invite participants at T2) and service provision post-codes (collected to calculate the IMD index) helped to identify whether a participant completed the survey multiple times. Data cleaning involved checking for obvious errors, inconsistencies within datasets and missing data. A description outlining all changes made and a rationale to the changes was recorded. Proposed changes and any uncertainties were discussed with the supervisory team. Freely available government online calculators were used to generate the IMD quintile for service provision areas (England: (Ministry of Housing, Communities & Local Government, 2019a); Scotland: (Scottish Index of Multiple Deprivation, 2020)).

Analysis was conducted in SPSS (version 27). Owing to the small sample size, the Shaprio-Wilko test was used to test for normality (Mishra et al., 2019). Nominal and ordinal data were summarised at each survey time point using descriptive statistics (frequencies and percentages). The median and range were calculated to report on central tendency of continuous data. The hours worked or volunteered during a week prior to the pandemic and at T1 was compared using the Wilcoxon-signed rank test. The Wilcoxon-signed rank test is a non-parametric test and can be used to compare data obtained from the same participants. The hours worked or volunteered during a regular week across all survey timepoints were compared with the Friedman Test. The Friedman Test is a non-parametric test suitable when one sample is tested three or more times. As the Friedman Tests did not show any statistically significance differences, post hoc tests were not conducted.

The initial analysis reported on all variables collected and can be found in **Appendix P**. When reporting on all variables, 27 participants had complete data at T1 and 11 participants at T2. Following discussions with the supervisory team, to increase the number of data entries included in the analysis, it was decided to remove a layer of detail and to not report on whether services were delivered in a group or one-to-one format. Therefore, the initial analysis reports on whether services were delivered in-person, hybrid or remotely, and whether they were delivered in group or one-to-one formats. However, the final analysis only reports on whether services were delivered in-person, hybrid or remotely. The final analysis is reported in the **fourth** chapter.

## 3.8.2 Semi-structured interviews

### 3.8.2.1 Reflexive thematic analysis

Braun and Clarke's reflexive TA (2006) was undertaken as it enabled descriptive and interpretative accounts of participants' experiences to be generated.

Following the six phases of reflexive TA, I commenced by familiarising myself by reading each transcript multiple times. Subsequently, I coded each transcript manually (Braun & Clarke, 2006). Coding is the systematic engagement with a dataset and is defined as the '*the process of exploring the diversity and patterning from the dataset, developing codes, and applying code labels to specific segments of each data item'* (Braun & Clarke, 2022, p.53). In TA, coding can embody inductive, deductive or a mixture of orientations. Whereas deductive orientations to coding are guided by researcher-led or theoretical underpinnings, inductive orientations are data driven (Bruan & Clarke, 2022). A combination of deductive and inductive orientations to coding was employed. Both semantic and latent codes were generated. Semantic codes included information that explicitly described how social care and support services were delivered or accessed, whereas latent codes referred to contextual factors shaping service delivery or access. **Table 10** provides a selection of code labels and data extracts. An example of part of a coded transcript can be found in **Appendix Q**.

**Table 10** An example of three code labels and data extracts

| Label | Description | Data extracts |
|---|---|---|
| 1. | Benefits acquired from remote services | |
| | Some service recipients were able to benefit from accessing services remotely. | *'…but what I am getting is the emotional support through peers and people have been on the journey and that is invaluable…we share skills that we can do to make things, to raise funds for [organisation] so it's quite a good circle of life as it were and I've made a good few friends from there*.' **Former unpaid carer to her Mother, and current unpaid carer to her Mother-in-Law, Female (C2)**<br><br>'*to hear the differences so and it is like a protected space you know when we talk and there's only a small group of us and I felt that was really useful you know because we can find out different things'* **Unpaid carer to her husband, Female (C5)** |
| 2. | Not the same as in-person services | |
| | Remotely delivered services were unable to replicate in-person services | *'…um as great as Zoom has been it just can't replicate actual human interaction in any way'* **Paid provider in the Third sector, Male (P5)**<br><br>*'There is no doubt that when it comes to visiting via zoom it's better than not having it at all but it is really sort of not not you know the personal touch of being with someone and being able to touch them'* **Volunteering provider in the Public Sector, Male (P12)**<br><br>*'We can vent vent all our problems living with dementia this way. But we still can't have total contact like we did have…'* **Person with dementia, Male (P1)** |
| 3. | Unpredictability | |
| | Responding to service recipients' | *'I suppose one thing is to be prepared for all sorts of different types of problems and requests for help'* **Paid provider in the Third sector, Female (P10)** |

| | |
|---|---|
| varied needs were unpredictable | *'So then then so it's a very topsy turvy thing, you couldn't be sure until you rang and there was people who needed that support I was you know I was ringing them every day sometimes you know to see how they were doing in those circumstances'* **Paid provider in the Third sector, Female (P4)**<br><br>*'...you never knew what you were going to find'* **Paid provider in the Third sector, Female (P9)** |

The codes of one transcript were discussed with my primary supervisor. Furthermore, I trained my public advisor (materials in **Appendix R**; see section 3.10.2) on coding. They coded two transcripts and we discussed them together. Subsequently, to gain an understanding of the patterns within the dataset, codes were grouped through a shared concept or idea, which is referred to as a 'theme' (Braun & Clarke, 2022). Visually mapping the association between codes and themes assisted the refinement of pilot themes and sub-themes (Braun & Clarke, 2022). To assess the referential competency of the analysis, the pilot themes and sub-themes were compared to the raw data (Nowell et al., 2017). A pragmatic 10% of transcripts from each study population was compared to the pilot themes and sub-themes. Alongside reflexive journaling (see section 3.8.2.2), the evolution of the analysis was documented. Regular meetings with my public advisors and wider supervisory team occurred throughout, and final themes and sub-themes were collectively agreed upon. When writing-up the findings, a mixture of short and longer excerpts of raw data were used to illustrate analytical points. To depict the breadth of participants represented in the analysis, each quote includes a unique code given to each participant (Nowell et al., 2017).

### 3.8.2.2 Researcher reflexivity

Assuming a constructivist epistemology, knowledge is co-constructed between the researcher and participant. Instead of seeking objective and bias-free knowledge, researchers' experiences, assumptions and values, are central to the epistemology. Articulating one's positionality and critically assessing how it may influence the research is important to the trustworthiness of qualitative research (see section 3.8.2.3). Positionality *'... both describes an individual's world view and the position they adopt about a research task and its social and political context'* (Holmes, 2020, p.1). Positionality is temporal and is likely to be shaped by multiple factors. Examples of factors include one's religion, political orientation, gender, ethnic group and social class (Berger, 2015; Holmes, 2020). Beliefs and values relating to the research design, experience and expectations of findings should also be considered. Positionality may influence the research process in different ways. For example, participants may be more amenable to sharing their experiences with a researcher they perceive as being informed regarding their situation, and researcher's worldwide views coupled with prior experience, is likely to shape how an individual interprets participants' narratives (Berger, 2015).

Reflexivity is key to gaining insight into one's positionality. Reflexivity is a recursive process of engaging in self-reflection to identify and articulate one's role within the research process (Berger, 2015). I commenced my reflexive practice by following Braun and Clarke's 'activity pause' (Braun & Clarke, 2022, p. 16-18) within their practical guide to reflexive TA. Based on Wilkinson's (1988) proposed types of reflexivity, the activity directed me to think about how my personal identity, life experiences and research knowledge related to the topic and execution of the study. To assist my ongoing reflexivity, I kept a research journal, and overall reflective piece, created by aggregating sections of my journal entries, can be found in **Appendix T**.

#### 3.8.2.3 Positionality

Adopting a constructivist epistemology, I acknowledge my involvement in the generation of knowledge. My interest in health service research, notably from the service provider's perspective, is likely to stem from my background in physiotherapy. While I have worked with people with dementia and unpaid carers, my scope as physiotherapist was considerably different to services provided by social care and support providers, and I would not consider myself as an 'insider' researcher. An 'insider' researcher is when a one identifies themselves as a member of the study population, whereas and 'outsider' researcher is when one does not belong to group studied (Berger, 2015). These represent two distinct research positionalities along a continuum, and each garners advantages and disadvantages. Although it is likely that my previous clinical practice has influenced, to some degree, how I undertook the research and interpreted participants' responses, the ongoing collaboration with my public advisors helped to ground the study within the lived experience of social are and support providers and service recipients. By sharing their expertise and insights, working with my public advisors has made me aware of some of my assumptions. While I found it easier to relate to social care and support provider participants during the interviews, I would not consider myself as belonging to either group I am studying, which is likely to have benefited the objectivity of my research. Albeit gravitating towards the 'outsider' end of the continuum, I consider myself somewhere in between the two research positionalities.

## 3.9 Methodological rigour

Quantitative and qualitative research paradigms employ disparate criterions to assess methodological rigour, which poses challenges while assessing mixed-method studies. Indeed, a shared understanding regarding how mixed-method studies should be evaluated has yet to be achieved (Morse & Neihaus, 2009). Nevertheless, some authors suggest employing qualitative and quantitative validity criteria (Sale & Brazil, 2004), and Teddlie and Tashakkori (2009) propose that the quality of a mixed method study can be evaluated by considering the quality of each study component. The following sections separately discuss the rigour of my survey and interview study.

### 3.9.1 Longitudinal quantitative survey

The validity of data relates to the degree to which it represents the intended construct, and the reliability refers to the degree to which the data represents the construct consistently and accurately (Teddlie and Taskahkkori, 2009). Several subtypes of validity testing exist (Taherdoost, 2016). Face validity was the main measure of validity I employed, and it '…*is the degree to which a measure appears to be related to a specific construct*' (Taherdoost, 2016, p.29). Face validity is subjective and may not be a true representation of what was measured. Nevertheless, experts advising on whether the survey measures what it intends helps to increase the validity of a measuring tool. Alongside regular meetings with my supervisory team, a public advisor who is an expert by experience, was involved in the development of the measuring tool (see section 3.10.2). Testing for validity is difficult and resource intensive. Owing to the limited research resources and cognisant of the changing COVID-19 public health measures, extensive piloting of the measuring tool was not feasible.

Initial non-response during recruitment, whereby potential participants are invited to participate do not respond, may hinder the validity of the findings as non-respondents are likely to be different to respondents (Cohen et al., 2011). To reduce initial non-responses, I engaged with several recruitment avenues and sent multiple reminders. While information on initial non-response was not collected, some people emailed back explaining why they were unable to participate in the survey. Moreover, the loss of participants between survey timepoints forms an important threat to the validity of longitudinal study designs. Many strategies to possibly minimise the dropout rate exist (Booker et al., 2011; Cohen et al., 2011; Teague et al., 2018) and to help retain participants, I sent several reminders, provided the opportunity to win shopping vouchers at each timepoint and to receive a lay summary of the findings. Furthermore, I was the only researcher participants were in contact with, and the survey could be competed online or by telephone, which are aspects that may increase participant retention between data collection timepoints (Booker et al., 2011; Cohen et al., 2011; Teague et al., 2018).

Lastly, the reliability of the survey was enhanced using simple and clear wording and piloting the measuring tool with members of the supervisory team and public advisors. The public advisor and one member of the supervisory team have experience in delivering social care and support services prior to and during the pandemic.

### 3.9.2 Semi-structured interviews

To assess the rigour of qualitative research, Lincoln and Guba (1985) suggest appraising the 'trustworthiness' of a study. Trustworthiness consists of four domains, (credibility, transferability, dependability and confirmability) and the authors propose measures to increase a study's rigour. The following paragraphs explain the measures undertaken within each domain of trustworthiness.

Credibility refers to the ‘*fit’ between respondents’ views and the researcher’s representation of them*’ (Tobin & Begley, 2004, p.391). I undertook several measures to increase the credibility of my findings. In addition to spending time engaging with the raw transcripts, I discussed some coded transcripts with my primary supervisor and my public advisor. All members of the supervisory team and both public advisors were involved throughout the process of interpreting my findings, and the pilot themes and sub-themes were compared with some raw transcripts (Nowell et al., 2017).

Transferability relates to generalisability of the findings to different contexts. Qualitative studies often have smaller sample sizes, and it is difficult to know whether my findings are transferable to other settings. To enable readers to conclude whether my findings may be transferable to other contexts, I have detailed the sampling strategies, participants, interview process and analytical process (Lincoln & Guba, 1985).

Dependability refers to ensuring that the research process is ‘*…logical, traceable and clearly documented*’ (Tobin & Begley, 2004, p.392), and confirmability refers to ensuring that the interpretations of the data and findings stem from the data. The dependability and confirmability of a study can be displayed by an audit trail (Tobin & Begley, 2004). Throughout the analysis phase, I kept a record summarising the evolving analytical process, including inputs from my public advisors (see section 3.10.2) and wider supervisory team.

Lastly, Reflexivity is key to enhancing all domains of trustworthiness (Lincoln & Guba, 1985). Providing an explicit and transparent account of one’s positioning enables readers to gain an understanding of the researcher’s possible influences on the presented findings (Berger, 2015). An overall reflexive piece, consisting of aggregated research journal entries, can be found in **Appendix T**.

## 3.10 Patient and Public Involvement

### 3.10.1 Patient and public involvement: principles and benefits

The inclusion of Patient and Public Involvement (PPI) within research is increasing (Lang et al., 2022) and can be defined as *‘...research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them’* (National Institute of Health and Care Research [NIHR], 2021a). The inclusion of PPI within research designs encourages a democratic process, whereby people who are impacted by the output are entitled to impart to the research (NIHR, 2021b). Members of the public can be involved by participating in a singular meeting, or continuously throughout the lifespan of a research project (NIHR, 2021c).

Members of the public are experts by experience. Involving members of the public, including people with dementia, promotes the relevance of the research, includes unique and valuable lived experience,

and can increase the impact and trust of research findings (Crocker et al., 2017; Giebel et al., 2017b; Gove et al., 2018; NIHR, 2021b). Nevertheless, success observed by public involvement ought to be reciprocal, and members of the public need to benefit from their involvement in the research process.

The involvement of people with dementia in research is endorsed by Alzheimer's Europe (Gove et al., 2018) and was highlighted within the Prime Minister's Challenge on Dementia 2020 (Department of Health, 2015; 2016). Researchers have a moral and legal duty to ensure the safety and the wellbeing of people with dementia and that the involvement is meaningful (Gove et al., 2018). To this end, the Scottish Dementia Working Group (SDWG) published core principles to involving people with dementia in 2013, and more recently, a position paper by Alzheimer's Europe (Gove et al., 2018) provides recommendations to conducting inclusive and meaningful involvement. These include ensuring that people with dementia have received and understood information to make an informed decision regarding their involvement, and that tasks are tailored and appropriate to individuals' needs (SDWG, 2013; Gove et al., 2018; Morbey et al., 2019). Contributions made by members of the public needs to be document, acknowledged and compensated appropriately. Furthermore, it is important that research findings are shared with members of the public who have been involved (SDWG, 2013; Gove et al., 2018).

To guide researchers to involve people with dementia as co-researchers across the lifespan of a research project, Swarbrick and colleagues (2019) co-produced a co-research model coined CO-researcher INvolvement and Engagement in Dementia Model, abbreviated to the COINED model. Spanning from ongoing consultations to discussing future work, the COINED model outlines how people with dementia can be co-researchers across the lifespan of a research project, which may include reading study information sheets, developing data collection tools and interpreting the findings (Swarbrick et al., 2019).

Furthermore, reporting the involvement of PPI is important yet largely remains limited within the published literature. To bridge this gap, Staniszewska and colleagues developed the Guidance for Reporting Involvement of Patients and the Public (GRIPP) checklist to assist researchers to document the process of PPI undertaken and to evaluate its impact (Staniszewska et al., 2011). The checklist was updated in 2017 and is referred to as the 'GRIPP2' (Staniszewska et al., 2017). The long form is suitable for studies specifically exploring PPI, and the short form is recommended for studies where PPI is not the prime focus (Staniszewska et al., 2017).

### 3.10.2 Patient and public involvement: my Ph.D. project

Two public advisors, a person living with dementia and a former unpaid carer, formed part of my research team. The public advisors were invited due to their interest, expertise in dementia, and

experience in delivering and accessing social care and support services prior to and/or during the pandemic. Both public advisors have been involved in numerous research projects led by my primary supervisor. Largely through remote meetings and regular emails, both public advisors were actively involved throughout my Ph.D. project. Meetings were held remotely due to the ongoing COVID-19 public health measures and was the preferred method to communicate by the public advisors. Prior to each activity, each public advisor was asked if they would like to be involved, and if so, how. Following each activity contributions made were recorded and public advisors were paid according to the National Institute of Health and Care Research (NIHR) standardised fees (2022).

My public advisors were involved in numerous aspects throughout my Ph.D. project. Employing the GRIPP2 short form (Staniszewska et al., 2017), **Table 11** outlines the involvement of my public advisors in each study. I briefly describe the involvement of my public advisors below.

Firstly, while undertaking my systematic review, input from my public advisor assisted in the operationalisation of the term 'post-diagnostic support' which facilitated the development of the search strategy and inclusion criteria. Discussions with my public advisor helped to interpret the findings within lived experience, notably in relation to digital inequalities. My public advisor was involved in the dissemination of the findings of my systematic review by reviewing the manuscript and is a co-author in the published paper. Secondly, one public advisor was involved in devising and piloting the measuring tool and reviewed the study information sheet as part of my survey study. My public advisors were involved in the interpretation of the findings, assisted the development of a lay summary and are co-authors in the published paper. Thirdly, with regards to the interview study, both public advisors were involved in the development of the topic guides. While my public advisors assisted in sharing the research opportunity, they were not involved in collecting data. To involve my public advisors in interpreting the findings, I trained one public advisor on coding as part of reflexive TA and discussed the key findings with my other advisor. Both public advisors assisted the development of the lay summary and are co-authors on the submitted manuscript. Lastly, both public advisors were involved while planning the **sixth** chapter, which critically synthesis and discusses all my research findings and identifies priorities for future research. Reflections on the value PPI added to my research, how I adapted my working approaches and used the GRIPP 2 short form (Staniszewska et al., 2017) are included in the **sixth** chapter.

**Table 11** GRIPP2 (Staniszewska et al., 2017) short form outlining PPI in each study and thesis overall discussion chapter

| Item definition | **Systematic review** | **Longitudinal quantitative survey** | **Semi-structured interviews** | **Discussion chapter** |
|---|---|---|---|---|
| *Aims* | | | | |
| Report the aim of PPI involvement in the study | To involve one public advisor who deliver and have accessed post-diagnostic support to discuss the included studies and to contribute the interpretation of findings. | To involve and receive input from social care and support providers and service recipients to design the tool, interpret the findings and disseminate findings. | To involve and receive input from social care and support providers and service recipients to design the tool, interpret the findings and disseminate findings. | To involve and receive input from social care and support providers and service recipients to discuss overall findings and recommendations to future research / policy. |
| *Methods* | | | | |
| Provide a clear description of the methods used for PPI in the study | Regular exchange of emails and frequent one-to-one remote meetings. | Regular emails to update on progress. Remote one-on-one meetings as and when required. | Updates through email and remote one-to-one meetings. I delivered training on coding to one public advisor. | Scheduled a remote one-to-one meeting. I sent a summary of the main findings from each study beforehand. |
| *Study result outcomes* | | | | |
| Report the results of PPI involvement in the study, including both positive and negative outcomes | Assisted to operationalise the term 'post-diagnostic support' which facilitated the development of the search strategy and screening of the references. Following the full text screening, we discussed the eligibility of studies identified, and those within the 'maybe' category. Assisted in the interpretation of results and reviewed the manuscript. | Involved in devising and piloting the measuring tool. Important for the face validity of the measuring tool. Following input, the order and wording of some questions changed, and some questions were added or removed. Involved in the overall interpretation of the findings. Reviewed study information sheet, consent form, study documents, lay summary and manuscript. | Actively involved during the development of the topic guides. I piloted the topic guides with one public advisors. Input from the public advisors ensured that the topic guide, study information sheet and consent form was appropriate and accessible for participants with dementia. One public advisor was trained on coding as part of reflexive TA and coded two transcripts. Both public advisors were involved while | Discussed my overall findings, and implications to policy and/or future research. |

| | | | | |
|---|---|---|---|---|
| | | | interpreting the findings, devising the lay summaries, and reviewed the manuscript. | |
| *Discussions and conclusion outcomes* | | | | |
| Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects | Input from the public advisor was important when discussing the eligibility of studies. Provided valuable insight, relevant to delivering and accessing remote post-diagnostic support, which ensured that the overall synthesis of the findings was relevant to practice and grounded within lived experience. Co-author on the published manuscript. | Input improved measuring tool. Discussing the findings with public advisors shaped discussion section. Public advisors are co-authors and reviewed the lay summary. | The topic guides were devised with public advisors, and during the pilot, provided suggestions on how to adapt my interviewing skills to participants with dementia. Both public advisors are co-authors on the manuscript. | Helped to critically synthesis all findings and identify recommendations. |
| *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. | Input from the public advisor was valuable and worked well together. Upon reflection, involving my public advisor while devising the protocol and shaping my review questions would have been beneficial and perhaps made the research more relevant. | Worked well together and helped to contextualise the findings. A public advisor was recruited following the data collection. Upon reflection, it may have been beneficial to engage with public advisors earlier on in the tool development phase and recruited public advisors working / volunteering different sectors. | Unlike the longitudinal quantitative survey, I had not drafted the topic guide prior to meeting with public advisors, enabling them to be involved in the development of the tool. Delivering a training on coding facilitated an analytical discussion. | Sent a summary of my findings beforehand to facilitate discussion. Helpful to draw further conclusions from the findings. |

## 3.11 Health Inequalities Assessment Tool

The Health Inequalities Assessment Tool (HIAT) assists researchers to embed a focus on health inequalities, and their causes, throughout the research process (Porroche-Escudero & Popay, 2020). The tool consists of four questions: (1) What are the health inequalities that influenced or created the problem being researched; (2) How will your proposed work tackle the socio-economic causes of inequalities in health; (3) How will you make sure that your evaluation and monitoring shows the effect of your activity on health inequalities and their causes; (4) What wider effect might your activity have on health inequalities and their causes and how can this be delivered?

The HIAT was completed at the inception of the project and updated every six months thereafter. The final version of the HIAT is in **Appendix S.**

## 3.12 Summary

This chapter explained the philosophical stance adopted and described the sequential explanatory mixed method study design employed. An explanation of the study populations and sampling strategies, ethical considerations and data collection methods undertaken is provided. The chapter concludes with PPI throughout my research and the use of the HIAT tool. The following chapter presents the findings from my survey, that compared the services delivered and delivery methods employed prior to and during the pandemic.

# CHAPTER 4: SOCIAL SUPPORT SERVICES FOR DEMENTIA DURING THE COVID-19 PANDEMIC: A LONGITUDINAL SURVEY EXPLORING SERVICE ADAPTATIONS IN THE UNITED KINGDOM

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The findings were published in *Health Expectations* in 2023 as detailed below:

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## 4.1Abstract

**Objectives:** To understand how the delivery of dementia-related social care and support services across the UK adapted during the pandemic.

**Methods:** I devised a two-part online and telephone longitudinal survey. Providers participated between March and June 2021, and again three months later. Information relating to services delivered and delivery methods employed was collected prior to and during the pandemic at two timepoints (T1 and T2).

**Results:** Seventy-five participants completed the survey at T1, with 58 participants completing the survey at both timepoints. Thirty-six participants had complete data at T1. Day care centres and support groups were the most delivered primary services. During the pandemic, services shifted from in-person to remote or hybrid. While in-person services started to resume at T2, most services remained hybrid. At T2, the frequency of service delivery increased, however, a decreasing trend in usage was observed across survey timepoints. The telephone was the most employed format to deliver remote and hybrid services, however, reliance on videoconferencing software significantly increased at T1. Videoconferencing software was often used alongside the telephone and emails to remotely deliver services.

**Conclusions:** Services were able to adapt and provided support to some service recipients. Complementing novel approaches to service delivery with more traditional formats may facilitate access to service recipients with limited digital literacy. Following the easing of public health measures, many service recipients may be reluctant to engage with in-person services. Thus, the provision of in-person and remote services needs to be carefully balanced amidst the current hybrid landscape.

**Keywords:** dementia; social support services; post-diagnostic support, COVID-19 pandemic; social care

## 4.2Background

Dementia is a growing public health issue. Characterised by declining cognitive functioning, dementia holistically impacts individuals' daily life (Grossman et al., 2006; WHO, 2021a). There are currently over 920,000 people with dementia in the UK, a number which is projected to rise to over a million by 2024 (Wittenberg et al., 2019). In the absence of a cure, equal access to responsive post-diagnostic support that addresses the needs of people with dementia and their unpaid carers is important to living well with the condition (Department of Health, 2009).

Post-diagnostic support includes all services that respond to the changing support and care needs throughout the disease trajectory (Prince et al., 2016). Good post-diagnostic support is characterised by the timely identification of needs and provision of holistic support (Bamford et al., 2021). Social care and support services form part of post-diagnostic support and can be defined as non-clinical services that aim to support community-dwelling people with dementia and unpaid carers to live well and independently. In the UK, social support services are provided by a mixture of public, private and voluntary sectors (Frost et al., 2021) and delivered across various care settings. Services may include peer support groups, befriending services, day care centres, social activities, respite care and paid home care.

The usage of social care and support services is likely to vary throughout the disease trajectory. Possible benefits include promoting independence and reducing feelings of loneliness among people with dementia (Kelly & Innes, 2016; Willis et al., 2018). Social care and support services may facilitate opportunities to engage in meaningful actives, which is considered important to living well with dementia (Nyman & Szymczynska, 2016; Reilly et al., 2020). Furthermore, unpaid carers may equally benefit from accessing social care and support services, and psychoeducation and psychosocial interventions are thought to positively impact on the perceived caregiving burden and depressive symptoms (Vandepitte et al., 2016a; Carter et al., 2020). While the use of social care and support services should be guided by people with dementia and unpaid carers' changing needs and preferences, access remains unequal (Giebel et al., 2021a; Watson et al., 2021; Van Horik et al., 2022). Barriers to access are numerous, and may include rural residency and being from an ethnic minority or a socio-economically deprived background (Bieber et al., 2019; Bayly et al., 2020; Nielsen et al., 2021).

The coronavirus (COVID-19) pandemic significantly impacted the lives of people with dementia and unpaid carers (Giebel et al., 2022a; 2022b), and is likely to have engendered long-term consequences (Dawson et al., 2023). Many social care and support organisations were required to stop in-person service delivery for extensive periods. The diminished opportunities to engage in activities and to socialise with others, is thought to have contributed to the overall worsening of dementia symptoms,

and general wellbeing of people with dementia and unpaid carers (Giebel et al., 2020b; 2021e; Hanna et al., 2021; Tuijt et al., 2021). Challenged with a lack of available respite care and often undertaking additional caregiving duties, some unpaid carers reported an increase in caregiving burden (Giebel et al., 2022b). Nevertheless, some social care and support organisations adopted novel approaches to service delivery and continued to provide support to people with dementia and unpaid carers.

The reliance on the use of information communications technologies (ICT) across the service delivery landscape increased during the pandemic. Research exploring the use of ICT to conceivably facilitate timely and flexible access to remote post-diagnostic support has largely focused on the medical management of people with dementia (Azad et al., 2012; Kim et al., 2017) and/or reducing the caregiving burden (Leng et al., 2020). However, prior to (Dal Bello-Haas et al., 2014; Ptomey et al., 2019; Howe et al., 2020) and during the pandemic (DiLorito et al., 2021; Lee et al., 2021; Masoud et al., 2021; Gerritzen et al., 2023b), some social care and support services for people with dementia or the dyad were delivered remotely. Largly delivered by videoconferencing software, services included peer support groups, memory cafes, and exercise health and singing classes. Accessing support remotely appears feasible, nevertheless, difficulties whilst navigating ICT were frequently experienced. Furthermore, while remote services were generally well received, many people with dementia and unpaid carers preferred accessing services in person (Masoud et al., 2021).

Despite a growing evidence base outlining the impact of the COVID-19 pandemic on people with dementia and unpaid carers (Giebel et al., 2022a; 2022b), little is known about how social care and support services across the UK have adapted during the pandemic from the service providers' perspective. Therefore, this longitudinal online and telephone survey sought to compare (1) the types of social care and support services delivered and (2) the delivery methods employed; prior to and at two time points during the pandemic. Findings may provide insights into planning the delivery of social support services in prospective public health crises and possibly help to satisfy the nationwide digital transformation agenda for health and care services (NHS, 2019).

## 4.3 Materials and Methods

The completed Consensus-Based Checklist for Reporting of Survey Studies (CROSS) (Sharma et al., 2021) can be found in **Appendix W**.

### 4.3.1 Participants and recruitment

This study defined community-based social care and support providers as someone who delivers non-clinical community-based social care and support services to people with dementia and/or to unpaid carers in a paid or unpaid (volunteer) capacity. Eligible social care and support providers met the following criteria: (1) currently working (paid capacity) or helping / volunteering (unpaid capacity) to

deliver social support services within the public, private or voluntary sector in the UK; (2) delivering social support services to people with dementia and/or to unpaid carers living in the community; (3) either directly involved in delivering social support services or involved in the management / organisation of the delivery of social care and support services and (4) at least 18 years of age.

Social care and support providers were recruited through convenience sampling. I contacted social care and support organisations (publicly available email addresses and telephone numbers), engaged with social prescribing routes, advertised the study on social media (X, formerly Twitter) and in internal University newsletters. Within this chapter, social care and support providers who have participated in this study will henceforth be referred to as 'participants' and the term 'service recipients' refers to people with dementia or unpaid carers who have accessed social care and support services delivered by participants in my study.

### 4.3.2 Ethical considerations

Ethical approval from the University of Liverpool (Ref: 9817) was sought prior to commencing the study. The study information sheet was disseminated to all participants and online written informed consent was obtained prior to participation.

### 4.3.3 Data collection

The study involved completing a survey at two time points (T1 and T2). T1 included retrospective details about pre-pandemic service delivery and current data. This generated three time points for analysis. The data collection period for the survey at T1 lasted from the 25th of March to 4th of June 2021. Participants were re-invited, via email, to complete the survey at T2 three months after they had completed the survey at T1. Three weeks were allocated to complete the survey at T2, with, if required, reminders sent to participants every six days after the initial invitation to complete the survey at T2. Data collection for the survey at T2 took place between 25th of June and 22nd of September 2021. Participants could choose to complete surveys online (Jisc Online Surveys) or by telephone. Where these were undertaken by telephone, a research team member scheduled a call and entered a participant's answers on the online version of the survey on their behalf.

The government imposed public health restrictions differed slightly across the nations. At T1 the restrictions were commencing to ease, gradually allowing a limited number of people to meet outdoors and, subsequently, indoors. Most restrictions were removed or considerably less restrictive at T2. A summary of the government imposed public health measures across the UK at each survey timepoint can be found in **Appendix I**.

### 4.3.4 Variable and tool

Information on the following variables were collected:

1. Characteristics of participants (age range, sex, ethnicity, years of full-time education completed and years of working or volunteering as a social care and support provider)
2. Characteristics of providers (sector, current contractual arrangement (paid / unpaid), postcode of service provision area)
3. Services delivered (types of services delivered, identification of primary service (primary service refers to the service participants were delivering the most))
4. Delivery methods employed (in-person, hybrid or remote, use of digital and non-digital formats)
5. Usage of primary service (service recipients; number of service recipients accessing service during a regular month)

The first survey obtained information on all variables listed above, and elicited information on service delivery prior to the pandemic (retrospectively) and at T1. The second survey solely obtained information regarding service delivery at T2.

The survey was piloted with a public advisor and with other research team members prior to data collection. Both public advisors and one member of the research team have experience in delivering dementia-related social support service prior to and/or during the pandemic in the UK.

### 4.3.5 Data analysis

Data was exported from Jisc Online Surveys to Microsoft Excel (version 2308). All analysis was conducted in SPSS (version 27). The sample characteristics, services delivered and delivery methods employed were summarised at each survey time point using descriptive statistics. The Shapiro-Wilko test was used to test for normality. The number of hours worked / volunteered prior to the pandemic and at T1 was compared using the Wilcoxon-signed rank test and compared across the three survey timepoints using the Friedman test.

Collected postcodes enabled the Index of Multiple Deprivation (IMD) quintile to be generated for each service provision area. Although the calculation of the IMD differs slightly across the countries within the UK, the index provides a relative measure of neighbourhood deprivation by considering multiple factors including income, employment, education, and health. The IMD score is ranked into five quintiles, with the first representing the most deprived and the fifth the least deprived areas (Department for Communities and Local Government, 2015). Obtaining the IMD quintiles of service provision areas may help to discover discrepancies in adaptation of service delivery across the UK.

## 4.4 Results

### 4.4.1 Survey completion

A total of 75 participants completed the survey at T1, and 58 participants completed the survey at both timepoints. Two participants at T1 and one at T2 completed the survey by telephone. The remaining participants completed the surveys online. As outlined in **Figure 5**, following the cleaning of the data sets, a total of 36 (48.0%) participants had complete data entries at T1, and 22 (37.9%) participants at all survey timepoints. Only participants with complete data entries were included in the analysis.

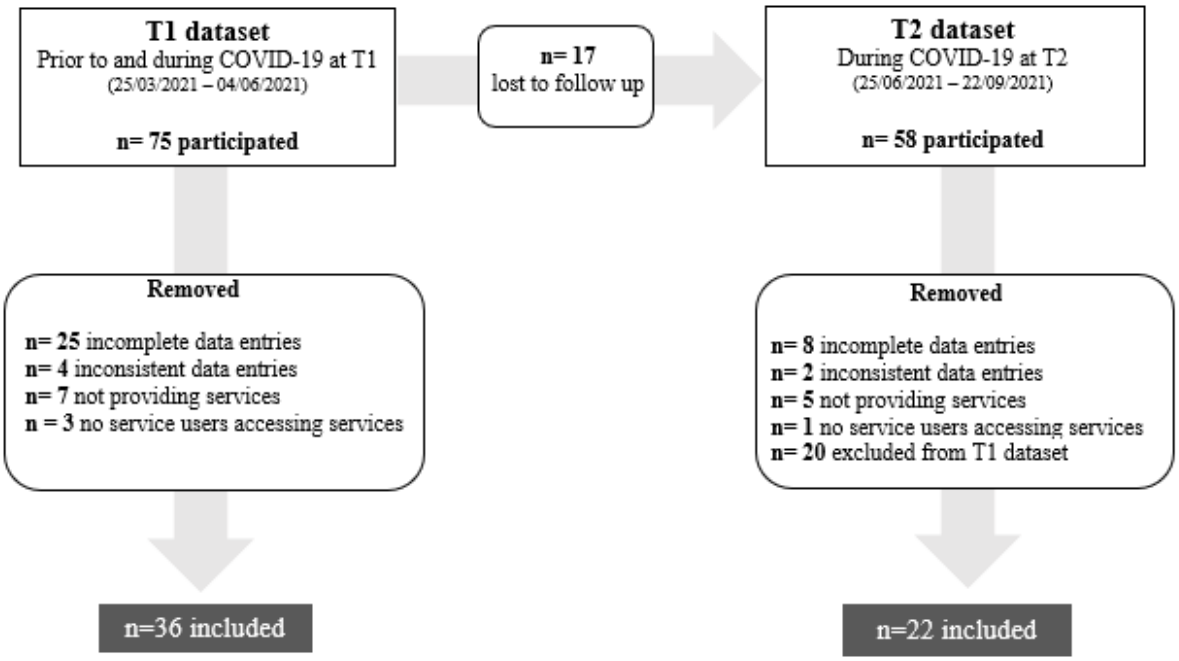


**Figure 5** Flowchart depicting participation flow and completion rates during the longitudinal study

The uppermost boxes indicate the number of participants who completed the survey at each timepoint. Following the removal of (1) incomplete data entries (missing responses), (2) inconsistent data entries (contradicting responses within the same data entry), (3) participants not delivering social support services, (4) no service recipients accessing social support services (5) losses to follow up (participants who did not complete the survey at both time points), a total of 36 participants has complete data at T1 and 22 participants had complete data at both survey timepoints.

### 4.4.2 Participant and Provider characteristics

Most participants identified as female, White and at least thirty-five years old. Participants mainly delivered services in a paid capacity, within the Third sector and in areas classified within the third and fifth IMD quintiles (**Table 12**). While the numbers of hours worked / volunteered slightly reduced at T1, participants worked or volunteered similar hours across survey timepoints ((median (range): prior COVID-19: 29 (2-50); T1: 21.3 (1-60); Z= -0.853, p= 0.394); (median (range): prior-COVID-19: 30 (2-40); T1: 25.5 (2-40); T2: 31.5 (1.5-45); $X^2$= 0.304, p=0.859)). A total of 9 participants (25.0%) paused service delivery at the beginning of the pandemic (median:6 weeks, range: 2-45weeks).

**Table 12** Participant socio-demographic characteristics (T1: n=36; T2: n=22)

| n (%) | **T1 dataset n=36** | **T2 dataset n=22** |
|---|---|---|
| **Gender** | | |
| Female | 27 (75.0) | 18 (81.8) |
| Male | 9 (25.0) | 4 (18.2) |
| **Age group** | | |
| 25-34 | 1 (2.8) | 1 (4.5) |
| 35-44 | 9 (25.0) | 8 (36.4) |
| 45-54 | 5 (13.9) | 3 (13.6) |
| 55-64 | 13 (36.1) | 6 (27.3) |
| 65 and over | 8 (22.2) | 4 (18.2) |
| **Ethnicity** | | |
| White | 34 (94.4) | 21 (95.5) |
| Mixed / Multiple ethnic groups | 2 (5.6) | 1 (4.5) |
| **Sector** | | |
| Public | 3 (8.3) | 3 (13.6) |
| Private | 2 (5.6) | 1 (4.5) |
| Third sector | 31 (86.1) | 18 (81.8) |
| **Contractual arrangement** | | |
| Paid | 24 (66.7) | 17 (77.3) |
| Volunteering | 12 (33.3) | 5 (22.7) |
| **Region** | | |
| East of England | 6 (16.7) | 5 (22.7) |
| Greater London | 3 (8.3) | 1 (4.5) |
| North East | 1 (2.8) | 1 (4.5) |
| North West | 7 (19.4) | 4 (18.2) |
| South East | 3 (8.3) | - |
| South West | 7 (19.4) | 5 (22.7) |
| West Midlands | 5 (13.9) | 3 (13.6) |
| Yorkshire and Humber | 3 (8.3) | 2 (9.1) |
| Scotland | 1 (2.8) | 1 (4.5) |
| **IMD quintile of service provision area in England** [α] | | |
| 1 | 4 (11.1) | 1 (4.5) |
| 2 | 5 (13.9) | 2 (9.1) |
| 3 | 10 (27.8) | 8 (36.4) |
| 4 | 6 (16.7) | 5 (22.7) |
| 5 | 10 (27.8) | 5 (22.7) |
| **Years full-time education** | | |
| Median (range) | 16.5 (4 – 23) | 17 (7 – 20) |
| **Years working/ volunteering as a social care and support provider** [β] | | |
| Median (range) | 10.5 (1.5 – 42) | 11.5 (1.5 – 39) |

[α] Excludes one participant delivering support services in Scotland. Area categorised within 3rd quintile within the Scottish classification. (Scottish Index of Multiple Deprivation, 2020)

[β] Refers to the cumulative number of years working / volunteering to deliver social support services to any service recipients, not necessarily within dementia care.

### 4.4.3 Service provision prior to and during the pandemic

Participants delivered a median of two services across all survey timepoints. Social activities and support groups, followed by day care centres and accompanying / befriending were most delivered services (**Table 19**).

#### 4.4.3.1 Types of primary services delivered

A total of 28 participants (77.8%) delivered the same primary service prior to the pandemic and at T1. Thirteen participants (59.1%) delivered the same primary services across all survey timepoints. Support groups, day care centres and social activities were the most delivered primary services across survey timepoints. Services were mainly delivered to people with dementia and unpaid carers (**Table 13** and **Table 14**).

#### 4.4.3.2 Delivery methods and formats employed to deliver primary services

A shift from in-person to hybrid or remote services was observed at T1 (**Table 13**). At T2, the number of remote services halved, and most services were hybrid (**Table 14**).

Telephone calls, emails, website resources and the post were used to deliver remote and hybrid services before the pandemic. While the telephone remained the most employed format to deliver remote and hybrid services during the pandemic, the use of videoconferencing software significantly increased at T1 (**Table 15** and **Table 16**). Compared to prior to the pandemic, 22 more participants used videoconferencing software at T1, and the format was most employed to deliver remote or hybrid support groups, advice and information provision and social activities (**Table 17**). Thirteen participants used videoconferencing software to remotely deliver services at T1 (**Table 15**). Apart from three participants (23.1%) who solely used videoconferencing software, most participants complemented the use of videoconferencing software with the telephone (n=9 (69.2%)) and/or emails (n=7 (53.8%)). The two participants (13.3%) who did not use videoconferencing software, remotely delivered services by telephone and post (**Table 15**)

At T1 and T2, a small number of participants employed formats to deliver remote and/or hybrid services (e-learning, internet forums and internet portals) that were not used prior to the pandemic (**Table 15** and **Table 16**).

**Table 13** A summary of primary services delivered, service recipients and usage per delivery method prior to the pandemic and at T1 (n = 36)

| | Prior COVID-19 n=36 (n (%)) | | | | T1 n=36 (n (%)) | | | |
|---|---|---|---|---|---|---|---|---|
| | **In person (n=26)** | **Hybrid (n=9)** | **Remotely (n=1)** | **Total (n=36)** | **In person (n=4)** | **Hybrid (n=17)** | **Remotely (n=15)** | **Total (n=36)** |
| **Primary services delivered** | | | | | | | | |
| Accompanying/ befriending | 1 (3.8) | 1 (11.1) | - | 2 (5.6) | 1 (25.0) | 2 (11.8) | 1 (6.7) | 4 (11.1) |
| Advice, support and information | 2 (7.7) | 3 (33.3) | 1 (100.0) | 6 (16.7) | - | 3 (17.6) | 2 (13.3) | 5 (13.9) |
| Day care centre | 9 (34.6) | 1 (11.1) | - | 10 (27.8) | 3 (75.0) | 6 (35.3) | - | 9 (25.0) |
| Social activities | 5 (19.2) | 2 (22.2) | - | 7 (19.4) | - | 3 (17.6) | 5 (33.3) | 8 (22.2) |
| Support groups | 9 (34.6) | 2 (22.2) | - | 11 (30.6) | - | 3 (17.6) | 7 (46.7) | 10 (27.8) |
| **Service recipients of primary services** | | | | | | | | |
| Unpaid carer (current / former) | 1 (3.8) | - | - | 1 (2.8) | - | - | 2 (13.3) | 2 (5.6) |
| Person with dementia | 7 (26.9) | - | - | 7 (19.4) | 1 (25.0) | 2 (11.8) | - | 3 (8.3) |
| Both | 18 (69.2) | 9 (100.0) | 1 (100.0) | 28 (77.8) | 3 (75.0) | 15 (88.2) | 13 (86.7) | 31 (86.1) |
| **How often primary services were delivered remotely** [α] | | | | | | | | |
| Never | 24 (92.3) | - | - | 24 (66.7) | 3 (75.0) | - | - | 3 (8.3) |
| Sometimes | 2 (7.7) | 7 (77.8) | - | 9 (25.0) | 1 (25.0) | 7 (41.2) | 2 (13.3) | 10 (27.8) |
| Often | - | 1 (11.1) | - | 1 (2.8) | - | 7 (41.2) | 1 (6.7) | 8 (22.2) |
| All of the time | - | 1 (11.1) | 1 (100.0) | 2 (5.6) | - | 3 (17.6) | 12 (80) | 15 (41.7) |
| **Satisfaction with primary service delivery** | | | | | | | | |
| Very satisfied | 21 (80.8) | 6 (66.7) | 1 (100.0) | 28 (77.8) | - | 4 (23.5) | 6 (40.0) | 10 (27.8) |
| Fairly satisfied | 4 (15.4) | 3 (33.3) | - | 7 (19.4) | 2 (50.0) | 13 (76.5) | 8 (53.3) | 23 (63.9) |
| Not satisfied | 1 (3.8) | - | - | 1 (2.8) | 2 (50.0) | - | 1 (6.7) | 3 (8.3) |
| **Average number of times primary services were delivered** [α] | | | | | | | | |
| Median (range) | 8.5 (1-40) | 4 (1-29) | 24 | 7.5 (1-40) | 20 (5-24) | 5 (1-25) | 6 (1.5-30) | 7 (1-30) |
| **Average number of service recipients accessed primary services** [α] | | | | | | | | |
| Median (range) | 27.5 (5-180) | 40 (12-320) | 100 | 30 (5-320) | 10 (5-21) | 25 (3-150) | 30 (4-220) | 24 (3-220) |

[α] During a regular month

**Table 14** A summary of primary services delivered, service recipients and usage per delivery method at T1 and T2 (n = 22)

| | T1 n=22 (n (%)) | | | | T2 n=22 (n (%)) | | | |
|---|---|---|---|---|---|---|---|---|
| | **In person (n=2)** | **Hybrid (n=12)** | **Remotely (n=8)** | **Total (n=22)** | **In person (n=4)** | **Hybrid (n= 14)** | **Remotely (n=4)** | **Total (n=22)** |
| **Primary services delivered** | | | | | | | | |
| Accompanying/ befriending | 1 (50.0) | - | - | 1 (4.5) | - | 1 (7.1) | - | 1 (4.5) |
| Advice, support and information | - | 2 (16.7) | 1 (12.5) | 3 (13.6) | - | 2 (14.3) | - | 2 (9.1) |
| Day care centre | 1 (50.0) | 5 (41.7) | - | 6 (27.3) | 2 (50.0) | 5 (35.7) | - | 7 (31.8) |
| Social activities | - | 2 (16.7) | 4 (50.0) | 6 (27.3) | - | 2 (14.3) | 4 (100.0) | 6 (27.3) |
| Support groups | - | 3 (25.0) | 3 (37.5) | 6 (27.3) | 2 (50.0) | 4 (28.6) | - | 6 (27.3) |
| **Service recipients of primary services** | | | | | | | | |
| Unpaid carer (current / former) | - | - | 1 (12.5) | 1 (4.5) | - | - | 1 (25.0) | 1 (4.5) |
| Person with dementia | - | 2 (16.7) | - | 2 (9.1) | 2 (50.0) | 2 (14.3) | - | 4 (18.2) |
| Both | 2 (100.0) | 10 (83.3) | 7 (87.5) | 19 (86.4) | 2 (50.0) | 12 (85.7) | 3 (75.0) | 17 (77.3) |
| **How often primary services were delivered remotely** [α] | | | | | | | | |
| Never | 1 (50.0) | - | - | 1 (4.5) | 3 (75.0) | 1 (7.1) | - | 4 (18.2) |
| Sometimes | 1 (50.0) | 4 (33.3) | 1 (12.5) | 6 (27.3) | 1 (25.0) | 5 (35.7) | - | 6 (27.3) |
| Often | - | 6 (50.0) | - | 6 (27.3) | - | 7 (50.0) | - | 7 (31.8) |
| All of the time | - | 2 (16.7) | 7 (87.5) | 9 (40.9) | - | 1 (7.1) | 4 (100.0) | 5 (22.7) |
| **Satisfaction with primary service delivery** | | | | | | | | |
| Very satisfied | - | 3 (25.0) | 3 (37.5) | 6 (27.3) | 4 (100.0) | 4 (28.6) | 1 (25.0) | 9 (40.9) |
| Fairly satisfied | 1 (50.0) | 9 (75.0) | 5 (62.5) | 15 (68.2) | - | 10 (71.4) | 3 (75.0) | 13 (59.1) |
| Not satisfied | 1 (50.0) | - | - | 1 (4.5) | - | - | - | - |
| **Average number of times primary services were delivered** [α] | | | | | | | | |
| Median (range) | 12.5 (5 – 20) | 10 (1 – 20) | 8 (2 – 22) | 8 (1 – 22) | 12.5 (4 - 46) | 14 (2.5 – 32) | 3 (1 -50) | 12 (1 – 50) |
| **Average number of service recipients accessed primary services** [α] | | | | | | | | |
| Median (range) | 14.5 (5 -24) | 27.5 (15 – 100) | 40 (4 – 220) | 27.5 (4 – 220) | 23 (6 - 46) | 28.3 (10 – 104) | 23.5 (5 – 358) | 26.8 (5 -358) |

[α] During a regular month

**Table 15** A summary of formats employed to deliver hybrid and remote primary services before the pandemic (n = 10) and at T1 (n = 32) (overall data set n = 36)

| | Prior COVID-19 n=10 (n (%)) | | | T1 n =32 (n (%)) | | |
|---|---|---|---|---|---|---|
| | **Hybrid (n=9)** | **Remote (n=1)** | **Total (n=10)** | **Hybrid (n=17)** | **Remote (n=15)** | **Total (n=32)** |
| **Formats employed to deliver primary service remotely** [α] | | | | | | |
| e-learning | - | - | - | 2 (11.8) | - | 2 (6.3) |
| e-mail | 8 (88.9) | 1 (100.0) | 9 (90.0) | 11 (64.7) | 8 (53.3) | 19 (59.4) |
| Internet forum | - | - | - | 1 (5.9) | - | 1 (3.1) |
| Internet portal | - | - | - | 2 (11.8) | 1 (6.7) | 3 (9.4) |
| Mobile applications | - | - | - | - | 1 (6.7) | 1 (3.1) |
| Post | 6 (66.7) | 1 (100.0) | 7 (70.0) | 6 (35.3) | 6 (40.0) | 12 (37.5) |
| Social media | 4 (44.4) | 1 (100.0) | 5 (50.0) | 6 (35.3) | 3 (20.0) | 9 (28.1) |
| Telephone calls | 9 (100.0) | 1 (100.0) | 10 (100.0) | 16 (94.1) | 11 (73.3) | 27 (84.4) |
| Text messaging | 4 (44.4) | - | 4 (40.0) | 8 (47.1) | 4 (26.7) | 12 (37.5) |
| Videoconferencing | 3 (33.3) | - | 3 (30.0) | 12 (70.6) | 13 (86.7) | 25 (78.1) |
| Website resources | 7 (77.8) | 1 (100.0) | 8 (80.0) | 5 (29.4) | 6 (40.0) | 11 (34.4) |
| **Average number of formats employed per participant** | | | | | | |
| Median (range) | 5 (2-7) | 5 (0-0) | 5 (2-7) | 3 (1-7) | 4 (1-7) | 3.5 (1-7) |

[α] Participants could select multiple formats

**Table 16** A summary of formats employed to deliver hybrid and remote primary services at T1 (n = 20) and at T2 (n = 18) (overall data set n = 22)

| | T1 n= 20 (n (%)) | | | T2 n =18 (n (%)) | | |
|---|---|---|---|---|---|---|
| | **Hybrid (n=12)** | **Remote (n=8)** | **Total (n=20)** | **Hybrid (n=14)** | **Remote (n=4)** | **Total (n=18)** |
| **Formats employed to deliver primary service remotely** [α] | | | | | | |
| e-learning | 1 (8.3) | - | 1 (5.0) | - | - | - |
| e-mail | 7 (58.3) | 3 (37.5) | 10 (50.0) | 9 (64.3) | - | 9 (50.0) |
| Internet forum | 1 (8.3) | - | 1 (5.0) | 1 (7.1) | - | 1 (5.6) |
| Internet portal | 2 (16.7) | 1 (12.5) | 3 (15.0) | 2 (14.3) | - | 2 (11.1) |
| Post | 3 (25.0) | 3 (37.5) | 6 (30.0) | 7 (50.0) | - | 7 (38.9) |
| Social media | 5 (41.7) | 2 (25.0) | 7 (35.0) | 5 (35.7) | 1 (25.0) | 6 (33.3) |
| Telephone calls | 11 (91.7) | 7 (87.5) | 18 (90.0) | 12 (85.7) | 3 (75.0) | 15 (83.3) |
| Text messaging | 5 (41.7) | 1 (12.5) | 6 (30.0) | 6 (42.9) | - | 6 (33.3) |
| Videoconferencing | 10 (83.3) | 6 (75.0) | 16 (80.0) | 9 (64.3) | 3 (75.0) | 12 (66.7) |
| Website resources | 3 (25.0) | 4 (50.0) | 7 (35.0) | 5 (35.7) | 1 (25.0) | 6 (33.3) |
| **Average number of formats employed per participant** | | | | | | |
| Median (range) | 3 (1-7) | 3.5 (1-5) | 3 (1-7) | 4 (1-9) | 1.5 (1-3) | 3.5 (1-9) |

[α] Participants could select multiple formats

**Table 17** Formats employed per hybrid or remote primary service at T1 (n = 32) (overall data set n = 36)

| | Accompanying/ Befriending (n=3 (%)) | Advice, information and support (n=5 (%)) | Day care centre (n=6 (%)) | Social activities (n=8 (%)) | Support groups (n=10 (%)) | Total (n=32 (%)) |
|---|---|---|---|---|---|---|
| **Formats employed to deliver primary services remotely** [α] | | | | | | |
| e-learning | 1 (33.3) | - | 1 (16.7) | - | - | 2 (6.3) |
| e-mail | 2 (66.7) | 3 (60.0) | 4 (66.7) | 7 (87.5) | 3 (30.0) | 19 (59.4) |
| Internet forum | - | - | 1 (16.7) | - | - | 1 (3.1) |
| Internet portal | - | 1 (20.0) | 2 (33.3) | - | - | 3 (9.4) |
| Mobile application | - | - | - | - | 1 (10.0) | 1 (3.1) |
| Post | 2 (66.7) | 4 (80.0) | 2 (33.3) | 3 (37.5) | 1 (10.0) | 12 (37.5) |
| Social media | - | 1 (20.0) | 4 (66.7) | 2 (25.0) | 2 (20.0) | 9 (28.1) |
| Telephone calls | 3 (100.0) | 5 (100.0) | 6 (100.0) | 7 (87.5) | 6 (60.0) | 27 (84.4) |
| Text messaging | 2 (66.7) | 2 (40.0) | 4 (66.7) | 1 (12.5) | 3 (30.0) | 12 (37.5) |
| Videoconferencing | 1 (33.3) | 4 (80.0) | 4 (66.7) | 6 (75.0) | 10 (100.0) | 25 (78.1) |
| Website resources | 2 (66.7) | 2 (40.0) | 2 (33.3) | 4 (50.0) | 1 (10.0) | 11 (34.4) |
| **Average number of formats employed per participant** | | | | | | |
| Median (range) | 6 (1-6) | 5 (2 -7) | 5.5 (3 -7) | 3.5 (2-7) | 2 (1-7) | 3.5 (1-7) |

[α] Participants could select multiple formats

#### 4.4.3.3 Frequency of service delivery and usage of primary services

Across the survey timepoints, the frequency of service delivery per regular month increased, and a small, but important, decreasing trend in usage was observed (**Figure 6** and **Table 19**). Compared with before the pandemic, in-person services at T1 were delivered more frequently but accessed by almost a third of service recipients (**Table 13**). At T2, the use of in-person services increased and the use of hybrid services remained similar to T1 (**Table 14**).

### 4.4.4 COVID-19 mitigation measures implemented to deliver services

All participants implemented mitigation measures when delivering in-person services (either as part of fully in-person or hybrid delivery methods) at T1 and T2. Social distancing, wearing personal protective equipment and the COVID-19 vaccination of social care and support providers, were the most implemented measures (**Table 18**)

### 4.4.5 Satisfaction with primary service delivery

Before the pandemic, participants were most satisfied when delivering services in-person (**Table 13**). At T1 and T2, remote and hybrid services yield similar satisfaction levels, and most social care and providers were ‘fairly satisfied’ (**Table 14**).

**Table 18** A summary of COVID-19 mitigation measures employed to deliver in-person or hybrid primary services at T1 (n = 14) and T2 (n = 18) (overall data set n = 22)

| | **T1 n=14 (n (%))** | **T2 n=18 (n (%))** |
|---|---|---|
| **COVID-19 measures employed to deliver primary services** [α] | | |
| Service recipients vaccinated | 10 (71.4) | 12 (66.7) |
| Service recipients bring food/drink | 3 (21.4) | 3 (16.7) |
| Service recipients contact details (track and trace) | 5 (35.7) | 8 (44.4) |
| Different activities | 11 (78.6) | 10 (55.6) |
| Minimise contact with service users | 10 (71.4) | 9 (50.0) |
| Shorter time spent with service users | 5 (35.7) | 3 (16.7) |
| Social distancing | 14 (100.0) | 16 (88.9) |
| Social care and support providers vaccinated | 12 (85.7) | 13 (72.2) |
| Wearing PPE[β] | 12 (85.7) | 12 (66.7) |
| **Average number of measures employed per participant** | | |
| Median (range) | 6 (2-9) | 5 (2-9) |

[α] Participants could select multiple measures. Abbreviation: PPE, personal protective equipment.

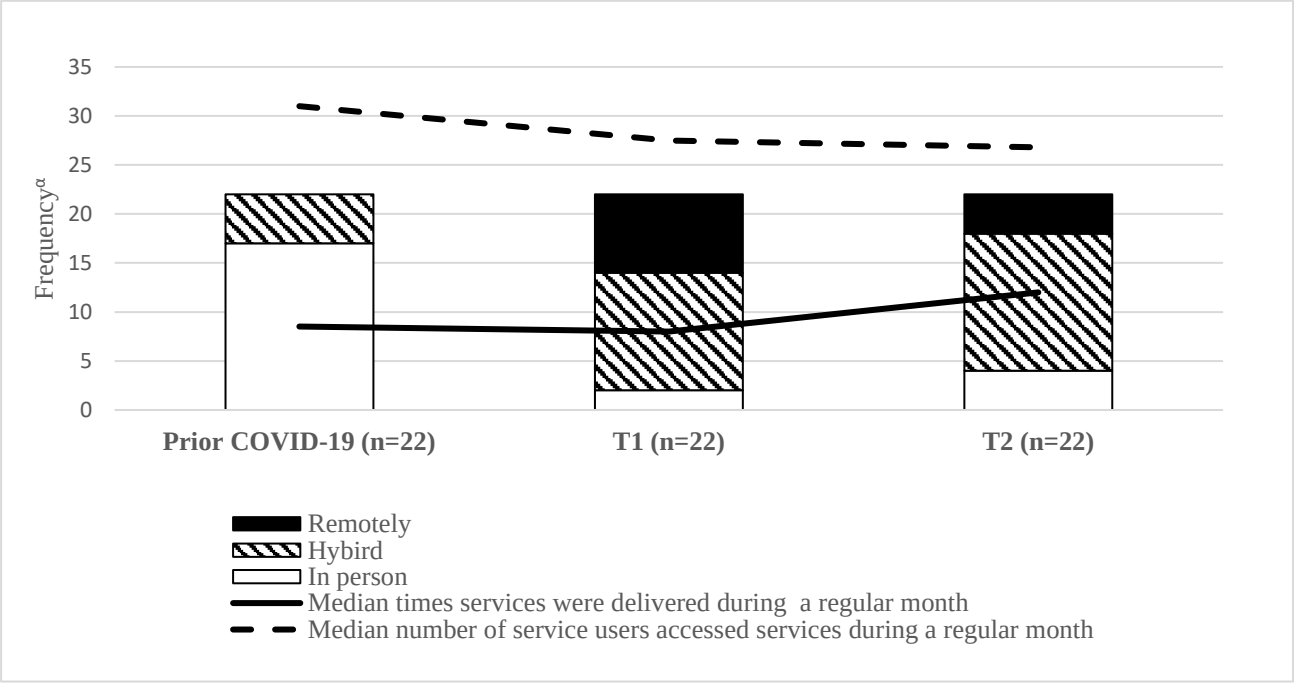


**Figure 6** Graph showing the shift in service delivery method, frequency of service delivery and usage of primary services across the three timepoints (n=22)

[α] Frequency relates to the number of services/average number of service recipients accessed services per regular month/average number of times services were delivered per regular month.

**Table 19** An overall longitudinal summary of primary services delivered, service recipients and usage prior to the pandemic, T1 and T2 (n = 22)

| | Prior COVID-19 (n=22) (n (%)) | T1 (n=22) (n (%)) | T2 (n=22) (n (%)) |
|---|---|---|---|
| **All services delivered** [α] | | | |
| Accompanying/ befriending | 7 (31.8) | 8 (36.4) | 6 (27.3) |
| Advice, support and information | 3 (13.6) | 5 (22.7) | 6 (27.3) |
| Day care centre | 8 (36.4) | 7 (31.8) | 7 (31.8) |
| Home meal delivery | - | 1 (4.5) | - |
| Paid home care | 1 (4.5) | 2 (9.1) | 1 (4.5) |
| Respite care | 3 (13.6) | 1 (4.5) | 1 (4.5) |
| Social activities | 16 (72.7) | 15 (68.2) | 13 (59.1) |
| Support groups | 17 (77.3) | 12 (54.5) | 15 (68.2) |
| Transport | 2 (9.1) | 1 (4.5) | 3 (13.6) |
| **Average number of services delivered per participant** | | | |
| Median (range) | 2.5 (1-5) | 2 (1-6) | 2 (1-7) |
| **Primary services delivered** | | | |
| Accompanying/ befriending | 1 (4.5) | 1 (4.5) | 1 (4.5) |
| Advice, support and information | 3 (13.6) | 3 (13.6) | 2 (9.1) |
| Day care centre | 7 (31.8) | 6 (27.3) | 7 (31.8) |
| Social activities | 3 (13.6) | 6 (27.3) | 6 (27.3) |
| Support groups | 8 (36.4) | 6 (27.3) | 6 (27.3) |
| **Service recipients of primary services** | | | |
| Unpaid carer (current / former) | 1 (4.5) | 1 (4.5) | 1 (4.5) |
| Person with dementia | 5 (22.7) | 2 (9.1) | 4 (18.2) |
| Both | 16 (72.7) | 19 (86.4) | 17 (77.3) |
| **Primary services delivery models** | | | |
| In person | 17 (77.3) | 2 (9.1) | 4 (18.2) |
| Hybrid | 5 (22.7) | 12 (54.5) | 14 (63.6) |
| Remotely | - | 8 (36.4) | 4 (18.2) |
| **How often primary services were delivered remotely** [β] | | | |
| Never | 15 (68.2) | 1 (4.5) | 4 (18.2) |
| Sometimes | 6 (27.3) | 6 (27.3) | 6 (27.3) |
| Often | 1 (4.5) | 6 (27.3) | 7 (31.8) |

| | | | |
|---|---|---|---|
| All of the time | - | 9 (40.9) | 5 (22.7) |
| **Overall satisfaction with primary service delivery** | | | |
| Very satisfied | 16 (72.7) | 6 (27.3) | 9 (40.9) |
| Fairly satisfied | 5 (22.7) | 15 (68.2) | 13 (59.1) |
| Not satisfied | 1 (4.5) | 1 (4.5) | - |
| **Average number of times primary services were delivered** [β] | | | |
| Median (range) | 8.5 (1-40) | 8.0 (1-22) | 12 (1-50) |
| **Average number of service recipients accessed primary services** [β] | | | |
| Median (range) | 31 (5-180) | 27.5 (4-220) | 26.8 (5-358) |

[α]Participants could select multiple services

[β]During a regular month

## 4.5 Discussion

This exploratory longitudinal study is one of the first to report on how dementia-related social care and support services have adapted during the pandemic. While a slight decrease at T1, participants worked or volunteered a comparable number of hours across the survey timepoints. Day centres, social activities and support groups were the most delivered primary services. During the pandemic, a shift from in-person to remote or hybrid services was observed. Although in-person services started to resume at T2, services were largely delivered by hybrid approaches. While the frequency of service delivery increased at T2, a small, but important, decreasing trend in usage was observed across survey timepoints. The reduced access aligns with previous research outlining the alarming consequences following the reduced service use during the pandemic (Giebel et al., 2020b; 2021c). This study adds to the growing evidence base by exploring the issue from the service delivery angle.

The adaptation of delivery methods is likely to depend on various factors, which may differ across sectors and/or by organisation size. Factors may include social care and support providers' access to ICT equipment, digital literacy and ability to receive support to navigate the technology (Lee et al., 2021; Naughton-Doe et al., 2021; Sadarangani et al., 2021; Tamplin & Thompson, 2023). While the telephone was the most employed format, akin to other studies, I observed an increased reliance on the use of videoconferencing software during the pandemic (DiLorito et al., 2021; Lee et al., 2021; Masoud et al., 2021; Gerritzen et al., 2023b). The use of videoconferencing software peaked when public health restrictions were most restrictive and may have been used as an interim to see one another when doing so in person was unsafe. Delivering services by videoconferencing software is likely to have engendered a steep learning curve, which may include adapting the content delivered (Lee et al., 2021; Sadarangani et al., 2021; Tamplin & Thompson, 2023) and identifying how to optimally facilitate engagement with people with dementia and unpaid carers (DiLorito et al., 2021; Gerritzen et al., 2023b). Delivering services by videoconferencing software may be time effective (Azad et al., 2012) and, compared to the telephone, the format offers visual cues which may help foster a sense of connection with people with dementia and unpaid carers (DiLorito et al., 2021). However, compared to delivering services in person, the use of videoconference software may present some drawbacks. For example, some providers reported challenges in assessing and progressing people with dementia participating in an exercise health programme (DiLorito et al., 2021), a lack of privacy during some medical follow-ups (Azad et al., 2012) and the audio latency formed a barrier to engaging in singing groups (Lee et al., 2021). While not collected in my survey, the use of videoconferencing software to deliver support asynchronously, largely by pre-recorded videos, is documented in other studies (Evans et al., 2021; Lee et al., 2021; Tamplin, J., & Thompson., 2023). This format may help to overcome issues relating to audio latency

and facilitate a timely and flexible access to support. Further research is required to explore the challenges and opportunities presented by using different ICT formats to deliver an array of services across the three sectors.

The ability to access, use and benefit from services delivered by videoconferencing software is unlikely to be equal among people with dementia and unpaid carers. Factors that may facilitate engagement may include higher socio-economic status (Robinson et al., 2015), less severe dementia stage and the ability to receive support to navigate and engage with remote services (Arighi et al., 2021; DiLorito et al., 2021). Most participants in my survey employed more than one format to remotely deliver services, and the use of videoconferencing software was frequently coupled with telephone calls and emails. The option to access remote services by means other than videoconference has been reported elsewhere (Capozzo et al., 2020; Evans et al., 2021; Lee et al., 2021), and is likely to facilitate access to people with limited digital literacy. Concerningly, I observed a reduced service usage during the pandemic. However, the option to access services by more traditional formats, alongside novel approaches, is likely to have helped to mitigate the widening of inequalities in access. Although not collected in my survey, other studies have sought to bridge people with dementia and unpaid carers' limited ICT access and literacy by providing devices and ongoing support throughout the study period (Ptomey et al., 2019; Howe et al., 2020). The planning of future service delivery may benefit from gaining an understanding of whether similar approaches have been employed during the pandemic, and whether these have facilitated access to services. However, being able to access support remotely may not necessarily translate to usage. People with dementia and unpaid carers have reported that accessing services remotely is 'not the same' as in-person services (Masoud et al., 2021; Gerritzen et al., 2023b), and their preferences on how support is accessed needs to be considered.

Although not a new delivery method in itself, I observed the reliance on hybrid services significantly increase during the pandemic. In my survey, hybrid services continued to feature as public health measures eased, and subsequently, removed. People with dementia and unpaid carers who accessed remote services during the pandemic valued the support received, however, many preferred in-person services (Masoud et al., 2021). Once legally allowed, services gradually began to deliver socially distanced in-person services, often in small groups and/or outdoors (Evans et al., 2021; Naughton-Doe et al., 2021). This aligns with my findings and is likely to explain the increased frequency but fewer service recipients accessing in-person services at T1. Nevertheless, the opportunity to access services remotely following the removal of the public health measures is likely to facilitate access to some service recipients in my survey. Subsequent to two years of confinement, people with dementia and unpaid carers remain cautious and fear engaging in-person activities (Naughton-Doe et al., 2021; Dawson et al., 2023). In addition, many people experienced a deterioration in their dementia symptoms

(Giebel et al., 2022a; Dawson et al., 2023), and accessing services in person may no longer be feasible or desirable. Thus, the ongoing opportunity to access services remotely, whilst in-person services are resuming, is likely to be important for some people with dementia and unpaid carers. Across the survey timepoints, I observed a slight change in the formats employed to deliver hybrid services. While the telephone and emails remained frequently used throughout, the use of videoconferencing peaked when public health measures were most restrictive. Further research is required to characterise the ongoing delivery of hybrid services which may help to guide the transition to from emergency to routine service delivery following future public health crises.

## 4.6 Strengths and Limitations

This appears to be the first survey to date which captured the fast-moving changes in adapting and delivering dementia-related social support services for dementia during the pandemic, from the service provider point of view. Given its novelty and attempt to longitudinally report on a broad range of social support services, this exploratory survey has multiple strengths. However, some limitations ought to be acknowledged whilst interpreting these my findings. Whilst my sample demographics are akin to those of the adult social care sector (Skills for Care, 2022) my sample lacked ethnic diversity and largely compromised of participants working or volunteering within the Third sector in England and Scotland. Therefore, my study provides a much required first snapshot of a variety of dementia-related social support services, with data collected at a time when social care and support providers were particularly struggling for time to engage with anything other than to provide support to people with dementia and unpaid carers. Despite piloting the tool prior to data collection, I identified that the wording of some questions could have been clarified. I noticed some discrepancies in how the same participants answered related questions, rendering it difficult, at times, to understand which formats were employed to deliver social support services remotely, and those used to engage with service provide support to service recipients outside of attending services. This may have been avoided had the tool been piloted amongst social care and support providers delivering different services across various sectors. The collected satisfaction levels provide a general insight into participants' satisfaction with primary service delivery methods throughout survey timepoints and would benefit from further (possibly qualitative) exploration. Lastly, my tool only identified formats used to deliver services, including a follow-up question asking participants to quantify how often they employed each format(s) to deliver primary services at each survey timepoint would have strengthened the tool.

## 4.7 Conclusions

During the pandemic, I observed a shift from in-person to remote or hybrid services. Compared to prior to the pandemic, following the removal of public health measures, services were delivered more

frequently, but accessed by fewer service recipients. While the telephone remained the most employed format, reliance on videoconferencing software significantly increased during the pandemic. Employing videoconferencing software alongside more traditional formats, such as telephone and emails, is likely to facilitate access to service recipients with limited digital literacy. Nevertheless, the ongoing opportunity to access services remotely while in-person services resume is likely to facilitate access to some service recipients. Thus, it is important that the provision of in-person and remotely delivered services is carefully balanced amidst the current hybrid landscape.

## 4.8 Acknowledgements

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## 4.10 Disclosure statement

The authors report there are no competing interests to declare.

## 4.11 Research developments from this chapter

This chapter presented the findings of my longitudinal quantitative survey. I observed a shift from in-person to remote or hybrid approaches to service delivery during the pandemic and a slight, but concerning, downward trend in the use of services. The use of the telephone remained the most employed ICT format across survey timepoints, however, videoconferencing software was frequently used while the COVID-19 public health measures were most restrictive. Accessing and delivering services by remote or hybrid approaches is likely to engender significant changes in how service recipients engaged with services and social support providers' working approaches. It will be important to provide meaning to the adaptation of service delivery during the pandemic, and lessons learned will be invaluable to guide the use of ICT within the current landscape, and amidst future public health crises. Therefore, to complement my survey findings (**fourth** chapter), I conducted semi-structured interviews with social care and support providers. Moreover, to expand upon my systematic review findings (**second** chapter), I conducted semi-structured interviews with people with dementia and unpaid carers to further explore their views on accessing social care and support services remotely during the pandemic.

# CHAPTER 5: "NECESSITY IS THE MOTHER OF INVENTION": LESSONS LEARNED FROM DELIVERING AND ACCESSING DEMENTIA-RELATED SUPPORT SERVICES DURING THE PANDEMIC IN THE UK

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**Author contributions:** TC: Conception, study design, execution, acquisition of data, analysis, interpretation of results, drafting or writing of the manuscript. CG: Offered considerations to the conception, study design, analysis, interpretation of results, reviewing the manuscript. SM, SR: Offered considerations to the study design, interpretation of results, reviewing the manuscript. HT: Offered considerations to the study design, analysis, interpretation of results, reviewing the manuscript. SL: Offered considerations to the interpretation of results.

## 5.1 Abstract

**Introduction**: The reliance on information communication technology (ICT) within dementia-related support services increased since the coronavirus (COVID-19) pandemic. To guide the current and future use of ICT, this study explored the barriers and facilitators to delivering and accessing social care and support services during the pandemic.

**Method**: Remote semi-structured interviews with service providers, people with dementia and unpaid carers were conducted between May-December 2022. Topic guides were co-developed with two public advisors (one unpaid carer, one person with dementia) and garnered information on the delivery and access to services before and during the pandemic. Audio recordings were transcribed verbatim. Employing a mixture of inductive and deductive analytic approaches, a reflexive thematic analysis was conducted.

**Results**: Twenty-one interviews (n=13 social care and support providers; n=7 service recipients; n=1 both) were conducted. Three themes were generated: meeting additional and enduring needs; adapting to changing circumstances; and ICT should be a tool, not the default. Existing support extended to meet service recipients' presenting needs. Service providers' resilience, creativity and motivation facilitated service adaptation, however, access to resources, guidance and wellbeing support varied. While some service recipients accessed and benefitted from remote services during the pandemic, the use of ICT was not suitable for everyone.

**Conclusions:** The use of ICT can both facilitate and hinder access to services, hence balancing the provision of in-person and remote services is important. Digital training and devising guidelines on the remote delivery of services may optimise the use of ICT within the current hybrid landscape and amidst future pandemics.

**Keywords:** Dementia, ICT, post-diagnostic support, support services, remote service delivery, pandemic

## 5.2 Background

An estimated 920,000 people currently live with dementia in the UK, which is anticipated to rise to over a million by 2024 (Wittenberg et al., 2019). While substantial progress to facilitate an early diagnosis has been made, greater efforts to enable access to responsive post-diagnostic support are required (Arbalster & Brennan, 2022).

Post-diagnostic support includes services that respond to the care and support needs experienced by people with dementia and unpaid carers, throughout the disease trajectory (Prince et al., 2016). Within post-diagnostic support, social care and support services can be defined as non-clinical services that support community-dwelling people with dementia, and unpaid carers, to live well. Social care and support services are provided by multiple sectors, providers and settings. Services are largely provided by local authorities and Third sector organisations, and services may include paid home care, befriending services, day care centres and respite care. Social care and support services are important to living well with dementia, and may promote independence, facilitate meaningful engagement and alleviate the carer burden (Camic et al., 2013; Kelly & Innes, 2016; Willis et al., 2018).

Access to post-diagnostic support can be problematic, and persisting unmet needs are unequally distributed (Bieber et al., 2019; Ketchum et al., 2022; Giebel & Heath, 2023). The use of information communication technology (ICT) within service delivery may present a convenient approach to accessing support (McLoughlin et al., 2023) and overcome barriers associated with rural residency (Bayly et al., 2020). However, benefits garnered from using ICT are likely to be influenced by factors associated with the social determinants of health, such as educational attainment, socio-economic status and previous exposure to ICT (Robinson et al., 2015; 2020). Thus, the over reliance on remote services may disenfranchise people with dementia and unpaid carers who are digitally excluded or prefer to access services in-person. The coronavirus (COVID-19) pandemic presents a unique opportunity to explore the barriers and facilitators to delivering and accessing social care and support services remotely, and to assess the appetite of using ICT within future service delivery.

Spanning from managerial to frontline positions, social care and support providers experienced significant changes in working practice. Several organisations delivered socially distanced door-step visits, established welfare calls (O'Rourke et al., 2021), and employed videoconferencing software to deliver live or pre-recorded support (Lee et al., 2021; Masoud et al., 2021; Cousins et al., 2022; Wheatley et al., 2022). Reactively turning towards digitally enabled solutions is likely to have involved numerous challenges, including tailoring the content of services to suit a remote format and assisting people with dementia and unpaid carers to access and engage with services (Di Lorito et al., 2021; Yi

et al., 2021). The pandemic engendered substantial hardship among people with dementia and unpaid carers (Giebel et al., 2022a, 2022b), and many services adjusted by delivering greater emotional support and preventing emergency hospital admissions (Wheatley et al., 2022). Documenting the barriers and facilitators to delivering social care and support services during the pandemic may help the preparedness of service delivery in the event of future public health crises.

Fewer people with dementia and unpaid carers accessed social care and support services during the pandemic (Giebel et al., 2021). Many services gravitated towards digital spaces (Bradbury et al., 2022) and accessing post-diagnostic support remotely appears feasible for some people with dementia and unpaid carers (Caprioli et al., 2023a). However, access often hinges on availability of devices, reliable connectivity, adequate digital literacy and/or the opportunity to receive support to navigate the technology (Robinson et al., 2015; 2020; Arighi et al., 2021;Yi et al., 2021). While the use of ICT to access support was welcomed by some people with dementia and unpaid carers, some experienced difficulties in engaging remotely and preferred accessing services in-person (Caprioli et al., 2023a). Barriers to engaging remotely may also include dementia-related factors, such as behavioural problems (Masoud et al., 2021), poor audio quality and hearing difficulties (Yi et al., 2021), limited ICT literacy and the inability to meaningful participate online. To overcome challenges relating to access and engagement with remote services, some studies provided devices, training and ongoing technology support (Yi et al., 2021; Caprioli et al., 2023a). Understanding how these possible barriers have been, or attempted to be, addressed during the pandemic may help to identify sustainable approaches to avoid leaving behind digitally excluded people with dementia and unpaid carers amidst future public health crises.

Thus, this qualitative study builds on my survey that compared the types of services and delivery methods employed in social care and support services prior to and during the pandemic (Caprioli et al., 2023b). In this study, I sought to (1) understand how the delivery of social care and support services adapted during the pandemic; (2) explore the experiences of delivering and accessing social care and support services during the pandemic; and to (3) understand the challenges and opportunities presented by using ICT within service delivery.

## 5.3 Methods

Grounded by a critical realist epistemological stance, a qualitative study design was applied to explore the experiences of people with dementia, unpaid carers, and social care and support providers (Gill et al., 2008). Critical realism adopts a realist ontology and a constructivist epistemology (O'Mahoney & Vincent, 2014), and enabled the contextualised exploration of the barriers and facilitators to delivering

and accessing social support services. The completed COREQ checklist (Tong et al., 2007) can be found **Appendix X.**

### 5.3.1 Participants and recruitment

Social care and support providers were defined as those who deliver non-clinical community-based social care and support services. The eligibility criteria are outlined in **Table 20** and social care and support providers were recruited from participants from my longitudinal quantitative survey who expressed interest in future research (Caprioli et al., 2023b). My previous survey compared community-based social care and support services delivered and delivery methods employed prior to and during the pandemic.

I endeavoured to engage a maximum variation sampling approach (Greene & Thorogood, 2018) to the recruitment of social care and support providers. The following previously collected elements guided the invitation of social care and support providers: socio-demographic factors; IMD quintile of service provision area (Department for Communities and Local Government, 2015); geographical location; sector and types of services delivered; and digital and non-digital formats employed. However, owing to challenges to recruit, the research opportunity was shared with all eligible participants (n=43).

People with dementia and current and/or former unpaid carers were eligible if they met the respective eligibility criteria outlined in **Table 20**. Service recipients were recruited by convenience sampling (Green & Thorogood, 2018). The research opportunity was shared on social media (X, formerly Twitter), at in-person dementia information events, amongst known social support service organisations and within social prescribing routes.

**Table 20** Eligibility criteria for each study population

| Social care and support providers | People with dementia | Unpaid carers |
|---|---|---|
| (1) currently working (paid capacity) or helping / volunteering (unpaid capacity) to deliver social support services within the public, private of voluntary sector in the UK; (2) delivering social care and support services to people with dementia and/or to unpaid carers living in the community; (3) either directly involved in delivering social care and support services or involved in the management / organisation of the delivery of social care and support services and (4) at least 18 years of age. | (1) lived in the community; (2) accessed social care and support services in the UK both prior to and during the COVID-19 pandemic; (3) had mental capacity; and (4) were at least 18 years of age. | (1) have accessed social care and support services prior to and during the COVID-19 pandemic in the UK that either addresses their needs, the needs of the person with dementia or the dyad's needs; and (2) at least 18 years of age. |

### 5.3.2 Data collection

Interviews were conducted remotely by Zoom or telephone between May and December 2022. Two semi-structured topic guides were co-developed with public advisers and with the wider research team (**Appendix K**). Topic guides garnered information relating to service delivery and access prior to and during the pandemic. A public advisor (HT) with experience in delivering and accessing support services prior to and/or during the pandemic was involved in piloting the topic guides.

I conducted all interviews. Interviews with provider participants were conducted on a one-to-one basis, and, depending on recipient participants' preferences, interviews were offered either on a one-to-one basis or as a dyad. Verbal informed consent was obtained and recorded prior to the interview. To assess the ability of potential participants with dementia to make an informed decision regarding their participation, individuals were asked to summarise their understanding of the study and reasons for participating in accordance with the Mental Capacity Act (2005). I conducted all mental capacity assessments, and a summary of the discussion was documented. CG, an experienced dementia researcher, was present during all assessments. Field notes were recorded following each interview to assist ongoing reflexivity. I transcribed verbatim a third of the audio-recordings and the remaining were transcribed by a professional transcription agency through the University of Liverpool.

To characterise the sample of recipient participants, age, gender, ethnic background, and if applicable, the type of dementia and time (years) since diagnosis, were collected.

### 5.3.3 Data analysis

I undertook a deductive and inductive reflexive TA to yield descriptive and interpretative accounts of delivering and accessing social support services. Following the six phases of TA (Braun & Clarke, 2006; 2022), transcripts were initially read multiple times. Subsequently, using a mixture of inductive and deductive analytic approaches, I systematically and manually coded all transcripts. One coded transcript was discussed with CG, and two coded transcripts with HT. Visually mapping the association between codes and themes assisted the development and refinement of pilot themes and sub-themes (Braun & Clarke, 2022). To assess the referential competency of the analysis, the pilot themes and sub-themes were compared to the raw data (Nowell et al., 2017). A pragmatic 10% of transcripts from each study population were compared to the pilot analysis. Alongside reflexive journaling, the evolution of the analysis was documented. Regular meetings with my public advisors and wider research team occurred throughout the data analysis phase, and the final themes and sub-themes were collectively agreed upon.

### 5.3.4 Public involvement

Two public advisors, a former unpaid carer and a person living with dementia (HT, SL), were actively involved throughout the study. Both HT and SL have experience in delivering and accessing social care and support services, before and/or during the pandemic. HT undertook training on coding as part of conducting reflexive TA and independently coded two transcripts. HT and SL attended meetings to design the study, interpret the findings and involved in writing a lay summary of the findings.

### 5.3.5 Ethical considerations

Ethical approval was granted by the University of Liverpool (Refence: 10786) prior to the commencement of the study.

## 5.4 Results

Twenty-one interviews were conducted (n=13 providers; n=7 service recipient; n=1 both) and lasted a mean of 32 minutes (range:11 - 60). Interviews with providers were slightly longer (mean: 36 minutes, range: 18-60) than interviews with service recipients (mean: 24 minutes, range: 11-50). All participants were interviewed on a one-to-one basis by video-conferencing software, except for one provider and one unpaid carer who participated by telephone.

Most providers identified as female and worked in a paid capacity within the Third sector. Service provision areas were mostly classified within the third to fifth IMD quintiles, representing areas in the middle to the least deprived (**Table 21**). All unpaid carers identified as female, and people with dementia as male **(Table 22).** One participant was diagnosed with mixed dementia and dementia with Lewy bodies six years ago, and one participant was diagnosed with Lewy body and Parkinson's Disease dementia 10 years ago.

As depicted in **Figure 7**, the analysis yielded three overarching themes: (1) meeting additional and enduring needs; (2) adapting to changing circumstances; and (3) ICT should be a tool, not the default. While quotes are included in the main text, additional quotes for each sub-theme can be found in **Table 24**.

**Table 21** Socio-demographic characteristics of the social care and support providers (n=14)

| **Social care and support providers n (%), n=14** | |
|---|---|
| Gender | |
| Female | 10 (71.4) |
| Male | 4 (28.6) |
| Age group | |
| 35-44 | 3 (21.4) |
| 45-54 | 3 (21.4) |
| 55-64 | 4 (28.6) |
| 65 and over | 4 (28.6) |
| Ethnicity | |
| White | 13 (92.8) |
| Mixed / Multiple | 1 (7.2) |
| Sector | |
| Public | 1 (7.2) |
| Private | 2 (14.3) |
| Third sector | 11 (78.6) |
| Contractual arrangement | |
| Paid | 9 (64.3) |
| Volunteer | 5 (35.7) |
| Region | |
| East of England | 3 (21.4) |
| Greater London | 1 (7.2) |
| North West | 5 (35.7) |
| South East | 2 (14.3) |
| West Midlands | 1 (7.2) |
| Scotland | 2 (14.3) |
| IMD quintile of service provision area[α] | |
| 1 | 2 (14.3) |
| 3 | 4 (28.6) |
| 4 | 3 (21.4) |
| 5 | 3 (21.4) |

[α]These represent the IMD quintiles of areas in England. Two participants provided services in Scotland, in areas classified in the third quintile (Scottish Index of Multiple Deprivation, 2020)

**Table 22** Socio-economic characteristics of service recipients (n=8)

| **Service recipients n (%)** | | | |
|---|---|---|---|
| | Unpaid carers (n=6) | People with dementia (n=2) | Total (n=8) |
| Gender | | | |
| Female | 6 (100.0) | - | 6 (75.0) |
| Male | - | 2 (100.0) | 2 (25.0) |
| Age | | | |
| 55-64 | 5 (83.3) | 1 (50.0) | 6 (75.0) |
| 65 and over | 1 (1.7) | 1 (50.0) | 2 (25.0) |
| Ethnicity | | | |
| White | 6 (100.0) | 2 (100.0) | 8 (100.0) |

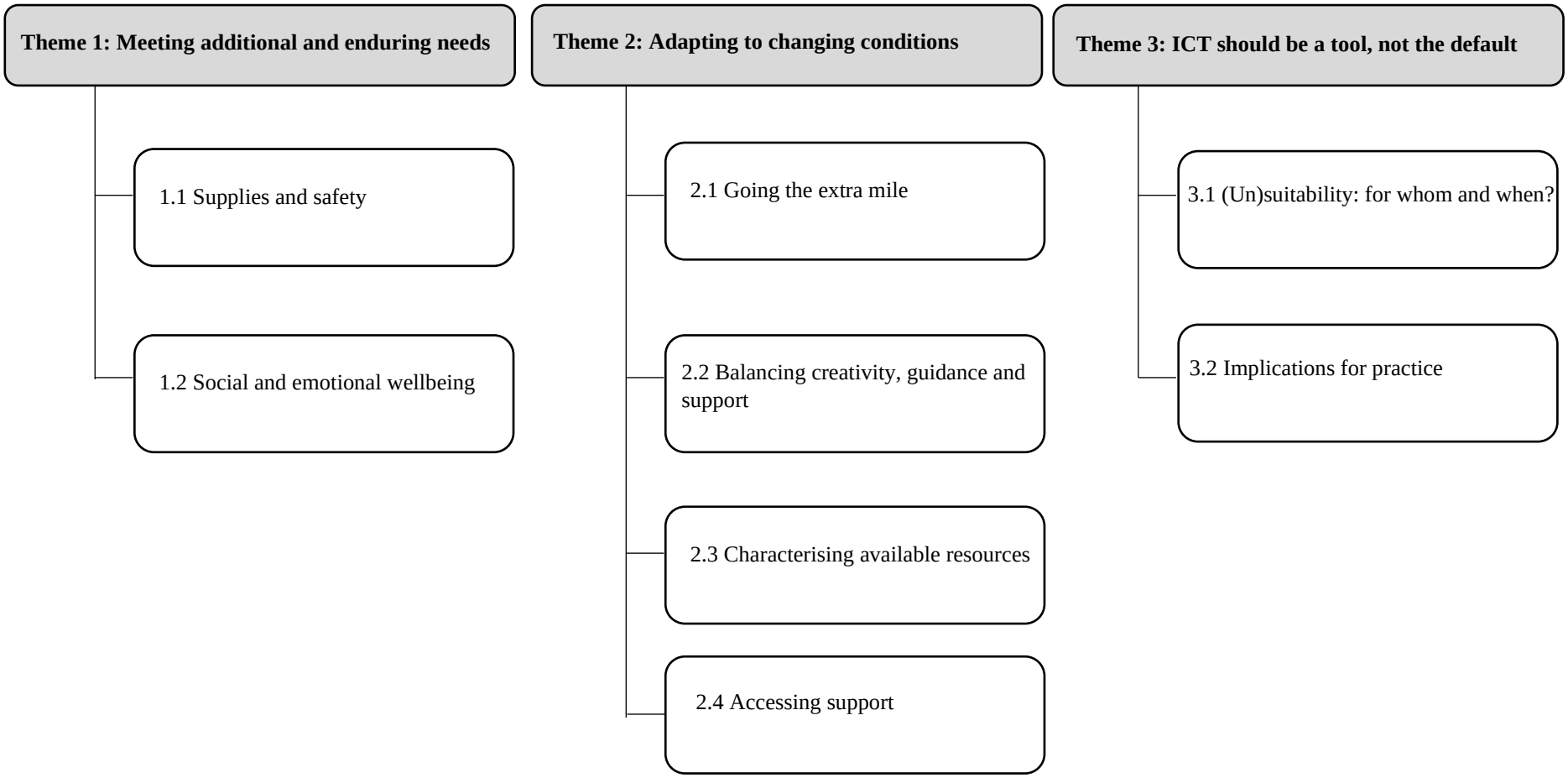


**Figure 7** Theme and sub-themes tree

### 5.4.1 Theme 1: Meeting additional and enduring needs

This theme reflects how the content of delivered social care and support services extended to respond to service recipients' additional needs during the pandemic, while addressing enduring pre-pandemic needs.

#### 5.4.1.1 Basic needs

The term 'basic needs' was narrowly conceptualised to refer to food, shelter and safety. When public health measures were most restrictive, society shifted towards digital spaces, and access to ICT devices and digital literacy often formed prerequisites to fulfilling one's basic needs. While some service recipients required little support to address their basic needs, some faced significant challenges. To this end, employing a mixture of proactive (e.g., regular welfare calls) and reactive approaches (e.g., helplines), providers organised food deliveries, distributed medical and non-medical equipment and collected prescriptions. One provider facilitated the payment of service recipients' bills when transactions were unable to be completed electronically. Moreover, some providers responded to safety concerns, which included supporting suicidal unpaid carers and organising the care of people with dementia when carers were hospitalised or unwell.

> '*We were you know, struggling for food, struggling for everything really'* **Unpaid carer to her husband, Female (C5)**
>
> *'…we were pretty self-sufficient, you know we got into a routine…'* **Former unpaid carer to her mother, Female (C4)**

Presenting needs were unpredictable and required prompt decision-making, often instilling concern and stress within providers.

> *'... I dreaded ringing. I dreaded picking, I don't mean I didn't do it, but it was like what will happen, will this be ok or not because the experience was showing that something that was ok last time was not ok the next time...'* **Paid provider in the Third sector, Female (P4)**

Furthermore, providers continuously disseminated safety advice regarding the fluctuating public health measures and advised on how to explain the ongoing restrictions to people with dementia. These became important when local restrictions were implemented. Meeting service recipients' basic needs was often in addition, and at times, instead of providing regular form of social care and support.

#### 5.4.1.2 Social and emotional wellbeing

From the sudden withdrawal of services during the initial phase of the pandemic, to daily living under lockdown, feelings of isolation and loneliness were abundant amongst service recipients.

> *'…I think with COVID the isolation of all these services dropping off because obviously Age Concern that dropped off, the luncheon club dropped off so we were, it was just me, my husband and my son'* **Former unpaid carer to her mother, Female (C4)**

Unpaid carers felt particularly isolated, notably if the person they were caring for became non-verbal or had died. Many unpaid carers undertook additional caring hours with limited or no respite and some navigated challenging decisions regarding the admission of the person they cared for to a long-term care facility. One provider reported that, prior to the pandemic, unpaid carers mostly used their service as respite. However, during the pandemic, the demand and use of support addressing unpaid carers' needs increased.

> '*It's not the time I would want to live through again, especially having to care 24/7, as well as keep him safe from COVID and keep myself safe from COVID, and [takes a deep breath] it was just the worst time I think ever*.' **Unpaid carer to her husband, Female (C5)**

> '*When we started to use electronic methods like this [videoconferencing software], visually and audially, and face-to-face, it brought me help. It brought me out of the depression.*' **Person with dementia, Male (PD2)**

To increase opportunities to socialise, providers established WhatsApp (an electronic messaging service) groups, interactive newsletters, post-card loops, peer support groups and delivered remote social activities. One provider loaned tablet and remotely assisted two service recipients to navigate the technology, enabling them to independently remain in contact. As the public health measures gradually eased, outdoor picnics, walks were organised and indoor gatherings slowly resumed. To support emotional wellbeing, some providers shared 'positive' messages and encouraged recipients to look forward to in-person gatherings. Furthermore, to help manage stress, pre-recorded de-stress videos, crossword and jigsaw puzzles were made available to unpaid carers.

### 5.4.2 Theme 2: Adapting to changing conditions

The introduction of the COVID-19 public health measures led to a shift from in-person to remote services, with service providers having to '*re-invent*' (**Volunteering provider in the Third sector, Female (P11)**) themselves to meet service recipients' needs.

#### 5.5.2.1 Going the extra mile

Providers' professionalism, motivation and creativity facilitated the delivery of timely, personalised and flexible support. Through an ongoing process of trial and error and seeking input from service recipients, providers found the confidence to implement new ideas to adapt services to reflect service recipients' needs, preferences and digital abilities. Examples include delivering support by digital and non-digital media, convincing senior management to establish a weekend helpline, and advising family members about their right to visit a hospitalised relative with dementia in the last days of life.

> *'So, we really left it up to the carer to say this is what I feel I need and they could say oh can I have a fortnightly call but then say actually a weekly call would do me better'* **Paid provider in the Third sector, Female (P8)**

> '*... not all of our members initially wanted to engage [in zoom activities] ... so that was when we implemented the telephone calls to make sure that people weren't left in isolation and forgotten about*' **Volunteering Provider in the Third sector, Male (P13)**

Working hours during the height of the pandemic often extended into weekends and evenings, and exchanges with service recipients were lengthy. However, spending more time together, often on a one-to-one basis, fostered a deeper relationship with service recipients, which was valued by some providers.

#### 5.5.2.2 Balancing creativity, guidance and support

Many providers found the changing COVID-19 public health measures frustrating and/or difficult to comprehend in relation to delivering services. Guidance received varied among providers, with some receiving little guidance to establish remote care and resume in-person services. However, many providers enjoyed the creativity required to adapt services, and in the absence of guidance, some providers or organisations created internal procedures and/or sought advice from universities or other social care and support organisations. Sharing lessons learned with other organisations became a valued source of inspiration and support for some providers.

> *'…[the] organisation's approach was they set up very quickly a policy for conducting welfare calls…'* **Paid provider in the Third sector, Female (P4)**

> *'... I did get in touch with the local council and they sort of, there was no. I would have liked some sort of clarification on am I doing this right, am I doing that right. I felt like I was very much on my own…'* **Paid provider in the Private sector, Female (P7)**

Witnessing the deterioration of service recipients' health, or their death, was greatly upsetting. Providers were '*not immune to their problems*' (**Volunteering provider in the Third sector, Male (P12)**) and were simultaneously bearing the impact of the pandemic professionally and within their personal lives, with one provider reporting experiencing burnout. Access to wellbeing support within the workplace seemed limited. One provider received support from their manager to navigate feelings of culpability should virus transmission occur while attempting to safely re-open in-person memory cafés.

> *'...enormous number of deaths because of that they just gave up and we had to watch it happening or listen to it happening via the telephone and so on'* **Volunteering provider in the Third sector, Male (P12)**

> '*...bang straight working from home and the next days and you know and then I'm thinking right I need to ensure I can provide for my children and make sure they're safe for lockdown*' **Volunteering provider in the Third sector (P13)**

Nevertheless, some providers established wellbeing initiatives for their staff and volunteers. These took form of regular telephone calls, debrief sessions and social activities. Upon reflection, many providers would place greater efforts in promoting staff and volunteer wellbeing.

### 5.5.2.3 Characterising available resources

The types and number of resources varied across providers. The availability of funds differed. Smaller Third sector organisations were impacted by stalling funds, and stayed afloat due to prior budgeting, continuous donations and receiving the remaining funds of collapsed organisations. One provider introduced a small service charge, and some organisations received grants to cover postage costs and the cost of lending tablets to service recipients.

> *'We we didn't have sort of income over that period of time, other than the generosity of the community and so we were very fortunate in that respect that we kept some sort of financial flow'* **Volunteering provider in the Third sector, Male (P12)**

> *'Um uh but our income dropped like a stone as well. But that didn't matter. But next time, I would be more encouraging in saying, let's get out there in buying some IT equipment, give it to the people...'* **Volunteering provider in the Third sector, Male (P13)**

Furthermore, the regularity of access to ICT devices and digital literacy varied across providers. Some providers independently delivered services by videoconferencing software while home working and/or relied on the assistance of colleagues; however, others relied on external stakeholders or solely delivered services by telephone or postal services. One provider reported having difficulties delivering services by telephone due to limited mobile reception while working from home.

> *'That made life much easier because all of the staff of the day service had laptops…'* **Paid provider in the Public Sector, Male (P14)**

> *'Well, I don't know [what] Zoom is - nobody has ever said to me about Zoom -I- I haven't wouldn't know what to do about Zoom'* **Volunteering provider in the Third sector and unpaid carer to her husband, Female (P1)**

Through newly or previously forged partnerships, collaborations with external stakeholders were important when addressing service recipients' critical needs, receiving ICT support and delivering social activities. Stakeholders included other social care and support organisations, local authorities, libraries and local artists. Prior to the pandemic some providers relied on stakeholders to access physical spaces. When resuming in-person services, some providers were able to regain access to physical spaces, however, some stakeholders (e.g., church halls, organisations and community centers) had ceased operating during the pandemic.

> *'... everybody who attends the day service we provide them with the lunch so we had to work very closely with all partners in adult social care for them to understand that these people you*

*know the day center is closed so they had to have lunch delivered on that particular day*' **Paid provider in the Public Sector, Male (P14)**

Many volunteers were re-allocated and played a pivotal role in delivering services during the pandemic. Generally, volunteers are not contractually bound, and could decide whether to continue to deliver support as in-person services resumed. This facilitated the early delivery of in-person services in some instances, however, acted as a barrier in others.

*'…volunteers could decide whether or not they wanted to come. Other services in other sectors may not have been able to run such groups at the same time'* **Volunteering provider in the Third sector, Female (P3)**

'*... we've got fewer volunteers now, a lot of the didn't didn't want to come back afterwards for a little while they thought they would catch COVID at the café'* **Paid provider in the Third sector, Female (P6)**

When demand outweighed available resources, some service recipients' needs were prioritised. Key factors when prioritising needs included whether the person with dementia was living alone, and the needs reported by service recipients.

### 5.5.2.4 Accessing support

While it was not always communicated, many people with dementia and unpaid carers valued the endeavors social care and support providers undertook to continue to provide some form of support.

*'If people aren't falling over themselves to say thank you, they've got enough on their plate.'*

**Volunteering provider in the Third sector, female (P11)**

*'... we were grateful to do anything, so um, every time somebody said they'd be a Zoom, we'd be there'* **Volunteering provider in the Third sector and unpaid carer to her husband, Female (P1)**

*'…they were very prompt, they got back to us quickly, they were very helpful, told us what was available to us…'* **Former unpaid carer to her mother, Female (C4)**

Other service recipients reported on less positive experiences while accessing support during the pandemic. These included accessing peer support groups by video conferencing software that did not align with their presenting needs, a delayed home assessment, and receiving limited contact from providers.

'*…I joined a few times [peer support group], but … they were all people whose, it was their husband or their wife or their spouse or a person of the same you know they were in that type of relationship*.' **Unpaid carer to her mother, Female (C3)**

*'I think just the occasional phone call when they call you, I mean it did happen but maybe more structure around that and more regular'* **Former unpaid carer to her mother, Female (C4)**

Furthermore, services were frequently short-staffed, which resulted in unhelpful contact with providers and the provision of untimely or unreliable home care.

*'I think it was just, people didn't wanna be bothered… cos like obviously… a lot of places didn't have many staff… and so… ya longer to get through… or… find out things, ya know what I mean?'* **Person with dementia, Male (PD1)**

*'…during lockdown it was a bit sketchy they were short of staff, the timings were a bit out but of course, like everything, there's settling in periods to it as well…'* **Former unpaid carer to her mother, current unpaid carer to her mother-in-law, Female (C2)**

### 5.4.3 Theme 3: ICT should be a tool, not the default setting

While the COVID-19 public health measures were most restrictive, most providers employed telephone calls while some delivered services by videoconferencing software. Accessing services remotely was beneficial to some service recipients, and providers' views towards the use of ICT in future service delivery was mixed.

#### 5.5.3.1 (Un)suitability of using ICT: for whom and when?

Access to remote social care and support services varied. Service recipients were most familiar with landline telephones. While some service recipients had email addresses, internet connectivity and access to ICT devices, ownership did not always translate to the ability to access services. Barriers included a lack of confidence, fear of breaking ICT devices and ownership of outdated devices that were incompatible with recent videoconferencing software. Some people with dementia learned to navigate videoconferencing software independently or with support from unpaid carers, however, not all unpaid carers were able to provide support. Unpaid carers who were able to navigate videoconferencing software recognised their fortunate position.

*'…at first, I-I was a bit frightened about it … but when I-I got on to it, I-I found it really interesting because b-being able to contact people and stuff like that, and… and better than phone call…Cos you can actually see a person then*' **Person with dementia, Male (PD1)**

*'…people, people who couldn't afford the technology were really really adversely impacted. Um, but then, people who couldn't operate you know, and-and even like carers or like or family or paid carers, we found were struggling to be honest'* **Paid provider in the Third sector, Female (P2)**

Remote social care and support services were unable to replicate the companionship experienced and valued when accessing services in-person but produced many benefits in the absence of this option. While receiving newsletters by post was the preferred form of support for some service recipients, peer support groups by videoconference software were a '*God-send*' (**Person with dementia, Male (PD2)**) to some. The visual cues offered by videoconferencing software were valued by some people with dementia, whereas it was a sensory overload for others. Some people with dementia were able to, either independently or with assistance, engage in services delivered by videoconference software, however, some found the format confusing and/or minimally engaging. Furthermore, some people with dementia preferred engaging with social care and support services on a one-to-one basis by videoconferencing

rather than within a group. Compared to people with dementia, unpaid carers seemed to garner more benefits from accessing social care and support services remotely.

> *'…if I had a choice, I would go back to one to one [in-person services], but without technology I would have been in a very different place emotionally and physically I think yeah.'* **Former unpaid carer to her mother, current unpaid carer to her mother-in-law, Female (C2)**

> *'Um… wasn't as good for [Husband with dementia] because it's very flat, isn't' it? You know, um he still will look at a Zoom call, um… he does go on Zoom with me, but he doesn't like it as much as seeing somebody in the room.'* **Volunteering provider in the Third sector and unpaid carer to her husband, Female (P1)**

Providers' views towards using ICT in future service delivery were mixed. While some recognised the value ICT may offer when complementing in-person services, some providers opposed its use. Remote services can offer benefits such as bypassing geographical barriers, facilitate access to service recipients who are housebound and may enable short-term support during adverse weather or illness. Furthermore, following the removal of the COVID-19 public health measures, many service recipients were anxious to resume attending services in-person, and the ongoing opportunity to access services remotely was important.

> *'…it's possible that-that the people receive lots of different ideas and toolkits and resources to help them. But, but honestly, it needs scaffolding by real people in the room.'* **Paid provider in the Third sector, Female (P2)**

However, remote social care and support services are unsuitable for some service recipients and types of support. Providing support to emotionally distressed service recipients requires in-person contact. Providers felt helpless when supporting suicidal unpaid carers remotely. Evaluating the risk of potential virus transmission and responding to serious safety concerns was challenging, and on critical occasions, in-person support was deemed necessary.

> '*When you've got a carer phoning up saying I'm going to kill myself then we've kind of got to say well actually we're got to go we've got to go and do something face to face with them*.' **Paid provider in the Third sector, Female (P8)**

Furthermore, the use of ICT may provide non-service recipient facing benefits. One provider, who largely delivered services by home visits prior to the pandemic, commented on the possible time-effectiveness of delivering services remotely. The pandemic digitalised some elements of the internal working of two organisations, and one provider reported establishing a WhatsApp (an electronic messaging service) group among staff and volunteers which facilitated prompt decision- making.

### 5.5.3.2 Implications for practice

Providers undertook several measures to increase service recipients' access and engagement with remote services. To bridge the limited ICT device ownership, some providers loaned tablets, sometimes with data plans, to service recipients. Tablets were rendered more accessible by undertaking steps

outlined in **Table 23**. However, remotely assisting service recipients to navigate videoconferencing software was challenging. Owing to the anticipated difficulties to deliver remote ICT training, one provider avoided lending tablets, and another provider overcame these challenges by delivering socially distanced training at service recipients' doorstep.

> *'…but literally took me two hours, just to get her to turn the device on, because, she was turning it on, and then instantly turning it back off again. She just got into this loop.'* **Paid provider in the Third sector, Male (P5)**

Two providers received specialised devices to loan to people with dementia. While not all people with dementia were able to use the specialist devices, they proved to be beneficial to some. Alternatively, to remove difficulties with navigating new ICT, one provider delivered singing sessions by Microsoft Teams (videoconferencing software), which enabled service recipients to access sessions from landline telephones. Once in-person services resumed, some providers established ICT sessions / workshops. Sessions involved guidance on ICT skills, including the use videoconferencing software. Nevertheless, as tablet lending schemes ended, some service recipients' access to tablets or internet connectivity adjourned.

> *'Whereas when we did the pilot project it was free to use because it was funded. And it worked off the mobile signal so I think that would be a big barrier for people extra cost of setting up broadband.'* **Paid provider in the Third sector, Female (P10)**

To facilitate the engagement with services delivered by videoconferencing software, some providers shared discussion themes prior to peer support groups, added hand movement to songs and sent lyrics ahead of singing sessions (**Table 23**). The use of pre-recorded videos gained popularity. The asynchronous medium of communication enabled service recipients to access singing classes, exercise health sessions and workshop materials at convenience.

Furthermore, to promote the safety of service recipients while accessing services by videoconference software, one provider used the same meeting login link and password and one provider reported that their staff had access to a virtual private network while working from home.

**Table 23** A summary of practical suggestions to facilitate engagement and access to services delivered by videoconferencing software

**Preparing ICT devices**

- Downloading and installing videoconferencing software beforehand
- Increasing font size
- Devising device specific manual
- Locking the emplacement of Apps on home screen
- Extending screen automatic lock-out times
- Removing passwords

**Facilitating engagement**

- Joining online and offline support (providing a schedule of online activities in newsletters, sending song lyrics beforehand)
- Sending multiple reminders
- Sharing the schedule of online activities provided by other organisations
- Communicating themes / topics beforehand so service recipients can prepare
- Maintaining a regular schedule
- Mirroring the schedule employed whilst delivering in-person services
- Pre-recorded videos (shared by email, social media and web pages)

**Table 24** Additional quotes

## 1. Meeting additional and enduring needs

### 1.1 Basic needs

*'There were some people who had enormous problems with some very basic issues like how to get food because of being unable to use the internet to get shopping…. like for example I set up a system for vulnerable people to access a supermarket which is actually quite a way away from here where they were prepared to deliver food for people and they could pay on the telephone with a card'* **Paid provider in the Third sector, Female (P10)**

*'…we did find some elderly people quite poorly you know and you had to act one it'* **Paid provider in the Third sector, Female (P9)**

### 1.2 Social and emotional wellbeing

*'... you know I suppose I was aware that a lot of people were actually deteriorating in terms of their mental wellbeing quite speedily, in the first, especially in the first biggest lockdown period I think'* **Paid provider in the Third sector, Female (P10)**

*'... and they'd all moan or chat to each other or tell each other what they were doing and then they got, gradually got the hang of it [WhatsApp] and they put pictures of what their garden was like and all the things that they were doing that was really nice'* **Paid provider in the Private sector, Female (P6)**

## 2. Adapting to changing conditions

### 2.1 Going the extra mile

*'I mean we were doing it, but it [singing sessions] got better all the time. So, we had to learn how to do it effectively…'* **Volunteering provider in the Third sector, Female (P3)**

*'... more meaningful relationships because we were forced into a situation that required it and that was one of the beautiful things that came from it I think …'* **Paid provider in the Third sector, Female (P4)**

### 2.2 Balancing creativity, guidance and support

'*All of a sudden it was like imagination and creativity could happen. Things that people said we can't do that because we don't do that that way, we've never done that like that before we do it like this. All of a sudden it was like wow you know like things can be achieved that wouldn't have been if we were asking for them before the pandemic.'* **Paid provider in the Third sector, Female (P4)**

*'... we didn't really have any support as organisers we just got on with it…'* **Paid provider in the Private sector, Female (P6)**

**2.3 Characterising available resources**

*'…we would rely on the Library to the calls for the telephone singing the group telephone singing because we don't have… I don't know how you get [Microsoft] Teams… but I imagine it's megabucks and we don't have an income'* **Volunteering provider in the Third sector, Female (P11)**

'*…I was at home with him, so we were deemed non-essential*' **Unpaid carer to her husband, Female (C5)**

*'…keep your volunteers engaged. As well. Because, you know, we've got [name] who volunteered in the kitchen every week, you know making tea and coffee. She lost that responsibility, and she loved that….so, her needs weren't being met'* **Volunteering Provider in the Third sector, Male (P13)**

**2.4 Accessing support**

*'Social services had said they'd be out every six months to do an assessment, but it took them 11 months there, so they have just come out, they've done an assessment, bit disappointed, they were only in 8 minutes and they didn't give us any feedback so I'm assuming everything is okay'* **Former unpaid carer to her mother, current unpaid carer to her mother-in-law, Female (C2)**

## 3 ICT should be a tool, not the default setting

**3.3 (Un)suitability: for whom and when?**

*'…but strangely enough one of the things that we found is that older people are really adaptable and they really showed that they could change up to meet the needs of the new world order'* **Paid provider in the Public sector, Male (P14)**

*'…somebody said it made her feel, more lonely that ever. Because in normal singing [in-person format] she'd be able to turn around and smile at someone or put her around them, whereas you couldn't do that…'* **Volunteering provider in the Third sector, Female (P11)**

'*I think it must be very difficult if you haven't got any computer skills or if you are isolated that must be a nightmare because you would really feel so alone you know*' **Unpaid carer to her mother, Female (C3)**

*'I think there's a place for it and I think that my view is that it can work hand in hand [with in-person services] …'* **Paid provider in the Public sector, Male (P14)**

*'I am still a bit wary about meeting up in person with people mainly because I want to keep safe so that I can still see my husband*' **Unpaid carer to her husband, Female (C1).**

*'To me it's not the way forward but that might be my grey hairs*.' **Volunteering provider in the Third sector, Female (P3)**

*'…having to rely on having a connection at a certain time, having the apparatus being able to nail somebody with memory loss to a small screen and engage with… a group activity at a distance. They just hated it…'* **Volunteering provider in the Third sector, Female (P11)**

### 3.4 Implications for practice

*'one of the things that really has come out of the whole experience is really thinking about being creative, so now we have IT classes that we provide online, at the service sorry, so that if somebody, because a lot of things moved on line so you know whether somebody is paying their rent, whether somebody is writing to the council, whether somebody you know making an appointment with a GP or something, you know we've had older people saying oh I need an email address, I haven't got one, you know can you help me set something up. We've bought tablets so that people can use them on site.*' **Paid provider in the Public sector, Male (P14)**

## 5.5 Discussion

This study adds to the evidence-base by exploring the barriers and facilitators to adapting the delivery of a breadth of social care and support services from the providers' perspective and provides insights to guide the use of ICT in the current landscape and amidst future public health crises. Social care and support providers' demonstrated resilience and professionalism while adapting service delivery, however, many lacked guidance, resources and/or wellbeing support. The reliance on ICT increased, which benefitted some service recipients, but excluded others. Moving beyond the pandemic, using ICT to complement in-person services may help avoid widening inequalities in access, while empowering service recipients with the choice of how support is accessed.

Akin to other studies, social care and support providers in my study adapted services by extending the scope of support to include helping service recipients' meet some of their basic needs (Paplikar et al., 2022) and continued to promote emotional and social wellbeing (Evans et al., 2021). Through an ongoing process of trial and error, sustained by resilience, creativity and motivation, I found that services were adapted and tailored to service recipients' needs, preferences and digital abilities. Similar to therapists delivering an exercise intervention remotely during the pandemic (DiLorito et al., 2021; Cowley et al., 2023), social care and support providers in my study appreciated the creativity required to adapt services, and that the experience may benefit their professional development (Blake et al., 2021), and service innovation beyond the pandemic (DiLorito et al., 2021). Cognisant of the rising demand in services and widspread issues relating to social care and support recruitment and retention (Foster, 2023), innovations are important to the sustainability of services, and forms a key pillar in the governments' social care reform White paper (DHSC, 2021b).

Alongside bearing the impact of the pandemic in their personal lives, social care and support providers in my study witnessed the deterioration of dementia symptoms, death of service recipients, and reactively responded to unpredictable needs. While delivering post-diagnostic support during the pandemic, providers in Wheatley and colleagues' (2022) study reported on the negative emotional and physical impact of delivering services during the pandemic, and the limited opportunities to access peer support owed to home working. Although some social care and support providers in my study did establish wellbeing initiatives for their staff and volunteers, few providers had access to wellbeing support, which may engender long-term negative mental health repercussions (Anderson et al., 2021). Promoting the wellbeing of social care and support providers, during the aftermath and beyond the pandemic, aligns with recent governmental initiatives (DHSC, 2021b) an is paramount to the sustainability of the workforce (Anderson et al., 2021). It is important that social care and support

providers are involved in the discussions to identify how wellbeing needs can be addressed amidst future public health crises, and may include providing talk-based support, offered on an individual and group basis, and wellbeing resources (Boettcher et al., 2023).

In addition to the limited access to wellbeing support, I found that the availability of resources and degree of guidance received varied across social care and support providers. This is likely to be influenced by the size of the social care and support organisation and the sector it operates in (Chapman, 2022). A financial buffer and collaborations with external stakeholders are perhaps more likely to facilitate service adaptation during the pandemic (Sadarangani et al., 2021). My findings suggest that while some collaborations existed prior to the pandemic, new partnerships are likely to have been forged during the public health crisis. If collaborations are sustained, this may help to foster an integrated service commissioning and delivery, which is conducive to good post-diagnostic support (Bamford et al., 2021; Department of Health, 2009), provide better care experiences (House of Lords, 2017) and may help to redress the unequal distribution of post-diagnostic support across areas (Wheatley et al., 2021).

Furthermore, the availability and readiness of social care and support organisations' ICT capacity and infrastructure are likely to have influenced how services adapted during the pandemic. Recent governmental guidance to digitalise aspects of social care includes equipping the workforce with adequate ICT training (DHSC, 2023). Volunteers are important to the delivery of dementia social care and support services (Sun et al., 2021), and thus, it is crucial that paid and volunteering providers receive task-appropriate ICT training. Training providers may help guide the optimal use of ICT within the current hybrid landscape, assist service recipients to navigate ICT, and benefit the preparedness of service delivery in the event of future pandemics. Furthermore, while guidance on remote memory clinics was published in some clinical networks (e.g., (NHS London Clinical Networks, 2021)), no national guidance to deliver social care and support was available. Consequently, some organisations and social care and support providers in my study established internal policies while delivering services remotely and resuming in-person services. The availability of national guidance is likely to promote a standardised delivery and benefit service providers and recipients. For example, when comparing the implementation of safe long-term care visitation guidance in the Netherlands during the height of the pandemic to the lack of guidance in the UK, Giebel and colleagues (Giebel et al., 2023b) found that standardised guidance benefited providers, residents and their families.

Aligning with previous studies (Masoud et al., 2021; McLoughlin et al., 2023), my findings suggest that people with dementia and unpaid carers' ability to access, engage and benefit from accessing services remotely varied. Several reasons may underpin service non-use. These may include limited

access to ICT devices, connectivity and/or poor digital literacy (Robinson et al., 2015; 2020). To bridge limited access to ICT devices and connectivity, some social care and support providers in my study established tablet lending schemes. While some service recipients benefited from the scheme, difficulties in assisting some people to navigate the ICT remotely may have undermined possible benefits. To this end, once legally allowed, some social care and support providers in my study delivered in-person ICT sessions. Attending in-person ICT training has shown to increase people with dementia and unpaid carers' engagement with a dementia social networking website (Cunnah et al., 2019). While factors conducive to successful ICT training would benefit from further research, my analysis suggested applicable factors may include service providers' digital literacy, service recipients' regular access to devices and internet connectivity, and whether digital autonomy is maintained over time. Moreover, as my findings suggest, once remote support services are accessed, additional barriers may be encountered, including services not tailored to needs or delivered at inconvenient times. Nevertheless, accessing services remotely may offer benefits, such as convenience (McLoughlin et al., 2023), overcome barriers associated with rural residency (Bayly et al., 2020) or limited mobility (Masoud et al., 2021) and enable access to people with dementia and unpaid carers who are reluctant, following the pandemic, to engage in in-person services. Thus, the use of ICT within service delivery facilitates and hinders access to social care and support services, and the provision of in-person and remote services needs to be carefully balanced amidst the current hybrid landscape. Empowering service recipients with the choice of how social support services are accessed is important to the delivery of person-centred care and will help to reduce inequalities in access.

## 5.6 Strengths and limitations

This study adds to the evidence-base by exploring the barriers and facilitators to adapting the delivery of a breadth of social care and support services during the pandemic from the providers' perspective. Two public advisors were involved throughout, which strengthened the development of the topic guides and the interpretation of my findings. However, several limitations restrict the transferability of my findings. While most interviews with social care and support providers yielded rich data, most providers delivered services within the Third sector and served relatively affluent areas (based on IMD quintile of service provision areas). Thus, my findings may not be representative of service adaptation across sectors or organisations serving more deprived areas. Furthermore, it is possible that my sample consists of social care and support providers whose services optimally adapted during the pandemic, and I did not collect information on whether providers undertook frontline and/or managerial duties or on the sizes of organisations, which is likely to have influenced their experiences. Lastly, while several recruitment avenues (remote and in-person) were undertaken and data collection timeframe was extended, the small size of service recipients is a limitation. The data collection timeframe was not

further extended due to resource constraints. Nevertheless, the small sample size of service recipients is complemented by the accounts provided by service providers.

## 5.7 Conclusions

Social care and support services adapted to address the presenting needs of some service recipients. While providers' professionalism, motivation and creativity facilitated service adaptation, access to resources, guidance and supportive structures varied. Devising sector-specific guidelines outlining best-practice for delivering social support services remotely and ensuring adequate wellbeing support are in place may assist the preparedness of service delivery to future public health crises. Digitally training providers may facilitate the improved use of ICT within the current hybrid service delivery landscape, nevertheless, it is important to consider the wider barriers to access service recipients may experience. Accessing services remotely may benefit some people with dementia and unpaid carers, but the use of ICT may disfranchise others. Thus, to empower service recipients with the choice of how services are accessed and to avoid widening inequalities in access, the provision of in-person and remote services needs to be balanced.


## 5.8 Acknowledgements

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# CHAPTER 6: DISCUSSION

This chapter critically synthesises and integrates findings from my systematic review, longitudinal quantitative survey and semi-structured interviews in relation to the objectives of my Ph.D. project and considers their wider implications to the current and future delivery of social care and support services. Subsequently, I recommend strategies to help overcome barriers that led to inequalities in access to social care and support services and the chapter concludes by reflecting on methodological strengths and limitations.

My Ph.D. project sought to explore barriers and facilitators to engaging with community-based social care and support services during the pandemic in UK, and was guided by the following objectives:

1. To understand how the delivery of community-based social care and support services adapted, and to map out the availability of services across the UK during the pandemic.
2. To explore the facilitators and barriers to delivering and utilising community-based social care and support services during the pandemic.
3. To recommend strategies to possibly overcome barriers that lead to inequalities in access and utilisation.

## 6.1 Summary of novel contributions to the literature

My Ph.D. project has contributed several novel findings to the growing evidence-base reporting on how the delivery of social care and support services adapted during the pandemic. In the following sections, organised by the objectives of my Ph.D. project, I critically discuss the contributions made, integrate my findings within existing evidence, and highlight their implications to the current and future service delivery.

### 6.1.1 To understand how the delivery of community-based social care and support services adapted, and to map out the availability of services across the UK during the pandemic

The COVID-19 public health measures invoked significant changes to the delivery of services and adapting towards remote service delivery often formed a prerequisite to continue to deliver support. Although not many social care and support services adapted (Giebel et al., 2020b; Morton et al., 2023), some did. My survey found that services shifted from in-person to remote and/or hybrid approaches to delivery during the pandemic (p.125). While this is not necessarily surprising, my survey advances our understanding of how services adapted by eliciting and comparing formats employed to deliver different types of social care and support services prior to, and at two timepoints, during the pandemic (p.125). Insights into the types of formats employed are informative to the development of guidelines advising

on the remote or hybrid delivery of social care and support services. Corroborating with Evans and colleagues' study (2021) that reports on how meeting centres adapted during the pandemic, I found that videoconferencing software was often used alongside other formats, including telephone calls, emails, website resources and postal services (p.125). The use of more 'traditional' formats in conjunction with a novel medium is likely to have facilitated access to digitally excluded service recipients. Employing a varied portfolio of technological and non-technological formats to remotely deliver is likely to avoid widening inequalities in access. This forms an important consideration while planning future remote service delivery and/or while introducing newer forms of technology into service delivery. The field of technology is continuously evolving, and while innovations to service delivery are fundamental to the sustainability of services, it is important that digitally excluded service recipients are not left behind.

Furthermore, my interview study provided meaning into how services adapted during the pandemic. Aligning with previous studies (Wheatley et al., 2022; Dai & Moffatt, 2023), I found that an iterative and enduring process of trial-and-error guided the adaptation of service delivery during the pandemic (p.150). While often constrained by available resources (p.159), the process of trial and error was sustained by social care and support providers' creativity and dedication (p.150). Social care and support providers' determination was exhibited by their perseverance in finding suitable technological and non-technological formats to help address service recipients' presenting needs. Akin to therapists delivering a remote exercise health intervention (DiLorrito et al., 2021; Cowley et al., 2023), social care and support providers I interviewed appreciated the opportunity to exploit previously unused creativity (p.151) to deliver person-centred care. Ensuring that social care and support organisations continue to foster and encourage creativity within their workforce is likely to benefit innovations to service delivery beyond the pandemic (DiLorito, 2021), which is important to the sustainability of services and may aid providers' career progression (Blake et al., 2021). In turn, opportunities for career progression may promote workforce retention rates (Foster, 2023), which are pressing issues faced by both the social care and Third sector (Blake et al., 2021; Skills for Care, 2022). Nevertheless, in addition to nurturing creativity in the workplace, social care and support providers' resilience in delivering person-centre care during the pandemic ought to be recognised and valued on par with providers working in healthcare settings (SCIE, 2020b).

In addition to a shift in service delivery methods, I found that the scope of support delivered during the pandemic expanded, to include assisting some service recipients to address their unmet basic needs (p.149). This took form of organising food deliveries and prescriptions, which has been reported elsewhere (Paplikar et al., 2022), and safeguarding service recipients' safety by managing situations concerning suicidal unpaid carers. Interestingly, my survey suggests that most social care and support providers delivered the same 'primary service' (p.125), defined as the service most delivered at the time

of completing the survey at each timepoint. However, when interviewed, providers described how the scope of support provided expanded (p.158). This may suggest that 'primary services' adapted by expanding their scope to reflect service recipients' presenting needs and/or that some needs were addressed by establishing additional forms of support alongside 'primary services.' There could be a temporal aspect to consider. Whereas my survey elicited information in mid-2021, as the COVID-19 public health measures were easing, my interview study obtained insights into how services were delivered throughout the pandemic, and unmet basic needs may have been more prominent during the earlier stages of the pandemic. Notwithstanding, it portrays social care and support providers' dedication and adaptability to addressing service recipients' presenting needs, often by undertaking an additional and different workload.

However, the additional and sustained workload did engender adverse repercussions on social care and support providers' wellbeing (p.151). Similarly, Gillen and colleagues (2022) found a significant increase in work-related burnout among social care workers. While not surprising, it is gravely concerning. Chronic underfunding, inadequate pay and workforce shortages prior to the pandemic (House of Lords, 2017; Bottery & Mallorie, 2023; Foster, 2023) are likely to have rendered social care and support workers vulnerable to experiencing burnout and lower wellbeing levels, which have been amplified by the additional strain exerted by the pandemic. In 2020, the SCIE (2020b) released a report calling for high quality trauma-informed psycho-educational support to adult social care frontline providers and managers. The following year, the DHSC (2021b) published a White paper highlighting the importance of addressing and prioritising the wellbeing of the social care workforce following the height of the pandemic. However, social care and support providers I interviewed reported that participating in my study provided an opportunity to reflect on delivering services amidst the pandemic. Interviews were conducted at least one year following the removal of the COVID-19 public health measures, suggesting that some providers may not have had the time or therapeutic input to process and reflect on challenges experienced. Cognisant of the long-lasting impacts this may beget, it is important that social care and support providers, across sectors, have access to wellbeing support at present, but likewise, that wellbeing support is included in contingency plans in preparation to future public health crises (DHSC 2021; Anderson et al., 2021; WHO, 2022). Nonetheless, available wellbeing support will only go so far in terms of upholding social care and support workers' wellbeing, and wider structural changes to the funding of services and adequate pay are required to invest in a sustainable workforce (Anderson et al., 2021).

### 6.1.2 To explore the facilitators and barriers to delivering and utilising community-based social care and support services during the pandemic

#### 6.1.2.1 Utilising social care and support services

The use of ICT as an infection control measure facilitated the access to social care and support services to some service recipients during the pandemic but acted as a barrier to others (p.154). Aligning with other studies (Masoud et al., 2021; Talbot & Briggs, 2022; Gerritzen et al., 2023a), my interview study suggests that while remote services were unable to replicate in-person services, these proved beneficial in their absence (p.154). Benefits included facilitating contact among service recipients which helped to combat feelings of isolation. However, benefits remained available to people with dementia and unpaid carers who were able to access ICT devices and possessed adequate digital literacy skills.

Concerningly, compared to prior to the pandemic, my survey depicts a small, but important, downward trend in the number of service recipients accessing social care and support services during the pandemic (p.131). To my knowledge, only one other study has longitudinally explored the use of social care and support services by surveying people with dementia and unpaid carers during the pandemic (Giebel et al., 2021c). Likewise, Giebel and colleagues (2021c) found that fewer service recipients used social care and support services during the pandemic, however, service non-use could be due to the withdrawal of services and/or people with dementia and unpaid carers not accessing available services. Therefore, my findings extend our understanding of service recipients' non-access during the pandemic by suggesting that, even while some social care and support services were available, these were accessed by fewer people with dementia and unpaid carers. This has important implications to the delivery of social care and support services amidst the current hybrid delivery landscape, and to avoid disfranchising digitally excluded service recipients, opportunities to access services in-person must remain.

To bridge some service recipients' limited access to ICT devices during the pandemic, several social care and support providers I interviewed established tablet device lending schemes (p.155). While some service recipients benefited from the schemes, challenges in delivering ICT training remotely may have undermined the success of the schemes. Interestingly, several studies in my systematic review provided ICT training to participants, which mostly facilitated access to remote post-diagnostic support (p.76). There could be a couple of reasons underpinning the disparity. Firstly, ICT training delivered in studies included in my review were mostly delivered in an in-person format and study teams provided ongoing technological support. While interviewing, I did not ask social care and support providers whether they provided ongoing technological support, however, acknowledging their extensive workload during the pandemic, their ability to do so is uncertain. Secondly, several studies included in my review required

an unpaid carer to act as a study partner (p.58) to satisfy their inclusion criteria. While assessing the feasibility and acceptability of using ICT to access post-diagnostic support in service recipients who are most likely to benefit from accessing an intervention remotely is important, they may not be reflective of all service recipients. Notably, of people with dementia living alone and/or unpaid carers who are unable to navigate the ICT. This forms an important consideration while translating evidence into practice, especially when service delivery is required to reactively adapt, such as during the initial stages of the pandemic.

Moreover, barriers to accessing in-person services are persisting and unequally distributed (see section 1.3.2; e.g., Brodaty et al., 2005; Bauer et al., 2019; Kerpershoek et al., 2019; Gately et al., 2022). Moving beyond the pandemic, the use of ICT may help to overcome some barriers by bypassing geographical barriers (Bayly et al., 2019; Vellani et al., 2022) and facilitating the access specific and/or tailored to the needs of people with rarer forms of dementia (Gerritzen et al., 2023a). Moreover, my interview study found that remote services provided an opportunity for service recipients who are housebound to access support (p.154). Cognisant of the extent to which the pandemic indirectly contributed to the worsening of dementia symptoms (Giebel et al., 2022a; Manca et al., 2022; Morton et al., 2023), it is likely that the number of people with dementia who are housebound has increased, and remote services may be the most feasible option to access support while residing in the community. However, it is important to consider the potential role of ICT within service delivery within the wider context of barriers in access people with dementia and unpaid carers experience. For example, as found in my interview study, even if accessing peer support groups remotely is convenient, these may not necessarily be suitable to service recipients' presenting needs (p.153).

Furthermore, my systematic review and interview study conveyed service recipients' mixed views on accessing services remotely. Remote services may empower service recipients with the choice of how services are accessed (p.77, p.154), which is conducive to delivering person-centred care. However, accessing services remotely was unsuitable or undesirable for some service recipients (p.77, p.154). Dementia symptoms, including challenging behaviours, sensory impairments and a limited attention span, rendered it difficult for some people to engage with remote social care and support services (p.77, p.197-199). Furthermore, some service recipients found it difficult to socially engage with others remotely (p.77, p.197-199). Cognisant that meaningfully engaging with others is important to living well with dementia (Reilly et al., 2020), my findings highlight that the provision of in-person services for service recipients who dislike or are unable to optimally engage with others remotely is fundemental.

### 6.1.2.2 Delivering social care and support services

Delivering social care and support services during the pandemic engendered numerous challenges. My interview study exposed the heterogeneity in access to ICT devices and digital literacy among social care and support providers (p.152). Acknowledging that the remote approach to data collection I undertook may have favoured the participation of providers with greater digtial literacy skills, the disparity in access to ICT devices and digial literacy among social care and support providers is likely to be far larger than observed. To reduce inequalities in the provision of remote social care and support services, it is important that additional resources are made avaliable, and are prioritised to level-up the ICT infrastructure and digital literacy across social care and support organisations.

Multiple factors, often acting together, are likely to contribute to the heterogeneity in access to ICT devices and digial literacy among social care and support providers. Factors may include the sector in which organisations operate, available resources to invest in ICT infrastructure (Blake et al., 2021; Charity Digital Skills, 2023), organisation size (Chapman, 2022) and the rurality of the area services serve (Brown et al., 2023). Furthermore, digital skills are likely to vary by job role. Compared to adult social care providers who hold managerial roles, care workers often have a lower digital skillset (Blake et al., 2021). While I did not collect information regarding job role or tasks, some social support providers reported on the disparity of digital ability across staff and volunteers (p.159). It is important to consider how digital literacy may differ across job roles, as factors relating to social determinants of health may be at play. For example, limited educational qualifications are often required to enter care work, and the work involves low pay (Allen et al., 2022; Foster, 2023) and poor working conditions. Cognisant that greater digital literacy is often associated with higher socio-economic status and educational attainment (Robinson et al., 2015; 2020), it is likely that these factors influenced the differences in digital skillsets among care workers and providers with managerial responsibilities (Blake et al., 2021). Furthermore, a sizeable portion of social care and support workforce operating within the Third sector rely on volunteers (Chapman et al., 2022). While not always the case, volunteers tend to be older adults (NCVO, 2021), and increased age is associated with lower digital literacy (Robinson et al., 2015; 2020).

In addition to differences in access to ICT devices and digital literacy, my interview study found that the guidance received to assist the adaptation of service delivery varied across social care and support providers (p.151). Unlike the availability of national guidance to deliver remote memory clinics in some clinical networks (e.g., (NHS London Clinical Networks, 2021)), no national guidance to deliver social care and support services was available. In the absence of national guidance, some social care and support organisations devised internal policies while delivering services remotely and resuming in-person services (p.151). The availability of national guidelines outlining best-practice is likely to be

conducive to the provision of standardised care and benefits social care and support providers and service recipients. For example, Giebel and colleagues (2023b) compared the management and implementation of safe visitation in long-term care facilities during the height of the pandemic in the Netherlands and in the UK. Compared to the UK, the Netherlands had standardised guidelines in place. Limited guidance from the UK government is likely to have contributed to discrepancies in opportunities to visit relatives in long-term care facilities and increased providers' workload (Giebel et al., 2023b; Hanna et al., 2022). Thus, the availability of safe visitation guidelines benefitted providers, service recipients and their relatives in long-term care facilities in the Netherlands (Giebel et al., 2023b). This highlights the need for guidelines outlining best practice while delivering different types of social care and support services remotely during routine and emergency situations.

However, my interview study depicted how external partnerships helped to mitigate some challenges experienced by social care and support providers (p.151 - 152). Spanning from sharing lessons learned while delivering services remotely, to providing access to ICT devices and software, partnerships were invaluable to adapting service delivery during the pandemic. While some partnerships were forged prior to the pandemic, some are likely to have been established during the public health crisis. If collaborations are sustained, this may help to foster an integrated service delivery, which is conducive to good post-diagnostic support (Department of Health, 2009; Bamford et al., 2021). Greater collaboration within service delivery may help to provide resource efficiencies and join-up the currently fragmented (House of Lords, 2017) delivery of post-diagnostic support (Wheatley et al., 2021), which is likely to play a pivotal role in meeting the rising demand of social care and support services.

Lastly, aligning with previous studies (DiLorito et al., 2021; Cowley et al., 2023) my interview study suggests that the use of ICT may offer non-service recipient facing benefits, including time efficiencies (by reducing the need to travel) and facilitating communications between providers, which promoted prompt decision making (p.159). Similarly, post-diagnostic support providers in Wheatley and colleagues' study (2022) reported that the digitalisation of services promoted greater inter-sectoral collaborations and fostered interdisciplinary working. While further research is required, these findings suggest that the use of ICT within service delivery may offer productivity gains for social care and support providers, which may, translate into cost savings by increasing the capacity of providers. Moreover, while interviewing social care and support providers, direct costs saving offered by remotely delivering services was not mentioned by participants. While possible cost savings offered by remote service delivery are often experienced when a certain threshold has been realised (once the initial expense associated with staff training / investing ICT infrastructure is balanced) (Snoswell et al., 2020), evidence relating to whether delivering services remotely reduces costs compared to delivering in-person services is somewhat inconclusive (Snoswell et al., 2020).

### 6.1.3 To recommend strategies to possibly overcome barriers that lead to inequalities in access and utilisation

#### 6.1.3.1 Future research

My findings provide insights into how the delivery to social care and support services adapted during the pandemic in UK and have important implications to avoid current and future inequalities in access. However, further research is required to identify how to capitalise on the possible benefits offered by ICT, without disfranchising digitally excluded service recipients.

*Cost-of-Living crisis*

My research focused on the delivery of social care and support services during the pandemic, however, the current 'cost-of-living-crisis', characterised by the raising costs of everyday goods since the pandemic (British Broadcasting Corporation [BBC], 2022), is likely to further impact the delivery of services. A recent report (Charity Digital Skills, 2023) found that the rising costs of living is likely to stall the investment in ICT within Third sector organisations that are in the early stages of digital development, or it may promote the adoption of ICT to benefit from potential efficacies (Charity Digital Skills, 2023). To my knowledge, one study has explored the impact of the rising cost of living on the access to social care and support services from the service recipients' perspective (Giebel and Heath, 2023), and the authors found a reduced use of services. Further research is required to understand how the rising costs of living has impacted the delivery of social care and support services from the providers' perspective and its impact on inequalities in access.

*Best-practice guidelines while delivering remote and hybrid services*

Remote or hybrid approaches to service delivery ought to complement, not replace in-person services. Nevertheless, further research is required to establish best-practice guidelines and identify which social care and support services, how, for whom and when, should be offered remotely or by hybrid approaches as part of routine service delivery.

Firstly, social care and support services encompass a range of services, and all services may not be suitably delivered remotely. My systematic review found evidence suggesting that accessing some forms of post-diagnostic support, including exercise health interventions and speech and language therapy sessions remotely, may be feasible and beneficial (p.75). However, social care and support providers I interviewed reported that comforting emotionally distressed unpaid carers remotely was not suitable (p.154), and my systematic review and interview study found evidence to suggest that some people with dementia and unpaid carers found it difficult to engage with others remotely (p.77, p.154). Cognisant that meaningfully engaging with others is important to living well with dementia (Reilly et al., 2020), the feasibility, acceptability and appropriateness of delivering a breadth of social care and

support services remotely, in a context where in person services are available, merits further investigation.

Secondly, additional research is required to identify how to optimally deliver different types of social care and support services by hybrid approaches. This includes identifying suitable technological and non-technological formats to employ, and how to implement hybrid services. For example, is it better to deliver hybrid peer support groups in-person with the option to join by videoconferencing software or is it more favourable to alternate meeting remotely and in person (McLoughlin et al., 2023). Furthermore, depending on the type of service delivered, services can be delivered in-person or remotely at different timepoints. For example, therapists of an exercise health programme in DiLorito and colleagues' study (2021), suggest that initial assessments should be conducted in-person, however, follow-up sessions could be performed remotely.

Lastly, identifying whom and when along the dementia trajectory may benefit from accessing different types of services remotely is required. For example, people with dementia's ability to access social care and support remotely is likely to decline as the disease progresses. However, unpaid carers may prefer accessing social care and support remotely during the latter stages of the condition. Moreover, experiences in accessing social care and support services remotely are likely to differ by subtype, and further research is required to understand how symptoms of different subtypes impact the ability to navigate ICT to access social care and support services.

### *Digitally training service recipients*

My interview study exposed the heterogeneity in digital literacy among service recipients (p.154) and people with dementia and unpaid carers have expressed interest in receiving digital training (Talbot & Briggs, 2022; McLoughlin et al., 2023; Wilson et al., 2023). Although digital spaces are relied on less since the height of the pandemic, they remain an important presence within our current society. Indeed, the use of digital technologies has increased within the delivery of dementia care, but equally in other aspects integral to daily living, including finance management (Giebel et al., 2023c). Thus, developing sufficient digital literacy remains an important skill to people with dementia and unpaid carers. While the proportion of older adults who can operate digital technologies to yield intended results is likely to increase as the population ages, it is important to acknowledge that the field of technology likewise advances. Thus, the skillset required to be 'digitally literate' is far from static (Helsper, 2021). Service recipients who are unable to continuously develop their skills, often associated with lower socio-economic status and educational attainment (Robinson 2015; 2020), may continue to experience the adverse impact owing to digital inequalities.

Therefore, it is important to explore how best to deliver training to people with dementia and unpaid carers. Successful training may include a combination of approaches (one-to-one and group-based) and gradually progressing the content of sessions from task reminders to independent use (Cunnah et al., 2019). Following the removal of the COVID-19 public health measures, several social care and support providers I interviewed established workshops to support service recipients in using ICT (p.160). Future research may benefit from exploring how ICT trainings were delivered, barriers experienced and identifying elements conducive to autonomous use.

#### 6.2.3.1 Policy and practice

Several recommendations to policy and practice can be drawn from my research. While most are relevant to reducing inequalities in access and utilisation to social care and support services amidst the current delivery landscape, service delivery needs to build resiliency towards future public health crises. The latter is particularly topical, as the COVID-19 inquiry (an independent and public investigation into the response to the pandemic in the UK) is ongoing at the time of writing (UK Covid-19 Inquiry, 2023). Evidence relating to the inadequate measures undertaken by the UK central government to assist the preparedness of service delivery has been shared (British Medical Journal [BMA], 2023a, 2023b), which is likely to have contributed to widespread shortcomings of the pandemic response, including the delivery of social care and support services.

*Delivering services amidst the current hybrid landscape*

While the use of ICT can facilitate access to social care and support services for some service recipients, it hinders access to others. To avoid disenfranchising people with dementia and unpaid carers who are digitally excluded or service recipients who are unable to access services in-person, it is important that the provision of in-person and remotely delivered social care and support services are carefully balanced amidst the current hybrid landscape. Although guidelines outlining best-practice while delivering remote and hybrid services are required (see section 6.1.3.1), in the interim, employing a varied portfolio of technological and non-technological formats is likely to help avoid inequalities in access (p.125). However, the delivery of in-person and remote services is dependent on social care and support organisations' ability to sustain multiple service delivery methods, which the recommendations outlined below aim to bolster.

*Upskilling social care and support providers*

My interview study highlighted the heterogeneity in digital literacy across social care and support providers (p.152). To reduce discrepancies in service provision, it is important to acknowledge the differences, and target resources to address and level-up digital literacy across social care and support providers. This aligns with recent governmental guidance seeking to digitalise aspects of the social care

sector (DHSC, 2021b), priorities outlined by Third sector organisations (Charity Digital Skills, 2023) and is conducive to achieving aims outlined in the NHS Long-Term Plan (NHS, 2019). Social care and support providers, including volunteering providers, need to be equipped with task-appropriate digital skills. An NHSX and Institute of Public Care and Skills for Care report (Blake et al., 2021) found that, of the adult social care frontline providers who undertook digital training, few received training on how to remotely deliver services by digital technologies and/or how to assist service recipients in using digital technologies to support their needs. To facilitate the delivery and access to remote services, it is important that training provided encompasses the use of digital technologies while undertaking service recipient facing tasks.

Furthermore, indirectly, the provision of digital training may assist in promoting staff retention rates, challenges that are widespread across the social care and Third sector (Anderson et al., 2021; Chapman, 2022; Skills for Care, 2022; Morton et al., 2023). Acquiring new skills may benefit paid providers' career progression (Blake et al., 2021; Foster, 2023) and can form part of the reasons why people volunteer (NCVO, 2021). Indeed, the opportunity to receive digital training and/or to volunteer remotely, may facilitate the recruitment and retention of volunteers, notably of people with disabilities (Donahue et al., 2022). Retaining paid and volunteering providers is important, not only to avoid expenditures associated with recruitment, but to facilitate care continuity, which is important to people with dementia and unpaid carers (Arbalster & Brennan, 2022). However, the provision of digital training is unlikely to significantly promote workforce retention without extensive reforms to address poor working conditions and inadequate pay (Allen et al., 2022; Bottery & Mallorie, 2023; Foster et al., 2023), that continue to characterise social care work. Endeavours which have been promised by the UK central government but that remain insufficiently fulfilled at the time of writing (Wise, 2021).

### *Increasing access to ICT devices: social care and support providers and service recipients*

My interview study suggests that the delivery of remote services by some providers were hamstrung by limited ICT infrastructure (p.152), and greater investment in ICT infrastructure across social care and support organisations is required (SCIE 2020b; Blake et al., 2021; Charity Digital Skills, 2023). It is important to acknowledge the differences in current ICT infrastructure across social care and support organisations and to prioritise investment in organisations with limited ICT infrastructure. Furthermore, besides enabling the provision of remote services, access to adequate ICT infrastructure ensures that risks to privacy and security, including leaking service recipients' personal data, are minimised. Cognisant that people with dementia may be more at risk to scams and fraud, delivering services by suitable hardware and software forms an important pillar to safeguarding their vulnerability. Indeed, only one social care and support provider I interviewed reported that their staff has access to VPN while working from home (p.155).

During the height of the pandemic, some social care and support providers I interviewed successfully bridged some service recipients' limited access by organising tablet lending schemes. However, access to digital spaces adjourned when schemes ended (p.149, p.160). As digital technologies continue to prominently feature within daily living, local governments and policymakers have a responsibility to ensure that people with dementia and unpaid carers can access suitable ICT devices and reliable internet connectivity. A potential avenue to reduce digital inequalities at a local level is by leveraging tablet lending schemes organised by libraries (e.g., Wigan Council, n.d). Success of such lending schemes are likely to depend on ensuring that libraries are sufficiently funded and whether people with dementia and unpaid carers are aware of the opportunity. The latter could be facilitated by social care and support providers, notably by dementia Link workers, who play a key role in signposting local opportunities and resources to people with dementia and unpaid carers (Dementia Concern, n.d).

Lastly, my interview study suggests that some people with dementia benefitted from using dementia-specific ICT devices (p.155), which has been reported elsewhere (Tablot and Briggs, 2022; Wilson et al., 2023). Greater investment is required to develop ICT devices that are accessible to people with dementia. Nevethless, it is paramount that the development of such technologies embodies a participatory approach that actively seeks input from people with dementia and unpaid carers.

*Fostering person-centred care and integrated service delivery*

My interview study highlighted positive examples of person-centred care (p.150) and collaborative working during the pandemic (p.152), and it is important that these are sustained as the pandemic wanes. Person-centred care is important to people with dementia (Arbalster & Brennan, 2022) and may yield favourable results, including a greater quality of life in people with dementia and a reduction in dementia symptoms (Kim & Park, 2017). Furthermore, a systematic review conducted by Barbosa and colleagues (2015) found some evidence suggesting that the delivery of person-centred care may offer benefits to providers working in a long-term facility. Benefits included reducing stress, burnout and increasing job satisfaction (Barbosa et al., 2015). However, social care and support providers' ability to continuously provide high quality person-centred care is likely to hinge on multiple factors, including the availability of sufficient resources and adequate training (Bauer et al., 2019; Kerpeshoek et al., 2019; Dalgerno et al., 2021).

Dementia is a complex disease requiring input from multiple stakeholders across sectors. While integration has featured in governmental policies (DHSC, 2016), implementation has been somewhat slow (House of Lords, 2017). To encourage a coordinated approach within the general architecture of service commissioning, ICS were introduced by the 2022 Health and Care Act. While, at the time of writing, it is too early to assess the degree to which the ICS has facilitated integrated working, it is

hoped that these newly formed structures could carry the partnerships forged by social care and support providers during the pandemic. An integrative approach to service commissioning and delivery facilitates the provision of person-centred care, yields favourable service recipient experiences while accessing services, and may help to join-up the fragmented service delivery landscape (House of Lords, 2017). The provision of post-diagnostic support is currently characterised by the sparsity or duplicity of services across areas (Wheatley et al., 2021), and an integrated approach to service commissioning and delivery may offer resource efficiencies and help address the increasing demand in social care and support.

*Preparedness of service delivery amidst future public health crisis*

Service delivery was inadequately prepared for the pandemic and the delivery of social care and support services was disrupted. The disruption of services is likely to engender lasting adverse impacts on people with dementia and unpaid carers. However, the pandemic showed that widespread innovation is possible, and lessons learned are invaluable to help build a service delivery that is resilient to future public health crises. This is important, as the occurrences of pandemics and adverse weather conditions, including heat waves that disproportionately impact older adults (NHS, 2022b), are expected to increase (UNESCO, 2020; EEA, 2023).

A key component to building a resilient service delivery is the development of guidelines outlining best-practice in delivering social care and support services while escalating and de-escalating from public health crises. These should be specific to service type and sector, regularly reviewed and inclusive of people with dementia and unpaid carers with restricted opportunities to access ICT devices and/or with limited digital literacy. Guidelines should be created by relevant stakeholders, including the SCIE and leading charities within the Third sector such as Alzheimer's Society. Furthermore, my interview study found that many service recipients remained reluctant to attending services in-person following the removal of the COVID-19 public health measures and benefited from the opportunity to access services remotely (p.159). Though public health crisis dependent, the pacing of the transition of service delivery methods is likely to form an important consideration while devising service delivery guidelines during emergency situations.

Ensuring that social care and support providers have access to wellbeing support, notably while home working is extensive, forms a fundamental pillar to building a service delivery resilient to future public health crises (WHO, 2022) and to the sustainability of the workforce (Anderson et al., 2021). Social care and support providers across sectors should be involved in the discussions regarding unmet wellbeing needs, and how these could be addressed amidst future public health crises. This may include providing talk-based support, offered on an individual and group basis, and wellbeing resources

(Boettcher et al., 2023). Moreover, it is important that wellbeing support is adequately planned, evaluated and resourced - ready to be implemented at the outset of future public health crises.

## 6.2 Overall methodological strengths and limitations

I conducted my research through the lens of critical realism, a philosophical stance that adopts a realist ontology, and embodies a constructivist epistemology (Maxwell & Mittapalli, 2010; Koopmans & Schiller, 2022). Guided by the Dahlgren-Whitehead model (2021) and the HIAT tool (Porroche-Escudero & Popay, 2020), the philosophical stance helped to place and interpret my findings in the context of social determinants of health, encouraging me to explore how factors, often operating in chorus, facilitated and/or hindered the delivery or access to social care and support services during the pandemic, and for whom.

The HIAT tool (Porroche-Escudero & Popay, 2020) encouraged me to think about my research methods and avenues for knowledge dissemination, and the wider effects on health inequalities these may engender. While I found some aspects of the tool, notably those relating to monitoring and evaluating my research project, difficult to complete as my research did not involve an intervention, the tool helped to holistically think about, and integrate, inequalities in access into my research.

### 6.2.1 Systematic review

To my knowledge, my systematic review is the first to synthesis evidence relating to using ICT to access post-diagnostic support that address the needs of people with dementia or those of the dyad, and explored service recipients' views on accessing services remotely. Searches were conducted across six databases and studies written in English, German and French were considered for inclusion. While included studies were of good methodological quality, some limitations ought to be acknowledged when interpreting my results. Firstly, due to a lack of resources, only one study team member screened the citations, appraised the methodological quality of studies and extracted the relevant data. Although any uncertainties were discussed, the lack of a second reviewer independently screening the citations may have led to some citations being missed. Grey literature, defined as information produced by a wide range of sources (e.g., governmental, academic and industry) outside of commercial publishers (Paez, 2017), was not searched due to limited resources. Including grey literature in the search strategy may help to offset possible publication bias, whereby positive results are more likely to be published compared to negative results (Paez, 2017). In the context of my systematic review, excluding grey literature may have biased the account portrayed to favour positive outcomes and/or views towards accessing post-diagnostic support remotely.

Moreover, following the completion of the PRISMA checklist (Page et al., 2021) (**Appendix V**), I identified some aspects that could have been strengthened while reporting my findings. With regards to

the abstract, while challenging due to the limited word count, the overall number of participants from included studies, key aspects of the exclusion criteria and limitations could have been included. Furthermore, within my published paper (**second chapter**), while I quantified the reasons why references were excluded following the full-text screening in my PRISMA diagram (p.59), it is good practice to provide the citations and explain why they did not satisfy my inclusion criteria. Furthermore, while I provide the summary of

Lastly, while slightly mitigated by the updated search that identified three studies from higher middle-income countries, most of the evidence synthesised came from high income countries (mainly the US and UK). Only one study explored the access to remote post-diagnostic support with people from minority groups (Chodosh et al. 2015). Cognisant that access to ICT devices and digital literacy is likely to be influenced by several socio-economic factors (Robinson et al., 2015; 2020), my findings may not be representative or generalisable to settings which are less economically developed, or populations coming from minority groups. Furthermore, several included studies lacked long follow-up time frames, control groups and the support provided by unpaid carers was not systematically captured. The study designs and tools employed in future studies would benefit from including longer follow-up time frames, control groups, capturing the support provided by unpaid carers, as well as investigating the feasibility and acceptability of remotely accessing different types of post-diagnostic support.

### 6.2.2 Mixed methods study design

A sequential explanatory study approach enabled me to quantitatively document how social care and support services adapted during the pandemic, in real time, and subsequently, to expand and complement the findings through qualitative exploration. The survey was administered in mid-2021 when COVID-19 public health measures were easing. Thus, my survey did not capture how services adapted in the earlier stages of the pandemic but data pertaining to the initial adaptations to service delivery were obtained through the interviews. While the survey elicited primary services across survey timepoints, the interviews complemented my quantitative findings by adding meaning to the process of adapting services. Lastly, I interviewed people with dementia and unpaid carers which expanded the quantitative findings by gaining insights into the experiences of those accessing social care and support services during the pandemic. The rigour of a mixed method study can be appraised by assessing the quality of each study component (Teddlie and Taskahkkori, 2009). Thus, in the following paragraphs, I reflect upon the strengths and limitations of my survey and interview study.

#### 6.2.2.1 Longitudinal quantitative survey

My survey appears to be the first study that, longitudinally, captured how different social care and support services adapted during the pandemic from the providers' point of view. A public advisor was

involved in the development of the survey which is likely to have benefitted the face validity of the tool. Furthermore, two public advisors were involved while interpreting my findings, thereby ensuring that interpretations are grounded in lived experience. Nevertheless, some limitations ought to be acknowledged.

A sample size calculation forms an important aspect to planning a survey, a consideration which I omitted, and ought to be considered as a methodological limitation. Sample size calculations help researchers identify an appropriate and feasible sample size to address the aims of the study and draw precise and accurate conclusions (Nayak, 2010). Multiple sample size calculations exist, and the selection will depend on the study design, aims, hypothesis and statistical analysis employed. My longitudinal survey did not include a comparative element, nor did it seek to identify causation. Instead, my survey was exploratory and descriptive, and documented how the delivery of social care and support services adapted during the pandemic. Regarding descriptive studies, a sample size calculation is important to identify how precise the observed mean or proportion is expected to be in the target population (Eng, 2003), which in my work, refers to social care and support services across the UK. While seeking input from a statistician is often advised, two main approaches to sample size calculations for descriptive studies exist (Eng, 2003; Sharma et al., 2019; Althubaiti, 2022). One approach is suitable for descriptive surveys seeking to estimate the mean of a phenomenon, and the other is appropriate for surveys focused on estimating proportions (Eng, 2003; Sharma et al., 2019; Althubaiti, 2022). My survey largely elicited nominal and categorical data and conducting a sample size calculation for descriptive studies designed to measure proportions prior to data collection would have been beneficial. Furthermore, accounting for non-responsiveness also forms an important consideration while estimating sample size ahead of data collection (Althubaiti, 2022), notably for longitudinal study designs, which often report considerable attrition rates between study waves (e.g., Wood et al., 2004; Abdullah et al., 2021).

The small sample size of my survey limits the generalisability of my findings. Indeed, difficulties faced while recruiting participants may indirectly reflect the limited availability of services during the pandemic (Giebel et al., 2021b; Morton et al., 2023). Therefore, my study provides a much required first snapshot of a variety of dementia-related social care and support services. Approximately 23% of participants were lost to follow-up, which aligns with wide attrition rates reported in the literature (e.g., Wood et al., 2004; Abdullah et al., 2021), however, the short timeframe between waves in my study needs to be acknowledged. While I did not collect information on non-response, some people emailed explaining why participation at T2 was declined. Reasons included no longer delivering social care and support services and participants had moved to work or volunteer elsewhere. Although collecting

information on non-response is valuable, cognisant of the high workloads social care and support providers experienced at the time of data collection, it was deemed unsuitable.

In addition, the non-randomised sampling approach undertaken limits the generalisability of my findings (Althubaiti, 2016; Andrade, 2021), and the remote approach to data collect may have favoured the participation of social care and support providers who are digitally literate and/or whose service adapted to online formats. While my sample demographics are akin to social care and support providers in the public and Third sector (NCVO, 2021; Skills for Care, 2022) the sample lacked ethnic diversity and largely compromised of participants working or volunteering within the Third sector in England and Scotland.

Moreover, while efforts were made to increase the user-friendliness of survey, such as including instructions throughout (p. 101), and piloting the tool (p. 101), my dataset included a considerable number of missing entries. Several methods to handle missing data exist and can be broadly divided into imputation and deletion techniques (Fox-Wasylyshyn and El-Masri, 2005). Although imputation methods may offer some benefits, large sample sizes are generally required to ensure accuracy. Given my small sample size, I decided not to employ any imputation method. Deletion methods span from listwise deletion, where data entries are deleted if one variable / item is missing, to pairwise deletion, where data entries with some missing data are included in parts of the analysis (Fox-Wasylyshyn and El-Masri, 2005). I employed a listwise deletion approach, which reduced the sample size and increased the confidence intervals of my findings. While it would have resulted in a different sample size for each variable, a pairwise approach to deletion may have helped to retain the sample size and is a technique I may consider employing while analysing future survey data.

Furthermore, although I reported on collected variables within my published paper (**fourth chapter**), as outlined within the CROSS checklist (Sharma et al., 2021) it is good practice to include the number of questions and/or to provide the measuring tool as an appendix. The tool relied on self-reported answers and information obtained relating to service provision prior to the pandemic is subject to recall bias (Althubaiti, 2016). However, it can be argued that the self-reported nature of the questions allowed participants the time to verify numbers reported (e.g., number of times primary services delivered, number of service recipients accessing services during a regular month). Despite piloting the tool prior to data collection, I identified that the wording of some questions could have been clarified. I noticed some discrepancies in how the same participants answered related questions, rendering it difficult, at times, to understand which formats were employed to deliver social care and support services remotely, and those used to engage with service recipients outside of attending services. This may have been avoided had the tool been piloted amongst social care and support providers delivering different services

across various sectors. Lastly, the tool could have been strengthened by including some additional questions asking participants to quantify how often they employed each format(s) to deliver primary services at each survey timepoint, whether ICT formats used were provided by the organisation or whether participants were using personal devices and collecting information on participants' job role or tasks. Furthermore, future research may benefit from including proxy indicators to gain an understanding of organisation size, which may include organisations' annual income (Chapman, 2022; Charity Digital Skills, 2023) and/or the number of paid and volunteering employers (Kateb et al., 2022).

#### 6.2.2.2 Semi-structured interviews

My study adds to the evidence-base by exploring the barriers and facilitators to adapting the delivery of a breadth of social care and support services from the providers' perspectives. Two public advisors were involved in the development of the topic guides, data analysis and interpretation of the findings which is likely to have strengthened my findings. Nevertheless, some limitations ought to be acknowledged.

While completing the COREQ checklist (Tong et al., 2007), I found some aspects that could have been strengthened while reporting my findings. Although I articulate positionality (p. 108) and describe my ongoing reflexive practice to enhance the trustworthiness of my findings in my thesis (p.279), these were omitted, largely due to word count limitations, in the submitted paper. Notably while employing a reflexive TA, it is important to describe and consider how I may have contributed to the knowledge produced.

Using the concept of information power (p. 94-95) (Malterud et al., 2016), I established a provisional sample size of 30 participants, 15 social care and support providers and 15 service recipients (people with dementia and unpaid carers). Although I interviewed fewer social care and support providers than I had envisaged (interviewed n=13), most interviews yielded rich data. I did not seek to obtain reasons for declining participation, which may have been helpful, and would be important to consider in future research. However, the sample of social care and support providers interviewed mostly delivered services within the Third sector and served relatively affluent areas (based on IMD quintiles of service provision areas), which is important to acknowledge regarding the representativeness of my sample. However, interviews did exhibit considerable variation in terms of factors influencing how service delivery adapted, which I was able to explore and describe in my analysis.

Nevertheless, it must be acknowledged that information obtained could be subject to recall bias, notably when reporting on how service delivery adapted during the earlier stages of the pandemic, and to social desirability bias. Social desirability bias is the tendency of participants to answer questions in ways that they deem to be more favourable to others and possible biases were mitigated by ensuring that

participants knew that information provided would remain anonymous (Althubaiti, 2016). In addition, the remote approach to data collection is likely to have favoured the participation of social care and support providers who are more digitally literate or whose services successfully adapted during the pandemic. In hindsight, my topic guide could have been strengthened by asking social care and support providers whether they undertook frontline and/or managerial duties, as this is likely to have influenced their experiences of delivering services during the pandemic and their digital literacy.

Moreover, I faced considerable challenges while recruiting service recipient participants. While several recruitment avenues (remote and in-person), including dementia-specific avenues (e.g., join dementia research and sharing the research opportunity at a dementia information day (p. 96-97)), were undertaken and the data collection timeframe was extended, the small size of service recipients is a limitation (interviewed n=8; n=6 unpaid carers; n=2 people with dementia). The data collection timeframe was not further extended due to resource constraints. The adequacy of a sample size should not solely be based on the number of interviews conducted, considerations to the data provided by each interview and the study's aims, should also be given (Malterud et al., 2016; Vasileiou et al., 2018). My study's aims were relatively narrow, and with regards to service recipients, sought to explore their experiences of accessing social care and support services during the pandemic. The provisional sample size was established to gain a diverse account of experiences and acknowledged my limited interviewing experience as a novice researcher, which was likely to require additional interviews (p. 94-95) (Malterud et al., 2016). When establishing my provisional sample size, it had not occurred to me that social care and support providers would provide, by proxy, accounts of service recipients' experiences in accessing social care and support services. While it is preferable to obtain information first-hand, the experiences obtained by proxy largely aligned with those received from service recipients interviewed. This instilled confidence that, the accounts obtained by people with dementia and unpaid carers interviewed, are likely to be representative of wider experiences and indeed, align with previous research (e.g., Masoud et al., 2021; Gerritzen et al., 2023a; 2023b). Thus, the accounts provided by people with dementia and unpaid carers, complemented by those provided by proxy, enabled me to describe and provide meaning to accessing services during the pandemic. However, it should be acknowledged that I did not verify the dementia diagnosis reported by people living with dementia or collect information regarding the diagnosis of the person (people) cared by unpaid carers interviewed. This is important as experiences of accessing services remotely are likely to differ between dementia subtypes and may benefit from being included within future research.

Furthermore, compared to interviews with social care and support providers, interviews with service recipients were shorter. However, the topic guide used while interviewing service recipients contained fewer questions than the guide used for interviews with social care and support providers (see **Appendix**

**K**). I conducted most interviews with service recipients after interviewing a sizeable number of social care and support providers. The additional interviewing experience is likely to have helped to build rapport with people with dementia and unpaid carers interviewed, which may have benefited the quality of the dialogue produced (Malterud et al., 2016).

Lastly, member checking can be used to enhance the rigour, notably the credibility, of qualitative research (Lincoln & Guba, 1985). Member checking can take several forms and can be understood as the process of providing the opportunity to participants, by returning interviews or analysed data, to establish whether researchers have understood, and interpreted participants' narratives as intended (Birt et al., 2016). Returning interview transcripts is a form of member checking, which may help to ensure the accuracy of the transcription. My interviews were audio-recorded and were transcribed verbatim by myself or a professional transcription agency through the University of Liverpool. Cognisant of the additional resources it would entail and possible discomfort some participants may experience when reading their spoken word (Birt et al., 2016), I decided not to return interview transcripts. However, I acknowledge that returning interview transcripts can be helpful at times, and going forwards, I would discuss the appropriateness of this form of member checking with public advisors. Returning analysed transcripts is another form of member checking (Birt et al., 2016). However, qualitative data analysis is lengthy, and returning analysed transcripts was not feasible. Furthermore, it is important to consider how participants may be impacted by receiving analysed transcripts (Birt et al., 2016), notably given the stresses of delivering and accessing social care and support services during the pandemic and/or progression of dementia symptoms since the interview. The involvement of my public advisors during data analysis (p. 107) ensured that the interpretation of the findings was grounded in lived experience. One public advisor was involved when interpreting the findings and one public advisor was involved in analysing the data. Discussing two coded transcripts was beneficial, notably to draw out different factors that influenced adaptions to service delivery. Benefits of involving members of the public while analysing qualitative data are reported elsewhere (e.g. Gillard et al., 2012; Cowley et al., 2019). These include ensuring that the voice of people who are affected by the research are present within the analysed data and identifying key aspects within the data which may have been missed without PPI input (Gillard et al., 2012; Cowley et al., 2019), which is likely to have strengthen the credibility of the findings produced.

### 6.2.3 Patient and Public Involvement

Two public advisors, a person with dementia and a former unpaid carer, were involved throughout the lifespan of my Ph.D. project. Both public advisors have experience in accessing and delivering social care and support services prior to and/or during the pandemic.

Towards the beginning of my Ph.D. project, I was unsure how best to involve my public advisors in my research. However, familiarising myself with relevant past literature (e.g., SDWG, 2013; Giebel et al., 2017b; Gove et al., 2018; Swarbrick et al., 2019), disucssions with my supervisiory team and building working relationships with my public advisors helped me to adapt my working approaches to further PPI in my research. For example, when devising my survey, I had drafted the measuring tool prior to seeking input from my public advisor. However, I sought input from my public advisors prior to devising topic guides for my interview study. Fostering a working relationship with my public advisors helped to ensure that the proposed involvement in my research aligned with their preferences and abilities. For example, to ensure that the findings from the interview study were grounded in lived experience, I trained one public advisor on coding as part of data anaysis, and I discussed key aspects that emerged from the interviews with the other advisor. I found that sharing overarching points to loosely structure our discussions ahead of meetings facilitated greater involvement from both advisors.

Spanning from designing materials to discussing priorities for future work, the involvement of my public advisors strengthened my research process, and findings produced. Their continuous input helped broaden my understanding of dementia and the delivery of social care and support services. Discussions often led me to question my assumptions and/or consult the literature to gain insights into aspects I had not considered. Upon reflection, cognisant of the numerous services, providers and sectors involved in the delivery of social care and support services, it may have been beneficial to include someone delivering statutory services within the public advisory team.

I found the GRIPP2 short form (Stanisewska et al., 2017) useful to plan, document and reflect on the involvement of my public advisors. Critically reflecting on the value of PPI following each study, helped me to think about how to further PPI in my subsequent study. Upon reflection, while I did seek my public advisors' opinions regarding their involvement throughout my Ph.D. project, going forwards, it may be helpful to reflect and complete the GRIPP2 short form together.

## 6.3 Conclusions

Findings from my Ph.D. project have furthered our understanding of how social care and support services adapted during the pandemic in the UK. With the aim of reducing inequalities in access to social care and support services, my findings provide important implications to the current novel hybrid service delivery landscape, and to help build service delivery resilient to future public health crises.

Amidst the hybrid landscape, balancing the provision of in-person and remote services will ensure that digitally excluded service recipients are not disenfranchised, while empowering people with dementia and unpaid carers with the option of how to access social care and support services. Further research is required to identify how to capitalise on possible benefits offered by using ICT within service delivery

and establish standards of best practice. Nevertheless, in the interim, remotely delivering services by employing a varied portfolio of technological and non-technological tools is likely to promote inclusivity. Moreover, greater investment is required to level up the current heterogeneity in ICT infrastructure and digital capacity across social care and support organisations. Providers, including volunteers, need to be equipped with task-appropriate digital skills, which may, indirectly, be conducive to promoting workforce retention. Furthermore, as the use of ICT is likely to remain a prominent feature within our current society, it will be important that people with dementia and unpaid carers have the opportunity to receive digital training and access adequate devices and internet connectivity.

To help increase the preparedness of service delivery amidst future public health crises, guidelines are required to guide the delivery of services while escalating and de-escalating from emergency situations. Guidelines should be sector specific and designed by relevant stakeholders, including the SCIE and leading charities such as Alzheimer's Society. Moreover, it is critical that wellbeing support for social care and support providers is planned for, and ready to be implemented at the outset of future public health crises.

# APPENDICES

## Appendix A References retrieved in the pilot

**Table 25** Initial key terms and controlled vocabulary searched in the titles and abstracts of studies in PubMed (Date of search: 12/02/2021; restrictions applied: studies published from 1990 – 2021 and only included studies written in English, German or French)

| **Population** | | | **Intervention** | | | **Evaluation** | | |
|---|---|---|---|---|---|---|---|---|
| No. | Key terms | Results | No. | Key terms | Results | No. | Key terms | Results |
| 1 | Dement* | 101,877 | 1 | Tele* | 142,296 | 1 | "post diagnostic support" | 39 |
| 2 | Alzheimer* | 145,269 | 2 | Technolog* | 462,279 | 2 | "social support" | 38,489 |
| 3 | "mild cognitive impairment" | 17,707 | 3 | Online | 147,779 | 3 | "social care" | 6,254 |
| 4 | MCI | 16,553 | 4 | Internet | 54,323 | 4 | Communit* | 535,965 |
| 5 | "dementia" [Mesh] | 147,068 | 5 | Electronic | 246,800 | 5 | "day cent*" | 473 |
| | | | 6 | Computer* | 178,964 | 6 | "day service" | 185 |
| | | | 7 | Digital* | 117,761 | 7 | outpatient | 123,052 |
| | | | 8 | "e health" | 2,415 | 8 | Ambulatory | 63,767 |
| | | | 9 | ehealth | 6,363 | 9 | "home based" | 10,696 |
| | | | 10 | App* | 27,365 | 10 | befriending | 188 |
| | | | 11 | Mobile | 92,362 | 11 | respite | 1,653 |
| | | | 12 | Videoconference* | 2,639 | 12 | Psychoeducational | 3,068 |
| | | | 13 | Web* | 121,048 | 13 | psychosocial | 92,767 |
| | | | 14 | ICT | 5,644 | | Peer support | 4,689 |
| | | | 15 | "information communication technologies" | 82 | | Support* | 1,452,626 |
| | | | 16 | Gerontechnology | 103 | | "social support" [Mesh] | 66,350 |
| | | | 17 | Virtual | 62,303 | | "community health services' [Mesh] | 214,209 |
| | | | 18 | remote | 62,994 | | | |
| | | | 19 | "technology" [Mesh] | 352,776 | | | |
| | | | 20 | | | | | |
| | Terms 1-5 with OR | 245,704 | | Terms 1-20 with OR | 1,769,033 | | Terms 1-13 with OR | 2,269,087 |
| Population AND Intervention AND Evaluation = 4,802 | | | | | | | | |

**Table 26** Initial key terms and controlled vocabulary searched in the titles and abstracts of studies in APA PsychInfo (Date of search: 16/02/2021; restrictions applied: studies published from 1990 – 2021 and only included studies written in English, German or French)

| **Population** | | | **Intervention** | | | **Evaluation** | | |
|---|---|---|---|---|---|---|---|---|
| No. | Key terms | Results | No. | Key terms | Results | No. | Key terms | Results |
| 1 | Dement* | 67,670 | 1 | Tele* | 57,451 | 1 | "post diagnostic support" | 30 |
| 2 | Alzheimer* | 60,808 | 2 | Technolog* | 114,240 | 2 | "social support" | 47,504 |
| 3 | "mild cognitive impairment" | 10,592 | 3 | Online | 87,185 | 3 | "social care" | 4,321 |
| 4 | MCI | 7,284 | 4 | Internet | 39,389 | 4 | Communit* | 299,034 |
| 5 | "dementia" [Mesh] | 51,601 | 5 | Electronic | 31,450 | 5 | "day cent*" | 599 |
| | | | 6 | Computer* | 75,701 | 6 | "day service" | 130 |
| | | | 7 | Digital* | 7,968 | 7 | outpatient | 54,937 |
| | | | 8 | "e health" | 699 | 8 | Ambulatory | 7,645 |
| | | | 9 | ehealth | 753 | 9 | "home based" | 4,955 |
| | | | 10 | App* | 1,442,238 | 10 | befriending | 268 |
| | | | 11 | Mobile | 17,503 | 11 | respite | 1,662 |
| | | | 12 | Videoconference* | 488 | 12 | Psychoeducational | 5,530 |
| | | | 13 | Web* | 53,748 | 13 | psychosocial | 82,730 |
| | | | 14 | ICT | 4,179 | | "Peer support" | 5,569 |
| | | | 15 | "information communication technologies" | 180 | | Support* | 680,832 |
| | | | 16 | Gerontechnology | 129 | | "social support" [Mesh] | 65,474 |
| | | | 17 | Virtual | 23,619 | | "community health" [Mesh] | 9,698 |
| | | | 18 | remote | 11,279 | | | |
| | | | 19 | "technology" [Mesh] | 61,515 | | | |
| | | | 20 | | | | | |
| | Terms 1-5 with OR | 109,242 | | Terms 1-20 with OR | 1,690,672 | | Terms 1-13 with OR | 1,029,608 |
| Population AND Intervention AND Evaluation = 8,611 | | | | | | | | |

## **Appendix B** Systematic review results following updated search (July 2023)

A total of nine papers reporting on seven studies were identified following the updated search.

### Study characteristics

Two studies employed a quantitative study design (Menengi˙ç et al., 2022; Sari et al., 2023), one a qualitative study design (Tablot and Briggs, 2022) and four employed a mixed-methods approach (Lima et al., 2022; Park et al., 2022; 2023; Vellani et al., 2022; 2023; Gerritzen et al., 2023a) (**Table 27**). Research emerged from six countries. Two studies collected data from the UK (Talbot & Briggs, 2022; Gerritzen et al., 2023a), one from Brazil (Lima et al., 2022), Turkey (Menengi˙ç et al., 2022) and Indonesia (Sari et al., 2023), Canada (Vellani et al., 2022; 2023) and the USA (Park et al., 2022; 2023).

A dementia diagnosis formed a requirement in seven studies (Lima et al., 2022; Menengic et al., 2022; Park et al., 2022; 2023; Vellani et al., 2022; 2023; Sari et al., 2023). Specifically, one study reported on people who had received a diagnosis prior to 65 years of age (Gerritzen et al., 2023a) and one study solely reported on people with Alzheimer's Disease (Menengi˙ç et al., 2022). One study reported on people who self-identified as living with dementia (Talbot & Briggs, 2022). The participation or presence of unpaid carers, alongside the person with dementia, formed a requirement in five studies (Lima et al., 2022; Menengi˙ç et al., 2022; Park et al., 2022; 2023; Vellani et al., 2022; 2023, Sari et al., 2023). Furthermore, Menengi˙ç et al. (2022) specified that unpaid carers were required to be digitally literate to participate.

Access to an ICT device formed a requirement in four studies (Lima et al., 2022; Park et al., 2022; 2023; Vellani et al., 2022; 2023; Sari et al., 2023), of which three specified access to internet connectivity (Park et al., 2022; 2023; Vellani et al., 2022; 2023; Sari et al., 2023). One study excluded people who were not comfortable accessing consultations remotely (Lima et al., 2022) and another excluded people who experienced difficulties adapting to the remote media (Menengi˙ç et al., 2022). People with dementia with visual and/or auditory impairments were excluded in three studies (Menengi˙ç et al., 2022; Vellani et al., 2022; 2023, Sari et al., 2023) and people with dementia with behavioural problems were excluded in one study (Menengi˙ç et al., 2022). Unpaid carers who were deaf and/or blind were excluded from enrolling as study partners in one study (Vellani et al., 2022; 2023). All studies collected data during the COVID-19 pandemic.

All included studies were of good methodological quality, with scores ranging between 34-36 points (**Table 29**).

**Table 27** Study characteristics of studies retrieved from the updated search

| Authors | Country | Aims | Design | Participants | Method | Results |
|---|---|---|---|---|---|---|
| Lima et al., (2022) | Brazil | To examine the feasibility of geriatric consultations via telemedicine to patients with dementia in the Brazilian public health system. | Mixed methods; single-centre, one arm study | n=89 PLWD participated, n=85 PLWD included in the analysis. n= 24 (28.2%) male: n=61 (71.8%) female; mean age: 81 ±12; n=60 (70.6%) less than 8 years education; n=50 (58.8%) living without a partner; n=32 (37.6%) AD; n=3 (3.5%) vascular dementia; n=12 (41.1%) Mixed dementia; n=3 (3.5%) Lewy Body dementia; n=30 (35.3%) under investigation to identify disease; n=3 (3.5%) other. | - As part of the consultation: FAST; Katz Activities of Daily Living; AMTA<br>- Self-administrated questionnaire: 12 questions using a VAS on feasibility, safety, satisfaction, effectiveness, acceptance, and one open-ended question. | - High patient recruitment (85.5%), attendance (97.7%) and satisfaction (97.6%)<br>- Low discomfort (9.4%): n=7 PLWDs experienced internet connection issues and n=1 non-compliant behaviour.<br>- Accessing consultation remotely decreased travel time and cost |
| Menengi˙ç et al., (2022) | Turkey | To investigate the effectiveness of exercise treatment via home-based telerehabilitation in AD | Quantitative; pilot RTC | Intervention group. n=10 PLWD, mean age: 77.7 (±5.29), n=7 (70%) female; n=3 (30%) male; n=6 (60%) full time home care, n=4 (40%) no home care.<br><br>Control group. n=10 PLWD, mean age: 80.6 (±6.11); n=7 (70%) female; n=3 (30%) male; n=1 (10%) full time home care; n=3 (30%) part time home care; n=6 (60%) no home care. | - Baseline and post-intervention: MMSE; 5XSST; TUG; OLST; Katz-ADL; FIM; GDS; BAS; ZCBS; WEMWBS<br>- Satisfaction questionnaire post-intervention | - Telerehabilitation may positively impact on PLWD cognition, mobility, functional independence and unpaid carers' wellbeing.<br>- Telerehabilitation may reduce anxiety and depressive symptoms in PLWD |
| Tablot & Briggs, (2022) | UK | To understand how, and why, people with mild to moderate dementia use digital | Qualitative | n=19 PLWD; n=7 female (36.8%) and n=12 (63.2%) male; mean age: 62.47 (age range:50 -84); All had | Semi-structured interviews | - During the pandemic digital technologies helped to reduce stress and |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | technologies during the COVID-19 pandemic. | | YOD (n=7 Alzheimer's Disease (36.8%); n=4 (21.1%); Mixed (2.1%); n=3 PCA (15.8%); n=4 Vascular (26.3%); n=1 Frontotemporal (5.3%)); n=14 lived with a family member (73.7%) and n=5 lived independently (35.7%). | | isolation facilitating social connection, self-actualisation, promote wellbeing, access to peer support groups and daily living.<br>- Challenges using digital technologies reported |
| Vellani et al., (2023) | Canada | To assess the feasibility, acceptability, and preliminary efficacy of the VYV intervention in community-dwelling older adults living with mild dementia and unpaid carers. | Quantitative; single group pre-test and post-test design | n=20 dyads<br>PLWD: n=10 (50%) female; n=10 (50%) male; mean age: 80 (67-91); living n=19 (95%) own home; n=1 (5%); retirement facility; n=3 (15%); living alone; n=11 (55%) living with spouse; n=6 (30%) living with children; n=11 married (55%); n=5 (25%) widowed; n=3 (15%) separated / divorced; n=1 (5%) single; n=2 elementary education (10%); n=9 (45%) high school; n=2 (10%) non university training; n=3 (15%) diploma / certificate; n=3 (15%) bachelor degree; n=1 (5%) professional degree; n=2 (10%) Black; n=11 (55%) White; n=1 (5%) Asian Chinese; n=5 (25%) South Asian; n=1 (5%) West Indian; mean Charlson Comorbidity Index[α]: 6.7 (3-15); QDRS: mean: 8.3 (2.5-15).<br>UNPAID CARERS: n=13 (65%) female; n=7 (35%) male; mean age: 62 (44-81); relationship to PLWD: | - Assessment of feasibility: recruitment rate, percentage of enrolled dyads; percentage of dyads completed VYV intervention; intervention fidelity (recorded and audited based on the fidelity checklist)<br>- Assessment of preliminary efficacy: outcome measures at baseline (T1) and 7-14 days post-intervention (T2): PLWD: 15-item ACP engagement questionnaire. UNPAID CARERS: 5-item DMC; DKAT; 10-item K-10<br>- VYV intervention by videoconferencing software over two sessions. | - Lower recruitment rate (52%) than expected (60%)<br>- High retention rate (94%)<br>- High intervention fidelity (20% sessions audited)<br>- PLWD improvement in ACP engagement<br>- Improved decision-making confidence and psychological distress in unpaid carers<br>- Minimal change in unpaid carers' dementia knowledge<br>- n=6 (30%) PLWD did not remember contents of VYV at T2 |

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| | | | | n=9 (45%) spouse; n=7 (35%) daughter; n=4 (20%) son; n=1 (5%) high school; n=1 (5%) non university training; n=6 (30%) diploma / certificate; n=10 (50%) bachelor's degree; n=2 master's degree (10%); n=2 (10%) Black; n=11 (55%) White; n=1 (5%) Asian Chinese; n=5 (25%) South Asian; n=1 (5%) West Indian; n=10 (50%) employed full time; n=1 (5%) unemployed; n=9 (45%) retired. n=18 dyads completed all study procedures. | | |
| Vellani et al., (2022) | Canada | - To explore the acceptability of the VYV intervention in terms of its contents and activities<br>- To explore the factors influencing the acceptability of the VYV intervention<br>- To explore participants' and researcher's experiences with VYV by videoconferencing software | Mixed methods | Same as Vellani et al., 2023, however only n=18 PLWD completed all study procedures. | - 7-14 days post-intervention: PLWD and UNPAID CARERS (separately): 11-item TEI (six open-ended questions added); VEQ-P.<br>- VEQ-R by the researcher after each session and kept a research diary throughout. | - Intervention rated acceptable by all participants<br>- PLWD living with unpaid carers were more likely to find the intervention acceptable<br>- Video and sound quality was highly rated by participants and researcher |
| Park et al., (2023) | USA | To identify benefits, challenges and facilitators in participating in remotely supervised online chair yoga and virtual socialisation from | Qualitative descriptive design | PLWD: n=8; n=5 (62.5%) Male, n=3 (37.5%) Female; mean age: 81.37 (SD = 8.7; range = 68-96); n=7 (87.5%); n=2 (24%) Alzheimer's disease; n=1 (12.5%) Lewy body dementia; n=5 (62.5%) | -Two focus groups pre-intervention[β]<br>- Two focus groups post-intervention | - Online chair yoga is feasible and acceptable by PLWD and unpaid carers<br>- Online chair yoga was beneficial to PLWD and unpaid carers (better sleep, stress |

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| | | the insights and perspectives of PLWD and unpaid carers | | Other; Mean MoCA Score = 15 (SD:6.4); Non-Hispanic White; n=1 (12.5%) African American; n=6 (75%) Married, n=1 (12.5%) divorced; n=1 (12.5%) widowed<br><br>UNPAID CARERS: n=9; n=2 (22%) Male; n=7 (78%) Female; mean age: 75.1 (SD= 9.27; range: 60-84); n=8 (89%) Non-Hispanic White; n=1 (11%) African American; n=8 (89%) Married; n=1 (11%) Single / never married; relation to PLWD: n=8 (89%) spouse / partner; n=1 (11%) daughter | | | reduction / management, less depressed, physical health benefits, increased concentration in PLWD) and they wanted to continue the intervention<br>- The remote format was convenient and enabled virtual socialisation |
| Park et al., (2022) | USA | - To assess the feasibility (retention, adherence and safety) of conducting a remotely supervised, home-based chair yoga<br>- To examine the relationship between the intervention and chronic pain, physical function or psychological symptoms<br>- To exploratively evaluate the ease and ability of unpaid carers and PLWD to record cardiac data remotely for offline analyses of the effect of the intervention | Quantitative one group pre-test / post-test design | n=11 PLWD: n=8 (72.7%) Male, n=3 (27.3%) Female; n=10 (90.9%) Caucasian, n=1 (9.1%) African American; n=2 (18.2%) divorced, n=1 (9.1%) widowed; n=1 (9.1%) less than high school, n=1 (9.1%) some high school, n=1 (9.1%) some college, n=4 (36.4%) college graduate, n=4 (36.4%) graduate degree; n=2 (18.2%) live independently, n=2 (18.2%) some assistance with complex activities, n=5 (45.5%) some assistance with basic activities, n=2 (18.2%) completely dependent. | - Retention defined as at least 70% of participants completing intervention and data collection. Adherence defined as participants participating in at least 70% of sessions. Safety defined as less than 10% of participant reporting adverse events.<br>- Data remotely collected at baseline, mid (after 8 sessions) and post -intervention (after 16 sessions): PROMIS PI-SF, SDI, de Jong Gierveld Loneliness Scale, BPQ-SF, TUG, cardiac data, | - Remotely supervised chair yoga is a feasible approach to manage physical and psychological symptoms in PLWD.<br>- No significant findings in pain interference, mobility, sleep or social loneliness, emotional loneliness significantly increased. |

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| Sari et al., (2023) | Indonesia | - To evaluate the feasibility of a 12-week telehealth home-based exercise program for PLWD, and subsequent 6-week self-maintenance period<br>- To investigate the preliminary effects of the intervention on physical activity, enjoyment, quality of life, behaviour on PLWD and impact on unpaid carers<br>- To assess the sustainability of exercise participation in 6-weeks self-maintenance period | Quantitative pre-post intervention single group study | n=30 PLWD, n=19 (63.3%) Female; mean age: 71.5 (SD:8.8), n=22 (73.3%) Alzheimer's Disease, n=6 (20%) Vascular dementia, n=1 (3.3%) Frontotemporal, n=1 (3.3%) Parkinson's dementia; mean dementia duration (years): 2.1 (SD:1.2), mean T-MMSE score: 15.0 (3.3); living location n=10 (33.3%) major city, n=11 (36.7) inner regional, n=7 (23.3%) outer regional, n=2 (6.7%) remote / very remote.<br><br>n=30 FAMILY CARERS, n=24 (80%) Female, mean age: 42.6 (SD: 11.3), mean days per week spent with PLWD: 6.9 (0.4).<br><br>n=10 PAID CARER, n=9 (90%) female, mean age: 33.2 (SD: 11.7), mean days per week spent with PLWD: 7 (SD:0). | - Data collected at baselines, 12 and 18 weeks: PASE; LLDI; Vitality Plus Scale; Icon-FES; PACES; QOL-AD; NPI-Q; Zarit caregiver burden scale<br>- Intervention was considered feasible if the mean adherence rate was at least 70%, if 30% or less of participants withdrew and 10% or less reported an adverse event.<br>- Dyads kept an exercise diary | - Feasible and safe. Median adherence was 84.1% during the intervention, and 66.7% in the self-maintenance period<br>- Physical activity level, enjoyment and health related benefits of exercising and quality of life significantly improved at 12 and 18 weeks. |
| Gerritzen et al., (2023a) | UK† | To explore which platforms people with YOD use for online peer support, reasons for using or not using online peer support and how to optimise potential benefits and accessibility. | Mixed methods | n= 69 PLWD. n=43 (62.3%) male, n=26 (37.7%) female; mean age: 60.06 (SD ±5.4), time since diagnosis: n=17 (24.6%) less than 1 year, n=21 (30.4%) 1-2 years, n=16 (23.2%) 2-3 years, n=15 (21.7%) over 3 years. Living situation; n=42(60.9%) with partner; n=18 (26.1%) with partner and family, n=1 (1.4%) with family, n=7 | Cross-sectional survey | - Zoom, followed by Facebook and Twitter were the preferred platforms to access peer support remotely<br>- Positives included sharing experiences, being part of a groups and able to join from home |

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| | (10.1%) alone, n=1 (1.4%) other. n=8 (11.6%) paid employment. n=65 (94.2%) White. Experience of online peer support: n=47 (68.1%) never used, n=6 (8.7%) previously used, n=16 (23.2%) current user. | | - Some people with YOD found it difficult to follow conversations online<br>- Poor signposting of available peer support groups |

Acronyms: 5XSST: Five Times Sit to Stand Test; ACP: Advanced Care Planning; AMTA: Abbreviated Mental Test 4; AD: Alzheimer's Disease; BAS: Beck Anxiety Scale; BPQ-SF: Body Perception Questionnaire – Short Form; DKAT: Dementia Knowledge Assessment Tool; DMC: Decision Making Confidence; FAST: Functional Assessment Staging Tool; FIM: Functional Independence Measurement; GDS: Geriatric Depression Scale-Short From; Icon-FES: Iconographical Falls Efficacy Scale; K-10: Kessler Psychological Distress Scale; Katz-ADL: Katz Activities of Daily Living Scale; LLDI: Late-life Function and Disability Instrument; MoCA: Montreal Cognitive Assessment; NPI-Q: Neuropsychiatric Inventory Questionnaire; MMSE: Mini Mental State Examination; OLST: One-leg Stance Test; PACES: Physical Activity Enjoyment Scale; PASE: Physical Activity Scale for the Elderly; PCA: Posterior Cortical Atrophy; PLWD: People with dementia; QDRS: Quick Dementia Rating Scale; QOL-AD: Quality of Life in Alzheimer's Disease; RTC: Randomized Controlled Trial; SD: Standard Deviation; SDI: Sleep disorder inventory; TEI: Treatment Evaluation Inventory; T-MMSE: Telephone Mini Mental State Examination; TUG: Timed up and Go; VAS: visual analogue scale; VEQ-P: Virtual Experience Questionnaire – participants; VEQ-R: Virtual Experience Questionnaire – researcher; VYV: Voice your Values; WEMWBS: Warwick-Edinburgh Mental well-being Scale; YOD: Young Onset Dementia; ZCBS: Zarit Caregiver Burden Scale.

[α] Missing for one PLWD.

[β] One PLWD did not attend the focus group.

[†] UK-based, but international participants were able to participate.

**Table 28** Summary of post-diagnostic support accessed and ICT formats employed in studies retrieved from the updated search

| Reference | ICT format (s) employed | ICT support provided | Post-diagnostic support accessed | Views on accessing remote post-diagnostic support |
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| ***Post-diagnostic support accessed by people with dementia or both members of the dyad*** | | | | |
| Lima et al., 2022 | - Telephone or WhatsApp to schedule consultation<br>- Consultation by WhatsApps (both video and text) | - Advised to hold consultation in a room with strong internet and unpaid carers to be present. | -One-time consultation by WhatsApp (between in-person consultations), by a medical doctor.<br>- Consultation involved treatment approaches, health promotion, drug prescription, complementary diagnostic tests, referrals to other health providers. | - n=7 PLWDs experienced internet connection issues and n=1 non-compliant behaviour. One drop out due to internet connection issues<br>-when accessing in-person consultations: 34.5% of unpaid carers forfeited work; mean earnings lost: 19.41 (38.26) reais[α]; round-trip mean 55.25 (SD: 60.67) mins; 35.31 (SD: 44.64) reais.<br>- Advantages: shorter timeframe between consultations (24%); faster response to problem solving (12%); avoids PLWD traveling (12%); receiving prescriptions without traveling (9%).<br>- Disadvantages: longer medical appointments duration (15%); bad internet connection (12%).<br>- How difficult to participate in consultation remotely: n=31 (36.5%) very easy; n=47 (55.3%) easy; n=1 (1.2%) indifferent; n=4 (4.7%) hard; n=2 (2.4%) very hard<br>- Satisfaction with remote consultation: n=37 (43.6%) very satisfied; n=46 (54.1%) satisfied; n=1 (1.2%) indifferent; n=1 (1.2%) unsatisfied<br>- Recommend remote consultations: n=29 (34.1%) certainly, n=35 (41.2%) yes; n=13 (15.3%) probably; n=7 (8.2%) maybe; n=1 (1.2%) never. |
| Menengi˙ç et al., 2022 | - Videoconferencing software<br>- Tablet device or computer | - Training to unpaid carers if required | - 25 sessions over 6 weeks. Supervised cognitive and seated physical health exercises supervised by a physical therapist. | - PLWD participation required unpaid carers to spend additional time: 14.3% strongly disagree; 14.3% disagree; 14.3% neither agree or disagree; 42.9% agree; 14.3% strongly agree. |

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| | | | - Intervention commenced with 15 mins sessions 5 times per week to 40 mins sessions 4 times a week.<br>- Sessions started with small talk, singing / keeping rhythm, simple seated exercises and progressive cognitive tasks.<br>- Unpaid carers from the intervention and control group were invited to online information meetings on AD | - PLWD participation restrained unpaid carers from doing their work: 28.6% strongly agree; 57.1% disagree; 14.3% neither agree or disagree.<br>- PLWD participation forced unpaid carers to provide device and internet connection: 42.9% strongly disagree; 42.9% disagree; 14.3% neither agree or disagree<br>- Online intervention can replace in-person practice: 28.6% disagree; 14.3% neither agree no disagree; 57.1% agree<br>- PLWD satisfied with intervention: 29% agree; 71% strongly agree<br>- Unpaid carer satisfied with intervention: 14% agree; 86% strongly agree |
| Tablot & Briggs, 2022 | - Videoconferencing software | - None reported | - Peer support groups, Pilates, aerobics and group reminiscence | - Online peer support groups more accessible as no traveling required<br>- As peer support groups moved online, participants attended more groups<br>- Online peer support groups provided the opportunity to connect with people from different places<br>- Not a replaced for in-person peer support – missed physical expressions of support (hugs, handshakes, pat on the back) |
| Vellani et al., 2022; 2023 | - Videoconferencing software (Microsoft Teams)<br>- Telephone<br>- Basic equipment: headphone, splitters and dongles | - Unpaid carers available to provide technological support<br>- Some participants required a telephone call from study members to help connect to videoconferencing software | - ACP intervention over two sessions.<br>- Session 1: (20-45 mins) gather information about PLWD understanding of dementia, desire to learn about dementia and ACP, life goas, fear / worries related to dementia diagnosis<br>- Session 2: (45-60mins) summary from the first session, tailored education about dementia and ACP, answer questions; coach PLWD to identify values and | - Sound (5-point scale able to hear: 1= none of the time; 5- all the time): average score (SD): Researcher (n=1) 4.8 (0.75); PLWD (n=19) 4.9 (0.23); UNPAID CARERS (n=20) 4.5 (0.76).<br>- Video (5-point scale able to see: 1= none of the time; 5-all the time): Researcher (n=1) 4.7 (0.45); PLWD (n=19) 4.8 (0.37); UNPAID CARERS (n=20): 4.7 (0.48).<br>- Video lag (5-point scale frequency of lags in video: 1= none of the time; 5-all the time): Researcher (n=1) 1.3 |

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| | | | | wishes for future healthcare in relation to terminal and vegetative states; document values and wishes.<br>- Written summary of PLWD values and wishes. | (0.50); PLWD (n=19) 1.3 (0.56); UNPAID CARERS (n=20) 1.7 (0.63).<br>- Saved time and travel, some experience technical glitches.<br>- Some PLWD required assistance from unpaid carers or researchers.<br>*'Definitely not the telephone, if the in-person was available yes, that would be nice but seeing someone on the screen really helped. In-person, the person can touch the other person, can reassure the older folks. I think for me that would be really helpful, and they can look right into the person's eyes, online you can, but in-person would be a lot better*.' Unpaid Carer<br><br>*'The only thing wrong with this whole process was our equipment and our lack of quality of internet. We had one session where her (facilitator) image froze on the screen and I couldn't get her facial expressions. . .'* PLWD<br><br>*'... like I know there was one session where I was quite upset and sad and tearful, and that wasn't acknowledged, which is fine; I can process that on my own, like I have my own support networks, but I think in other situations, that might be quite tough for somebody to manage on their own*.' Unpaid carer |
| Park et al., 2022; 2023 | - Videoconference software (Zoom)<br>- Email | - Research assistant sent Zoom link by email<br>- Research assistant called participants to ensure access to Zoom and yoga session<br>- Research assistant available for troubleshooting and sent email reminders | - Remotely supervised chair yoga (60-minute sessions) twice a week, for 8 eights: check in and socialisation (10 minutes); breathing techniques and intentional practice (10 minutes); physical postures (25 minutes); guided relaxation and visualisation (10 minutes); wrap up (5 minutes). | - Convenience, reduce stress associated with arranging travel and able to participate from own home<br>- Good as many were socially isolated due to the COVID-19 pandemic<br>- Experienced technological issues and some PLWD lacked attention span<br>- Not the same as in-person sessions, harder to socialise, some participant would prefer in-person sessions | |

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| | | - Telephone meeting with participants to show how to use Zoom and the video application<br>- Unpaid carers received a manual with pictures to help download application and connecting earlobe optical sensor, pulse sensor and USB cable to home computer | - Conducted by a certified yoga instructor<br>- Graphic materials to help practice yoga outside class and participants had access to a video of previous sessions. | *'It's important to have research support to aid in solving [technical] problems'* PLWD<br>*'We were waiting for everybody to join and, by the time we started [yoga session], which was probably a 10–15- min period there, he lost interest. Then to get him back in was almost impossible and when he did, maybe after 20 min, he was ready to call it a day…'* Unpaid Carer<br><br>*'Going places can be challenging through the process of getting ready to get out the house, to get to the place. The convenience of doing it in your home has been phenomenal…'* Unpaid Carer |
| Sari et al., 2023 | - Videoconferencing software (Zoom)<br>- Email<br>- YouTube | - Orientation session to explain Zoom software, test camera sound, distance of device and environment. | - 12-week individualised home-based exercise intervention. 4 sessions were conducted online in real-time by videoconferencing software (weeks 1, 2, 6 and 10) by a physiotherapist. In between the sessions, researchers checked-up on dyads by videoconferencing<br>- Dyads instructed to continue the exercises for 5 days a week, 20-30 minutes each day between scheduled visits.<br>- Exercises included: warm up, balance, resistance and walking. Aiming for moderate intensity exercise level.<br>- Received an exercise booklet and YouTube link to explain how to perform exercises<br>- Dyads instructed to continue exercises for 6 weeks following the 12-weeks intervention. | - None reported |

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| Gerritzen et al., 2023a | - Videoconferencing software: Zoom, Microsoft Teams, Skype, GoToMeeting<br>- Text-based: social media (Twitter / Facebook), email, WhatsApp | -none reported | -Online peer support<br>-Most accessed online peer support weekly, and some monthly. | - May overcome geographical barrier, able to access from home and some people with YOD find it easier to meet new people online<br>- Different formats accommodates to needs and preferences<br>- Preference for in-person, harder to trust other people online, difficult to understand / follow conversations online<br>- Comorbidities and dementia symptoms may make it hard to use ICT<br><br>'*It was nice and friendly and we all had issues with online, but we supported each other and didn't have to worry that we might be rushed or judged'* (Female, 59, living with partner and other family members)<br><br>'*It's a good first step towards trying a group in-person as people feel freer to leave whenever it suits them if the meeting is becoming uncomfortable. People may find it more relaxed joining from their own from rooms. It also gives people a chance to check into several different groups and fine the one which appeals best to them*' (Female, 59, living alone).<br><br>'*Sharing tips and hobbies brings a purpose back to your life*' (Female, 57, living with partner) |

[α] Brazilian currency. Acronyms: AD: Alzheimer's Disease; APC: Advanced Care Planning; PLWD: People living with dementia; SD: Standard deviation.

**Table 29** Methodological appraisal of studies retrieved from the updated search (Hawker et al., 2002)

| Reference | Abstract | Introduction and aims | Methods and data | Sampling | Data analysis | Ethics and bias | Results | Transferability and generalizability | Implications and usefulness | Overall Score † |
|---|---|---|---|---|---|---|---|---|---|---|
| Talbot & Briggs, 2022 | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Vellani et al., 2022 | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Vellani et al., 2023 | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Park et al., 2022 | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Park et al., 2023 | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Lima et al., 2022 | Good | Good | Fair | Good | Good | Fair | Good | Good | Good | 34 |
| Gerritzen et al., 2023a | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Sari et al., 2023 | Good | Good | Good | Good | Good | Good | Fair | Good | Good | 36 |
| Menengi˙ç et al., 2022 | Good | Good | Good | Good | Good | Fair | Good | Good | Good | 35 |

ᵠ Very Poor =1; Poor =2; Fair=3; Good =4 points. Score range = 9-36 (minimum- maximum)

## Types of remote post-diagnostic support accessed

Studies described a range of remote post-diagnostic support which addressed the needs of people with dementia or of the dyad. All studies reported on post-diagnostic support accessed by people with dementia and/or both members of the dyad (**Table 28**).

All post-diagnostic support was accessed from service recipients' home, and four studies reported on post-diagnostic support accessed in a group format (Menengi˙ç et al., 2022; Park et al., 2022; 2023; Talbot & Briggs, 2022; Gerritzen et al., 2023) and three studies reported on support accessed on a one-to-one or dyadic format (Lima et al., 2022; Vellani et al., 2022; 2023; Sari et al., 2023). Three studies described exercise health classes (Menengi˙ç et al., 2022; Park et al., 2022; 2023; Sari et al., 2023), and Menengi˙ç et al. (2022) delivered dual cognitive-motor exercises. Two studies described remote peer support (Talbot & Briggs, 2022; Gerritzen et al., 2023a), one study reported on an advance care planning intervention (Vellani et al., 2022; 2023) and one study delivered a one-time dementia medical follow-up consultation (Lima et al., 2022). Some people with dementia and unpaid carers had previously accessed peer support (Talbot & Briggs, 2022) and a medical follow-up consultation (Lima et al., 2022) in-person.

Unpaid carers supported people with dementia to engage with remote exercise health classes by providing encouragements, assisting to execute exercises, and ensuring their safety throughout (Park et al., 2022; 2023; Sari et al., 2023). However, some people with dementia were unable to participate in all exercise sessions as unpaid carers were unavailable in one study (Sari et al., 2023). Support accessed ranged from a single medical follow-up consultation (Lima et al., 2022) to a 12-week exercise health intervention followed by six-week self-maintenance phase (Sari et al., 2023). One study included a control group (Menengi˙ç et al., 2022).

### Outcomes

Accessing exercise health sessions remotely yielded no adverse events and, overall, the adherence was high (Menengi˙ç et al., 2022; Park et al., 2022; Sari et al., 2023). However, Sari et al. (2023)'s study found that service recipients' adherence (average number of exercises performed per session and the average number of sessions attended) was higher in the phase under the supervision of a physiotherapist (weeks baseline-12) compared to the self-maintenance phase (weeks 12 – 18). Nevertheless, Sari et al. (2023) found that the intervention improved some aspects of functions and disability, health related benefits and quality of life of service recipients at 12 and 18 weeks. While accessing chair yoga by remotely did not significantly benefit service recipients' pain interference, mobility sleep or social loneliness (Park et al., 2022), some people with dementia and unpaid carers qualitatively reported that

the intervention improved their sleep, mental health and physical health (Park et al., 2023). However, throughout the intervention, service recipients' emotional loneliness statistically significantly increased (Park et al., 2023). Compared to the control group, people with dementia who accessed dual cognitive-motor exercises remotely had improved (not statistically significant) scores on the Mini Mental State Examination, time up and go, and sit-to-stands (Menengi˙ç et al., 2022). Furthermore, compared to the control group, people with dementia had statistically significant improvements in functional independence, anxiety and depressive symptoms (Menengi˙ç et al., 2022). Service recipient recruitment and attendance while attend a dementia-related medical follow-up by WhatsApp was high, 85.5% and 97.7% respectively (Lima et al., 2022). Lastly, while a somewhat low recruitment rate (52%), accessing an advanced care planning intervention by videoconferencing software yielded a high retention rate (94%) and high intervention fidelity (Vellani et al., 2022). Following the intervention, people with dementia statistically significantly increased their engagement with the advance care planning process and unpaid carers made statistically significant improvements in decision-making. Furthermore, unpaid carers' psychological distress decreased but no improvements in dementia knowledge were made (Vellani et al., 2022).

### ICT formats employed, issues encountered and technological support

Videoconferencing software was the most employed ICT format (Menengi˙ç et al., 2022; Park et al., 2022; 2023; Talbot & Briggs, 2022; Vellani et al., 2022; 2023; Gerritzen et al., 2023a; Sari et al., 2023). Dementia medical follow-up consultations in Lima et al. (2022)'s study was delivered by WhatsApp (video and text message) due to participants' familiarity with the ICT format and the software's end-to-end encryption. Gerritzen et al. (2023a) report on accessing online peer support by text-based formats including social medial (Facebook and X (formerly Twitter)), email and WhatsApp. While relatively uncommon, five studies report on ICT issues. These included internet connectivity problems (Lima et al., 2022; Park et al., 2023; Vellani et al., 2022) and difficulties navigating platforms to access post-diagnostic support (Menengi˙ç et al., 2022; Vellani et al., 2022, Gerritzen et al., 2023a).

Two studies provided orientation sessions to explain how to navigate videoconferencing software (Park et al., 2022; Sari et al., 2023) and two studies provided training if required by participants (Menengi˙ç et al., 2022; Vellani et al., 2022; 2023). The orientation session in Sari et al. (2023)'s study included the testing of the device's camera and sound, and the setup of the equipment to ensure that the environment was conducive to safely performing the exercises. Study team members in Park et al. (2022)'s study remained available to troubleshoot throughout the interventions and sent videoconferencing software meeting login details and reminders by email. Some people with dementia in Vellani et al. (2022) study relied on assistance from unpaid carers and/or study team members to navigate the videoconferencing software.

## Views on accessing post-diagnostic support remotely

Views on accessing post-diagnostic support remotely were obtained by six studies. Three studies obtained service recipients' views by mixed-method approaches. Lima et al. (2022) and Gerritzen et al. (2023a) administrated a mixed methods survey that was completed by people with dementia or unpaid carers and Vellani et al. (2022) conducted a mixed methods survey completed by both members of the dyad. Two studies explored service recipients' views through qualitative approaches. Park et al. (2023) conducted focus groups with people with dementia and unpaid carers, and Talbot and Briggs (2022) interviewed people with dementia. One study recorded service recipients' views by addressing a quantitative survey to unpaid carers who answered on the behalf of the person with dementia (Menengi˙ç et al., 2022). Furthermore, Sari et al. (2023) report that a qualitative exploration found that service recipients were satisfied while accessing the remote exercise health programme, however, the paper is unpublished at the time of writing and therefore is not included within following paragraphs.

Most service recipients were satisfied while accessing dual motor and cognitive exercises (Menengi˙ç et al., 2022) and found the advanced care planning intervention acceptable (Vellani et al., 2022). People with dementia were more likely to find the advanced care planning intervention acceptable if they lived with their unpaid carer (Vellani et al., 2022). While some service recipients reported to have evaluated the intervention lower than perceived due to fearing the removal of in-person services, most people with dementia and unpaid carers were satisfied while accessing medical follow-up consultations remotely (Lima et al., 2022). Furthermore, many service recipients would recommend accessing medical follow-up consultations (Lima et al., 2022) and peer support remotely to other service recipients (Gerritzen et al. 2023a).

### Reducing travel and costs

Accessing post-diagnostic support remotely may offer convenience. Convenience, conveyed by circumventing the need to travel and/or reducing associated costs, was reported while accessing medical follow-up consultations (Lima et al., 2022), exercise health classes (Park et al., 2023), advanced care planning intervention (Vellani et al., 2022) and peer support (Talbot & Briggs, 2022; Gerritzen et al., 2023a). Accessing post-diagnostic support remotely overcame geographical barriers, notably for service recipients residing in rural areas (Vellani et al., 2022; Gerritzen et al., 2023a). However, one unpaid carer in Vellani et al. (2022)'s study reported having to travel to the person with dementia's home to set-up the videoconferencing software to access the advanced care planning intervention remotely.

### Timely, inclusive and safe access

Remote post-diagnostic support may facilitate a timely, inclusive and safe access to support. Some service recipients in Lima et al. (2022)'s study reported that accessing follow-up medical consultations remotely reduced the time frame between appointments and some people with dementia in Talbot and Briggs (2022)'s study accessed peer support groups more frequently since transitioning from in-person to online formats. Some service recipients in Gerritzen et al. (2023a)'s study reported that accessing peer support remotely enabled them to access support in a format that aligned with their preferred method of communication (by text or verbally). Most service recipients felt safe accessing medical follow-up consultations remotely (Lima et al. 2022) and while performing exercises remotely (Park et al., 2023). However, one service recipient in Gerritzen et al. (2023a)'s study reported that they were unsure who to trust while accessing peer support online.

**Difficulties in accessing and engaging with remote formats**

Some service recipients experienced difficulties while accessing and engaging with post-diagnostic support remotely. Difficulties included navigating the ICT, sometimes due to dementia symptoms, comorbidities, and/or experiencing technical glitches (Menengi˙ç et al., 2022; Vellani et al., 2022; Gerritzen et al., 2023a; Park et al., 2023). Whereas most service recipients in Menengi˙ç et al. (2022)'s study reported that the technological problems experienced did not hinder the quality of the dual motor and cognitive exercises sessions accessed, several service recipients in Vellani et al. (2022) reported that technological problems caused frustration while accessing the advanced care planning intervention. Gerritzen et al. (2023a) report on reasons why people with dementia ceased accessing peer support remotely. Reasons included that navigating the platform was too difficult or their dementia symptoms was making too difficult to use the technology.

Difficulties in following conversations remotely and/or having too much background noise while accessing peer support remotely was reported by some people with dementia in Gerritzen et al. (2023a)'s study. Furthermore, some unpaid carers in Park et al. (2023)'s study reported that the person with dementia's attention span hindered their engagement while participating in exercise sessions. Lima et al. (2022) reported that one person with dementia exhibited non-compliant behaviours while accessing medical follow-up consultations remotely, and some unpaid carers reported that the behaviour of person they cared for changed during the consultation.

One study reported on the ability to assess non-verbal cues while accessing the advanced care planning intervention by videoconference software (Vellani et al., 2022). Whereas an unpaid carer reported that the facilitator was able to read the person with dementia' facial expressions (speech impairment due to dementia), the facilitator was unable to detect some emotions expressed by some service recipients.

Furthermore, one person with dementia found it difficult to read facial expressions due to the technological glitches (Vellani et al., 2022).

**Unable to replicate in-person services**

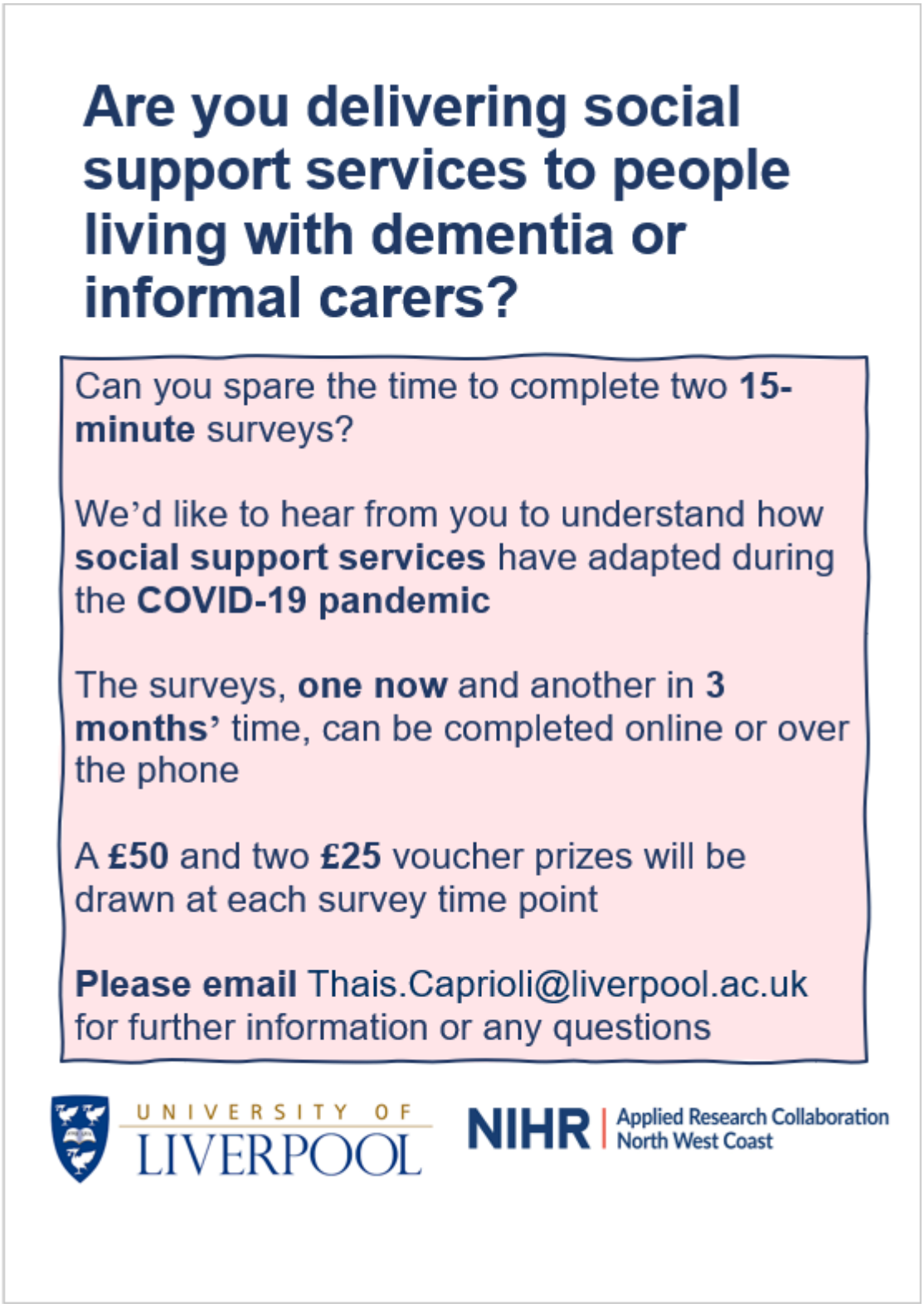
While most service recipients valued accessing support remotely during the COVID-19 pandemic, some people with dementia and unpaid carers preferred accessing services in-person (Park et al., 2022; Talbot & Briggs, 2022; Vellani et al., 2022; Gerritzen et al., 2023a). While accessing the advanced care planning intervention by videoconferencing software was the closest substitute to in-person services (Vellani et al., 2022), the format was unable to carry some aspects valued when accessing services in-person. These included reassuring gestures, such as hugs and 'pats on the back' (Talbot & Briggs, 2022; Vellani et al., 2022), and many people with dementia 'missed' in-person contact while accessing peer support online (Gerritzen et al., 2023a). Whereas some service recipients, notably unpaid carers, benefitted from the social aspect provided by accessing exercise health sessions remotely, some people with dementia found socialising remotely challenging and/or preferred the opportunity to hold private conversations (Park et al., 2023). However, socialising remotely may benefit people with dementia who find it daunting to meet new people and/or as a 'step-in' to accessing peer support in-person (Gerritzen et al., 2023a).

Furthermore, one person with dementia ceased accessing peer support online due to 'not liking it' (Gerritzen et al., 2023a) and two dyads declined accessing medical follow-up consultation remotely as they preferred in-person services (Lima et al., 2022).

**Suggestions to improve remote service delivery**

Two studies report on service recipients' suggestions to improve the delivery of remote post-diagnostic support. Service recipients in Gerritzen et al. (2023a)'s study suggest ensuring that a skilled and experienced facilitator is present to facilitate online peer support meetings, send out meetings links and provide instructions explaining how to use the technology required. Furthermore, limiting the number of people attending each meeting and establishing rules may be conducive to better online peer support meetings. Moreover, service recipients in Lima et al. (2022)'s study suggested providing more options when scheduling medical follow-up consultations and to alternate in-person and remote appointments.

**Appendix C** Longitudinal quantitative survey flyer



**Appendix D** Semi-structured interview flyer

**Appendix E** Longitudinal quantitative survey – study information sheet

**Version 2**, Date: 10.03.2021

**Title**: How have social support services for dementia adapted during the COVID-19 pandemic in the UK?

(Longer title: Social support services for dementia during the COVID-19 pandemic: A longitudinal study exploring how social support services have adapted in the UK)

**Chief Investigator:** Dr Clarissa Giebel, University of Liverpool/ NIHR ARC NWC

**Co-Investigators:** Prof. Mari Lloyd-Williams, Prof. Siobhan Reilly and Thais Caprioli

**Participant information sheet**

**Invitation Paragraph**

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please do take the time to read the following information carefully, and feel free to as us if you would like more information or if there is anything you do not understand. We would like to stress that you do not have to accept this invitation, and you should only take part if you would like to. Thank you for reading this.#

**What is the purpose of the study?**

The purpose of this study is to understand how social support services for people with dementia and informal carers (both current and former) within the paid or voluntary sectors have adapted during the corona virus (COVID-19) pandemic. By social support services we are referring to non-clinical services to support people with dementia living in their own homes and informal carers to live well in their communities. Social support services can, for example, include paid home care, day care, support groups and organised social activities.

**Why have I been chosen?**

We are inviting all social support service providers who are working (paid capacity) or volunteering / helping (unpaid capacity) to deliver social support services to people with dementia living in the community or to informal carers in the UK. We are inviting all social support services providers as we are interested in understanding how social support services in dementia care have adapted during the COVID-19 pandemic.

**Do I have to take part?**

No, taking part in this study is completely voluntary. If you would like to participate in this study, you are free to withdraw your participation at any time, without providing an explanation, and without experiencing any disadvantages. You do not need to take part in the second survey.

**What will happened if I take part?**

The study involves completing two short surveys (approximately 15 minutes each), one now and another in three months' time. We will be asking you general questions about yourself and the social support service organisation you work or help / volunteer for. Both before the COVID-19 pandemic and at the time completing the two surveys, we will ask you about the type of social support service you are primarily delivering, and how this type of social support service is being delivered. We are also interested about the use of technology in the delivery of social support services, and if this have changed during the COVID-19 pandemic.

The study is conducted by Thais Caprioli (PhD student). Each survey should take approximately 15 minutes and can be completed online (through Jisc Online Surveys) or through the telephone. If you would like to complete the survey through the telephone, please contact a member of the study team.

**How will my data be used?**

The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of "advancing education, learning and research for the public benefit".

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The Principal Investigator acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to Dr Clarissa Giebel (clarissa.giebel@liverpool.ac.uk or 0151794996).

Further information on how your data will be used can be found in the table below

| | |
|---|---|
| How will my data be collected? | Through two short surveys (approximately 15 minutes long each) that can be completed online or over the telephone |
| How will my data be stored? | All data will be anonymised and securely stored on a password-protected University of Liverpool computer (M drive). |
| How long will my data be stored for? | Data will be stored on the M drive for ten years, after which it will be deposited into the University of Liverpool's Archive. The University of Liverpool will keep identifiable information about you for 10 years after the study has finished, after which it will be securely destroyed. |
| What measures are in place to protect the security and confidentiality of my data? | All data obtained will be anonymised and kept confidential. Data will be securely stored on a password-protected University of Liverpool computer. All authorised persons who have access to the data will have a duty of confidentiality to anyone taking part in the study. |

| | |
|---|---|
| How will my data be anonymised? | Each participant will have an individual code and all identifiable information will be removed from the analysis. This means that we will not be able to identify who participated in the study. |
| How will my data be used? | Your data will help us to understand how social support services have adapted during the COVID-19 pandemic. Findings will be written up for academic publication and to present at conferences. A lay summary will also be written. |
| Who will have access to my data? | Only members of this study from the University of Liverpool will have access to your data. Study data and materials may be looked at by individuals from the University of Liverpool for monitoring and auditing purposes. Only authorised persons of this organisation would be able to see the data and would have a duty of confidentiality to anyone taking part in the study. |
| Will my data be archived for use in other research projects in the future? | Your data will be archived after ten years and may be shared and used by other authorised researchers to support future research. |
| How will my data be destroyed? | We will delete the electronic files once the 10 years storage period has passed. |

**Are there any risks in taking part?**

You will be asked to give up some of your time to participate in the study, approximately 15 minutes for each survey. There are no direct risks in participating in this study as you will be able to complete the survey online from anywhere which is convenient for you and has access to the internet. The surveys can equally be completed through the telephone. The surveys should not cause any distress as the questions relate to the types of social support services you are delivering how they are being delivered. However, if you do feel distressed or any experience any disadvantage as part of the research, please contact the any of the research study team members immediately.

**Are there any benefits in taking part?**

By taking part in the study, you can provide information on how social support services for people with dementia or informal carers were delivered before and during the COVID-19 pandemic. Information collected during this study may help to inform the delivery of support services in future public health crises.

As a thank you, shopping vouchers prizes – one worth £50 and two worth £25, will be drawn after both survey time points

**What will happen to the results of the study?**

Your data will be anonymised and remain confidential. You will not be able to be identifiable from the results. Findings will be written up for academic publication and to be presented at conferences. A lay

summary will also be written. If you would like, the lay summary of the results can be sent to you by email or through the post.

**What will happen if I want to stop taking part?**

You can withdraw from the study at any time, without providing an explanation. If you decide to withdraw from the study, the information you have already provided may be used if you are happy for us to do so. Otherwise, the information you have provided will be securely destroyed and will not be used. However, there are some limitations as you will only be able to withdraw the information you have provided before the results are anonymised. You may withdraw your data until three months after the completion of the initial survey. Once you have completed the second survey, you will not be able to withdraw your data from the first or second survey. Please contact the principal investigator, Dr Clarissa Giebel (clarissa.giebel@liverpool.ac.uk or 0151794996), if you would like to withdraw from the study.

**What if I am unhappy or if there is a problem?**

If you are unhappy, or if there is a problem, please let us know by contacting the principal investigator Dr Clarissa Giebel (clarissa.giebel@liverpool.ac.uk or 0151794996) and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to use with, the please contact the Research Ethics and Integrity Office at ethics@liv.ac.uk . When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so it can be identified), the researcher(s) involved and the details of the complaint you wish to make.

The University of Liverpool strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 03031201113.

**What do I do next?**

If you would like to participate in this study, please make sure you meet all of the following criteria:

1. You are working (paid capacity) or helping / volunteering (unpaid capacity) to deliver social support services within the paid or voluntary sector in England
2. You are delivering social support services to people living with dementia and /
3. or to informal carers living in the community
4. You are either directly involved in delivering social support services to care recipients or you are involved in the management / organisation of the delivery of social support services
5. You are at least 18 years old

**Thank you for reading about our study!**

**Who can I contact if I have further questions?**

Please feel free to contact the study team members on the contact details below:

**Principal Investigator**

Dr Clarissa Giebel

University of Liverpool

Waterhouse Building Block B

Brownlow Hill,

Liverpool

**Other study team members**

Prof. Mari Lloyd-Williams

University of Liverpool

mlw@liverpool.ac.uk

Thais Caprioli (PhD student)

University of Liverpool

Thais.Caprioli@liverpool.ac.uk

**Appendix F** Longitudinal quantitative study – consent form

**Participant consent form**

**Title:** How have social support services for dementia adapted during the COVID-19 pandemic in the UK?

**Name of researcher(s):** Dr Clarissa Giebel, Prof. Mari Lloyd-Williams, Prof. Siobhan Reilly, Thais Caprioli

Please initial box

1. I confirm that I have read and have understood the information sheet dated **10/03/2021** for the above study, or it has been read to me. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that taking part in the study involves completing two short 15-minute-long surveys, one now and another in three months' time. The surveys can be completed either online or over the telephone. ☐
3. I understand that my participation is voluntary and that I am free to stop taking part and can withdraw from the study at any time without giving any reason and without my rights being affected. In addition, I understand that I am free to decline to answer any particular question or questions. ☐
4. I understand that I can ask for access to the information I provide, and I can request the destruction of that information if I wish at any time prior to anonymisation (three months after the completion of the initial survey). I understand that following anonymisation I will no longer be able to request access to or withdrawal of the information I provide. ☐
5. I understand that the information I provide will be held securely and in line with data protection requirements at the University of Liverpool until it is fully anonymised and then deposited in the Archive for sharing and use by other authorised researchers to support other research in the future. ☐

6. I understand that signed consent forms and original surveys will be retained on the University of Liverpool's M Drive and Dr Clarissa Giebel, Prof. Mari Lloyd-Williams and Thais Caprioli will have access to the data for ten years, after which the data will be deposited in the Archive. ☐

7. I agree to take part in the above study. ☐

| _____ | _____ | _____ |
|---|---|---|
| Participant name | Date | Signature |
| _____ | _____ | _____ |
| Name of person taking consent | Date | Signature |


**Principal Investigator**

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**Student Investigator**

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**Other investigators**

Prof. Mari Lloyd-Williams

University of Liverpool

mlw@liverpool.ac.uk

**Appendix G** Semi-structured interviews – study information sheets

**Social care and support providers**

**Version 3,** Date: 13.04.2022

**Title**: Exploring the facilitators and barriers in accessing and delivering dementia-related social-support services during the COVID-19 pandemic in the UK

**Chief Investigator:** Dr Clarissa Giebel, University of Liverpool/ NIHR ARC NWC

**Co-Investigators:** Dr Stephen Mason, Prof. Siobhan Reilly and Thais Caprioli

**Participant information sheet – Social support provider participant**

**Invitation Paragraph**

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please do take the time to read the following information carefully, and feel free to ask us if you would like more information or if there is anything you do not understand. We would like to stress that you do not have to accept this invitation, and you should only take part if you would like to. Thank you for reading this.

**What is the purpose of the study?**

The purpose of this study is to further understand how social support services for people with dementia and informal carers (both current and former) have adapted during the corona virus (COVID-19) pandemic. We are interested in exploring your experiences in delivering social support services during the COVID-19 pandemic and the use of technology to provide remote service delivery. By social support services we are referring to non-clinical services to support people with dementia living in their own homes and informal carers to live well in their communities. Social support services can, for example, include paid home care, day care, support groups and organised social activities and can be provided both within the paid or voluntary sectors.

**Why have I been chosen?**

We are inviting social support service providers who participated in our recent survey study and who expressed an interest in receiving information relating to our upcoming interview study.

**Do I have to take part?**

No, taking part in this study is completely voluntary. If you would like to participate in this study, you are free to withdraw your participation at any time, without providing an explanation, and without experiencing any disadvantages.

**What will happened if I take part?**

The study involves taking part in a remote one-to-one interview which lasts no longer than 45 minutes. We will be asking questions to further understand how the COVID-19 pandemic has impacted and changed the delivery of social support services in dementia care. We are interested in exploring your experiences in delivering social support services during the COVID-19 pandemic and to understand the use of technology to deliver remote service delivery.

This study is conducted by Thais Caprioli (PhD student). The remote one-to-one interview can be conducted over Zoom or through the telephone. The date and time of the interview will be scheduled depending on your preferences and availability.

Depending on your preferences, the remote one-to-one interview can be completed through Zoom or the telephone. If you prefer to conduct the one-to-one interview through Zoom, you can choose whether you would like to enable the video icon. The PhD student will only enable their video icon if you choose to enable yours. To help with the analyses, the interview will be recorded and field notes taken after the interview. All data obtained will be annonymised and remain confidential.

**How will my data be used?**

The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of "advancing education, learning and research for the public benefit".

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The Principal Investigator acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to Dr Clarissa Giebel (clarissa.giebel@liverpool.ac.uk or 0151794996).

Further information on how your data will be used can be found in the table below

| | |
|---|---|
| How will my data be collected? | Through a remote one-to-one interview (no longer than 45 minutes) that can be completed over Zoom or over the telephone. Zoom will be used to record the audio recording of the interview. Even if you have decided to enable your video during the interview, only the audio recording will be saved. An audio recording device will be used if the interviews are conducted over the telephone Field notes will be written by the PhD student after the interview. These will remain anonymous and not be disseminated. |
| How will my data be stored? | All interviews will be audio recorded and transcribed. Once transcribed, the audio recordings will be securely deleted. The transcribed interviews and field notes will be anonymised and securely stored on a password-protected University of Liverpool computer (M drive). |
| How long will my data be stored for? | Once the interviews are transcribed, the audio recordings will be securely deleted. The transcribed interviews and field notes will be stored on the University of Liverpool's storage drive (M drive) for ten years, after which it will be deposited into the University of Liverpool's Archive. The University of Liverpool will keep identifiable information about you for 10 years after the study has finished, after which it will be securely destroyed. |

| | |
|---|---|
| What measures are in place to protect the security and confidentiality of my data? | All data obtained will be anonymised (unable to identify you) and kept confidential. You are free to switch off your camera, but even if it is left on, we will only save the audio file and upload onto the University of Liverpool's storage drive (M drive). As there is no option in Zoom to only record the audio, after uploading and saving the audio file onto the University of Liverpool's storage drive (M drive), all files (video and audio) will be securely deleted from Zoom. An audio recorder will be used if the interviews are conducted over the telephone. Once the audio file is uploaded and stored on to the University of Liverpool's storage drive (M drive), the audio files will be securely deleted from the audio recording device. The audio recording file will be securely stored on a password-protected University of Liverpool computer and the file will be securely deleted once transcribed. The transcribed interviews and field notes will be securely stored on a password-protected University of Liverpool computer. Only the members of this study from the University of Liverpool will have access to your data (Dr Clarissa Giebel, Dr Stephen Mason and Thais Caprioli). Study data and materials may be looked at by individuals from the University of Liverpool for monitoring and auditing purposes. Only authorised persons of this organisation would be able to see the data and would have a duty of confidentiality to anyone taking part in the study. |
| How will my data be anonymised? | Each participant will have an individual code and all identifiable information will be removed from the analysis. This means that we will not be able to identify who participated in the study. |
| How will my data be used? | Your data will help us to understand how social support services have adapted during the COVID-19 pandemic. Findings will be written up for academic publication and to present at conferences. A lay summary will also be written and available. |
| Who will have access to my data? | Only the members of this study from the University of Liverpool will have access to your data (Dr Clarissa Giebel and Dr Stephen Mason) and the PhD student (Thais Caprioli). Study data and materials may be looked at by individuals from the University of Liverpool for monitoring and auditing purposes. Only authorised persons of this organisation would be able to see the data and would have a duty of confidentiality to anyone taking part in the study. |
| Will my data be archived for use in other research projects in the future? | Your data will be archived after ten years |
| How will my data be destroyed? | We will delete the electronic files from the University of Liverpool's storage drive (M drive) once the 10 years storage period has passed. |

**Are there any risks in taking part?**

You will be asked to give up some of your time (no longer than 45 minutes) to attend the remote one-to-one interview. There are no direct risks in participating in this study as you will be able to attend the remote one-to-one interview from anywhere which is convenient for you.

The interviews should not cause any distress as the questions relate to the types of social support services you are delivering, how service delivery has changed during the COVID-19 pandemic and how technology has been used (if at all). However, if you do feel distressed or any experience any disadvantage as part of the research, please contact any of the research study team members immediately.

If you would like to stop the interview for any reason, you will be given the opportunity to complete the interview at a later date. Participation is voluntary, and you are free to stop taking part and can withdraw from the study at any time and decline to answer any questions without giving any reason and without your rights being affected. If you should disclose any information that might raise concerns, the PhD student will discuss this with their supervisory team and the research team reserves the right to contact the local authorities.

**Are there any benefits in taking part?**

By taking part in the study, you can provide information on how social support services for people with dementia or informal carers has been impacted by the COVID-19 pandemic and share your experiences in delivering services during the COVID-19 pandemic. The information collected during this study may help to provide policy recommendations to improve the delivery of social support services in dementia care during future public health crises.

As a thank you, each participant will receive a shopping voucher worth £10.

**What will happen to the results of the study?**

The audio recordings of the interviews will be transcribed. Once transcribed, the audio recordings will be securely deleted. To assist data analysis, anonymised field notes will be written after the interview and will not be disseminated. Your data will be anonymised and remain confidential.

**What will happen if I want to stop taking part?**

You can withdraw from the study at any time, without providing an explanation. If you decide to withdraw from the study or stop taking part at any time, the information you have provided will be securely destroyed and will not be used. However, there are some limitations as you will only be able to withdraw the information you have provided before the results are annonymised. You may withdraw your data until one week after the interview.

Please contact the principal investigator, Dr Clarissa Giebel (clarissa.giebel@liverpool.ac.uk or 0151794996) if you would like to withdraw from the study.

**What if I am unhappy or if there is a problem?**

If you are unhappy, or if there is a problem, please let us know by contacting the principal investigator Dr Clarissa Giebel (clarissa.giebel@liverpool.ac.uk or 0151794996) and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to use with, the please contact the Research Ethics and Integrity Office at ethics@liv.ac.uk . When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so it can be identified), the researcher(s) involved and the details of the complaint you wish to make.

The University of Liverpool strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 03031201113.

**What do I do next?**

If you would like to participate in this study, please make sure you meet the criteria below, and email Thais Caprioli (PhD student) thais.caprioli@liverpool.ac.uk to schedule a date and time for the remote one-to-one interview.

1. You are working (paid capacity) or helping / volunteering (unpaid capacity) to deliver social support services within the paid or voluntary sector in the UK
2. You are delivering social support services to people living with dementia in who live in the community and/or to informal carers
3. You are either directly involved in delivering social support services to care recipients or you are involved in the management / organisation of the delivery of social support services
4. You are at least 18 years old

**Thank you for reading about our study!**

**Who can I contact if I have further questions?**

Please feel free to contact the study team members on the contact details below:


**Principal Investigator**

Dr Clarissa Giebel

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L69 3GF

0151794996

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**Student investigator**

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**Other study team members**

Dr Stephen Mason

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Prof. Siobhan Reilly

University of Bradford

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**People living with dementia**

**Version 3, Date 13.04.2022**

**Title**: Exploring the facilitators and barriers in accessing and delivering dementia-related social-support services during the COVID-19 pandemic in the UK

**Chief Investigator:** Dr Clarissa Giebel, University of Liverpool/ NIHR ARC NWC

**Co-Investigators:** Dr Stephen Mason, Prof. Siobhan Reilly, and Thais Caprioli

## Participant information sheet – person living with dementia participant

### Invitation Paragraph

You are invited to participate in a research study. Before you decide whether you would like to participate, it is important to understand why we are doing this study and what it will involve. Please do take time to read the following information carefully, and feel free to ask us for more information or if you have any questions. You do not have to take part in our study, only if you would like to. Thank you for reading this.

### What is the purpose of the study?

This study is looking at how the delivery of support services for people living with dementia and carers have been impacted by the corona virus (COVID-19) pandemic. By support services we mean services such as home care, support groups, activity groups and day care, which support people with dementia and carers live well in the community.

We are interested in understanding your experiences of accessing support services during the COVID-19 pandemic. We are interested in understanding

your experiences in accessing both face-to-face or remote (such as through the telephone, online or post) services.

**Why have I been chosen?**

We are inviting people who live with dementia and who may be interested in sharing their experiences of accessing support services before and during the COVID-19 pandemic.

**Do I have to take part?**

No. Taking part in this study is completely voluntary. You can stop taking part in this study without giving any reasons or without experiencing any disadvantages.

**What will happened if I take part?**

This study involves taking part in a remote interview. Interviews will last no longer that 45 minutes. Depending on your preference, the interviews can be done over the telephone or through a video conferencing software (zoom). If you would prefer to conduct the interview over Zoom, you can decide whether you would like to enable the video icon. The PhD student will only enable their video icon if you decide to enable yours.

The interview will be scheduled on a day and time which is convenient for you. If you would like, you may invite a carer / supporter to attend the remote interview.

During the interview, we will ask questions about the types of support services you accessed before and during the COVID-19 pandemic, and how you accessed them. For example, face-to-face or through the telephone or online. We will also ask some general demographic questions (age, gender and ethnic background) and some questions about your dementia.

To help us analyse the information, the interview will be recorded. All data obtained will be annonymised (people will not be able to identify you) and will remain confidential.

**How will my data be used?**

The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of ‘public task’, and in accordance with the University’s purpose of “advancing education, learning and research for the public benefit”.

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The Principal Investigator acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to Dr Clarissa Giebel (clarissa.giebel@liverpool.ac.uk or 0151794996).

Further information on how your data will be used can be found in the table below

| | |
|---|---|
| How will my data be collected? | Through a remote interview (no longer than 45 minutes) that can be completed over Zoom or over the telephone. Zoom will be used to record the audio recording of the interview. Even if you have decided to enable your video during the interview, only the audio recording will be saved. An audio recording device will be used if the interviews are conducted over the telephone. Field notes will be written by the PhD student after the interview. These will remain anonymous and not be disseminated. |
| How will my data be stored? | All interviews will be audio recorded and transcribed. Once transcribed, the audio recordings will be securely deleted. The transcribed interviews and field notes will be anonymised and securely stored on a password-protected University of Liverpool computer (M drive). |
| How long will my data be stored for? | Once the interviews are transcribed, the audio recordings will be securely deleted. The transcribed interviews and field notes will be stored on the University of Liverpool's storage drive (M drive) for ten years, after which it will be deposited into the University of Liverpool's Archive. The University of Liverpool will keep identifiable information about you for 10 years after the study has finished, after which it will be securely destroyed. |
| What measures are in place to protect the | All data obtained will be anonymised (unable to identify you) and kept confidential. You are free to |

| | |
|---|---|
| security and confidentiality of my data? | switch off your camera, but even if it is left on, we will only save the audio file and upload onto the University of Liverpool's storage drive (M drive). As there is no option in Zoom to only record the audio, after uploading and saving the audio file onto the University of Liverpool's storage drive (M drive), all files (video and audio) will be securely deleted from Zoom. An audio recorder will be used if the interviews are conducted over the telephone. Once the audio file is uploaded and stored on to the University of Liverpool's storage drive (M drive), the audio files will be securely deleted from the audio recording device. The audio recording file will be securely stored on a password-protected University of Liverpool computer and the file will be securely deleted once transcribed. The transcribed interviews and field notes will be securely stored on a password-protected University of Liverpool computer. Only the members of this study from the University of Liverpool will have access to your data (Dr Clarissa Giebel, Dr Stephen Mason and Thais Caprioli). Study data and materials may be looked at by individuals from the University of Liverpool for monitoring and auditing purposes. Only authorised persons of this organisation would be able to see the data and would have a duty of confidentiality to anyone taking part in the study. |
| How will my data be anonymised? | Each participant will have an individual code and all identifiable information will be removed from the analysis. This means that we will not be able to identify who participated in the study. |
| How will my data be used? | Your data will help us to understand how social support services have adapted during the COVID-19 pandemic from the care recipient point of view. Findings will be written up for an academic publication and to present |

| | |
|---|---|
| | at conferences. A lay summary will also be written and available. |
| Who will have access to my data? | Only the members of this study from the University of Liverpool will have access to your data (Dr Clarissa Giebel and Dr Stephen Mason) and the PhD student (Thais Caprioli). Study data and materials may be looked at by individuals from the University of Liverpool for monitoring and auditing purposes. Only authorised persons of this organisation would be able to see the data and would have a duty of confidentiality to anyone taking part in the study. |
| Will my data be archived for use in other research projects in the future? | Your data will be archived after ten years |
| How will my data be destroyed? | We will delete the electronic files from the University of Liverpool's storage drive (M drive) once the 10 years storage period has passed. |

**Are there any risks in taking part?**

You will be asked to give up some of your time (no longer than 45 minutes). You can take part in the interview from home, where you will be in your own safe environment. Depending on your preferences, the remote interview can be conducted through the telephone or a video conferencing software (zoom). The questions during the interviews should not cause any distress as they are asking about how you have accessed support services during the COVID-19 pandemic. But if you do feel upset or distressed, please contact anyone from the research study members as soon as possible.

Taking part in this study is voluntary, and you should only take part if you would like to. You do not need to answer any questions you do not want to. You do not need to give us any reasons why and your rights will not be affected. If you do not feel like continuing the interview, the interview will stop, and, if you would like to, the interview can be finished another day. If you should disclose any information that might raise concerns, the PhD student will discuss this with their

supervisory team and the research team reserves the right to contact the local authorities.

**Are there any benefits in taking part?**

You can share your experiences on how you have accessed support services during the COVID-19 pandemic. The information gathered during this study may help to provide some recommendations to policy makers and to help improve the delivery of support services during future public health crises.

To thank you for your time, you will receive a £10 shopping voucher.

**What will happen to the results of the study?**

The audio recordings of the interviews will be transcribed, and securely deleted. To help with the data analysis, anonymised field notes will be written after the interview and will not be shared. Your data will be anonymised and remain confidential. You will not be able to be identifiable from the results.

Findings will be written up for an academic article and presented at conferences. A lay summary will also be written. If you would like, the lay summary of the results can be sent to you by email or through the post.

**What will happen if I want to stop taking part?**

You can stop taking from the study at any time, without needing to give any reasons. If you decide to stop taking part from the study, information you have provided will not be used and will be securely destroyed.

However, you will only be able to withdraw the information you have provided up until one week after the interview. This is because the information is then anonymised, so we will not be able to identify the participants.

Please contact the principal investigator, Dr Clarissa Giebel (clarissa.giebel@liverpool.ac.uk or 0151794996) if you would like to stop taking part in this study.

**What if I am unhappy or if there is a problem?**

If you are unhappy, or if there is a problem, please let us know by contacting the principal investigator Dr Clarissa Giebel (clarissa.giebel@liverpool.ac.uk or 0151794996) and we will try to help. If you are still unhappy or have a complaint which you feel you cannot come to use with, the please contact the Research Ethics and Integrity Office at ethics@liv.ac.uk . When contacting the Research

Ethics and Integrity Office, please provide details of the name or description of the study (so it can be identified), the researcher(s) involved and the details of the complaint you wish to make.

The University of Liverpool strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 03031201113.

**What do I do next?**

If you would like to participate in this study, please make sure you meet the criteria below and email Thais Caprioli (PhD student) thais.caprioli@liverpool.ac.uk.

- You live with dementia
- You live at home / community
- You are at least 18 years old
- You have accessed social support services in the UK before and during the COVID-19 pandemic

**Thank you for reading about our study!**

**Who can I contact if I have further questions?**

Please feel free to contact any of the study team members:

**Principal Investigator**

Dr Clarissa Giebel

University of Liverpool

Waterhouse Building Block B

Brownlow Hill,

Liverpool

L69 3GF

0151794996

Clarissa.Giebel@liverpool.ac.uk

**Student investigator:**

Thais Caprioli

University of Liverpool

Thais.caprioli@liverpool.ac.uk

**Other study team members**

Dr Stephen Mason

University of Liverpool

maceo@liverpool.ac.uk

Prof. Siobhan Reilly

University of Bradford

s.reilly@bradford.ac.uk

**Unpaid carers**

**Version 3**, Date 13.04.2022

**Title**: Exploring the facilitators and barriers in accessing and delivering dementia-related social-support services during the COVID-19 pandemic in the UK

**Chief Investigator:** Dr Clarissa Giebel, University of Liverpool/ NIHR ARC NWC

**Co-Investigators:** Dr Stephen Mason, Prof. Siobhan Reilly and Thais Caprioli

## Participant information sheet – Carer participants

### Invitation Paragraph

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please do take the time to read the following information carefully, and feel free to ask us if you would like more information or if there is anything you do not understand. We would like to stress that you do not have to accept this invitation, and you should only take part if you would like to. Thank you for reading this.

### What is the purpose of the study?

The purpose of this study is to gain an understanding of how social support services for people with dementia and carers (both current and former) have adapted during the corona virus (COVID-19) pandemic. We are interested in exploring your experiences in accessing social support services during the COVID-19 pandemic. By social support services we are referring to non-clinical services to support people with dementia living in their own homes and carers to live well in their communities. Social support services can, for example, include paid home care, day care, support groups and organised social activities and can be provided both within the paid or voluntary sectors.

### Why have I been chosen?

We are inviting all carers (both current and former) to someone living with dementia, who may be interested in sharing their experiences of accessing social support services before and during the COVID-19 pandemic.

### Do I have to take part?

No, taking part in this study is completely voluntary. If you would like to participate in this study, you are free to withdraw your participation at any time, without providing an explanation, and without experiencing any disadvantages.

**What will happened if I take part?**

The study involves taking part in a remote interview which should last no longer than 45 minutes. Depending on your preferences, the remote interview can be conducted over the telephone or through a video conferencing software (zoom). Remote interviews can be completed one-to-one or together, with the person living with dementia (if applicable).

We are interested in understanding how the COVID-19 pandemic has impacted the access to social support services. We will be asking questions about which types of social support services you accessed before and during the COVID-19 pandemic, and how you accessed these. We will also ask some general socio-demographic questions (age, gender and ethnic background) and your relationship with the person living with dementia (if applicable).

We are also interested in your experiences (if applicable) and thoughts on the use of technology to access remote social support services.

This study is conducted by Thais Caprioli (PhD student). The remote interview can be conducted over Zoom or through the telephone. If completing the interview through Zoom, you can decide whether you would like to enable the video icon. The PhD student will only enable their video icon if you decide to enable yours. The date and time of the interview will be scheduled depending on your preferences and availability. To help with the analyses, the interview will be recorded. All data obtained will be annonymised and remain confidential.

**How will my data be used?**

The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of "advancing education, learning and research for the public benefit".

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The Principal Investigator acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to Dr Clarissa Giebel (clarissa.giebel@liverpool.ac.uk or 0151794996).

Further information on how your data will be used can be found in the table below

| | |
|---|---|
| How will my data be collected? | Through a remote interview (no longer than 45 minutes) that can be completed over Zoom or over the telephone. Zoom will be used to record the audio recording of the interview. Even if you have decided to enable your video during the interview, only the audio recording will be saved. An audio recording device will be used if the interviews are conducted over the telephone. Field notes will be written by the PhD student after the interview. These will remain anonymous and not be disseminated. |
| How will my data be stored? | All interviews will be audio recorded and transcribed. Once transcribed, the audio recordings will be securely deleted. The transcribed interviews and field notes will be anonymised and securely stored on a password-protected University of Liverpool computer (M drive). |
| How long will my data be stored for? | Once the interviews are transcribed, the audio recordings will be securely deleted. The transcribed interviews and field notes will be stored on the University of Liverpool's storage drive (M drive) for ten years, after which it will be deposited into the University of Liverpool's Archive. The |

| | |
|---|---|
| | University of Liverpool will keep identifiable information about you for 10 years after the study has finished, after which it will be securely destroyed. |
| What measures are in place to protect the security and confidentiality of my data? | All data obtained will be anonymised (unable to identify you) and kept confidential. You are free to switch off your camera, but even if it is left on, we will only save the audio file and upload onto the University of Liverpool's storage drive (M drive). As there is no option in Zoom to only record the audio, after uploading and saving the audio file onto the University of Liverpool's storage drive (M drive), all files (video and audio) will be securely deleted from Zoom. An audio recorder will be used if the interviews are conducted over the telephone. Once the audio file is uploaded and stored on to the University of Liverpool's storage drive (M drive), the audio files will be securely deleted from the audio recording device. The audio recording file will be securely stored on a password-protected University of Liverpool computer and the file will be securely deleted once transcribed. The transcribed interviews and field notes will be securely stored on a password-protected University of Liverpool computer. Only the members of this study from the University of Liverpool will have access to your data (Dr Clarissa Giebel, Dr Stephen Mason and Thais Caprioli). Study data and materials may be looked at by individuals from the University of Liverpool for monitoring and auditing purposes. Only authorised persons of this organisation would be able to see the data and would have a duty of confidentiality to anyone taking part in the study. |
| How will my data be anonymised? | Each participant will have an individual code and all identifiable information will be removed from the analysis. This means that we will not be able to identify who participated in the study. |
| How will my data be used? | Your data will help us to understand how social support services have adapted during the COVID-19 pandemic. Findings will be written up for academic publication and to present at conferences. A lay summary will also be written and available. |
| Who will have access to my data? | Only the members of this study from the University of Liverpool will have access to your data (Dr Clarissa Giebel and Dr Stephen Mason) and the PhD student (Thais Caprioli). Study data and materials may be looked at by individuals from the University of Liverpool for monitoring and auditing purposes. Only authorised persons of this organisation would be able to see the data and would have a duty of confidentiality to anyone taking part in the study. |
| Will my data be archived for use in other research projects in the future? | Your data will be archived after ten years |

| | |
|---|---|
| How will my data be destroyed? | We will delete the electronic files from the University of Liverpool's storage drive (M drive) once the 10 years storage period has passed. |

**Are there any risks in taking part?**

You will be asked to give up some of your time (no longer than 45 minutes) to attend the remote one-to-one interview. There are no direct risks in participating in this study as you will be able to attend the remote one-to-one interview from anywhere which is convenient for you. Depending on your preferences, the remote one-to-one interview can be completed through Zoom or the telephone. The interviews should not cause any distress as the questions relate to the types of social support services, you are accessing and how you are accessed them before and during the COVID-19 pandemic. However, if you do feel distressed or any experience any disadvantage as part of the research, please contact any of the research study team members immediately. If you would like to stop the interview for any reason, you will be given the opportunity to complete the interview at a later date.

Participation is voluntary, and you are free to stop taking part and can withdraw from the study at any time and decline to answer any questions without giving any reason and without your rights being affected. If you should disclose any information that might raise concerns, the PhD student will discuss this with their supervisory team and the research team reserves the right to contact the local authorities.

**Are there any benefits in taking part?**

By taking part in the study, you can share your experiences in accessing social support services for people living with dementia or carers during the COVID-19 pandemic. The information collected during this study may help to provide policy recommendations to improve the delivery of social support services in dementia care during future public health crises.

As a thank you, each participant will receive a shopping voucher worth £10.

**What will happen to the results of the study?**

The audio recordings of the interviews will be transcribed. Once transcribed, the audio recordings will be securely deleted. To assist data analysis, anonymised field notes will be written after the interview and will not be disseminated. Your data will be anonymised and remain confidential.

You will not be able to be identifiable from the results. Findings will be written up for academic publication and to be presented at conferences. A lay summary will also be written. If you would like, the lay summary of the results can be sent to you by email or through the post.

**What will happen if I want to stop taking part?**

You can withdraw from the study at any time, without providing an explanation. If you decide to withdraw from the study or stop taking part at any time, the information you have provided will be securely destroyed and will not be used. However, there are some limitations as you will only be able to withdraw the information you have provided before the results are annonymised. You may withdraw your data until one week after the interview.

Please contact the principal investigator, Dr Clarissa Giebel (clarissa.giebel@liverpool.ac.uk or 0151794996) if you would like to withdraw from the study.

**What if I am unhappy or if there is a problem?**

If you are unhappy, or if there is a problem, please let us know by contacting the principal investigator Dr Clarissa Giebel (clarissa.giebel@liverpool.ac.uk or 0151794996) and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to use with, the please contact the Research Ethics and Integrity Office at ethics@liv.ac.uk . When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so it can be identified), the researcher(s) involved and the details of the complaint you wish to make.

The University of Liverpool strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 03031201113.

**What do I do next?**

If you would like to participate in this study, please make sure you meet the criteria below, and email Thais Caprioli (PhD student) thais.caprioli@liverpool.ac.uk to schedule a date and time for the remote one-to-one interview.

1. You are either a current or former carer (have or are currently providing unpaid care to a person living with dementia who lives at home / in the community)
2. You are at least 18 years old
3. You have accessed social support services before and during the COVID-19 pandemic in the UK that either addresses a) your needs, b) the needs of the person living with dementia or c) services that addresses both of your needs

**Thank you for reading about our study!**

**Who can I contact if I have further questions?**

Please feel free to contact the study team members on the contact details below:


**Principal Investigator**

Dr Clarissa Giebel

University of Liverpool

Waterhouse Building Block B

Brownlow Hill,

Liverpool

L69 3GF

0151794996

Clarissa.Giebel@liverpool.ac.uk

**Student investigator**

Thais Caprioli (PhD student)

University of Liverpool

**Other study team members**

Dr Stephen Mason

University of Liverpool

maceo@liverpool.ac.uk

Prof. Siobhan Reilly

University of Bradford

**Appendix H** Semi-structured interviews – consent forms

**Social care and support providers**

**Participant consent form - Social support provider participant**

**Version 3,** Date 13.04.2022

**Title:** Exploring the facilitators and barriers in accessing and delivering dementia-related social-support services during the COVID-19 pandemic in the UK

**Name of researcher(s):** Thais Caprioli, Dr Clarissa Giebel, Dr Stephen Mason, Prof. Siobhan Reilly

Please initial box

1. I confirm that I have read and have understood the information sheet dated **13.04.2022** for the above study, or it has been read to me. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that taking part in the study involves completing a one-to-one interview that will last no longer than 45 minutes. The interview can be conducted over Zoom or through the telephone. ☐
3. I understand and agree that my participation will be audio recorded, and I am aware of and consent to your use of these recordings for the following purpose: to analyse the data. Once the data has been transcribed, the audio recordings will be securely destroyed. ☐
4. I understand and agree that field notes will be taken, and I am aware of and consent to your use of the field notes for the following purpose: to analyse the data. The field notes will be anonymised, not be disseminated and stored on the University of Liverpool's M drive. ☐
5. I understand that my participation is voluntary and that I am free to stop taking part and can withdraw from the study at any time without giving any reason and without my rights being affected. In addition, I understand that I am free to decline to answer any particular question or questions. ☐
6. I understand that I can ask for access to the information I provide, and I can request the destruction of that information if I wish at any time prior to anonymisation. I understand that ☐



☐

☐

following anonymisation (one week after the completing the interview) I will no longer be able to request access to or withdrawal of the information I provide.

7. I understand that the information I provide will be held securely and in line with data protection requirements at the University of Liverpool until it is fully anonymised and then deposited in the Archive
8. I understand that signed consent forms, transcriptions and field notes will be retained on the University of Liverpool's M Drive and Dr Clarissa Giebel, Dr Stephen Mason and Thais Caprioli will have access to the data for ten years, after which the data will be deposited in the Archive. ☐
9. I understand that study data and materials may be looked at by individuals from the University of Liverpool for monitoring and auditing purposes. Only authorised persons of this organisation would be able to see the data and would have a duty of confidentiality to anyone taking part in the study ☐
10. I understand that the research team might contact the local authorities if some of the answers might need to be disclosed. ☐
11. I understand and agree that anonymised quotes from the interview may be used in reports and published materials ☐
12. I agree to take part in the above study.

| _____ | _____ | _____ |
|---|---|---|
| Participant name | Date | Signature |
| _____ | _____ | _____ |
| Name of person taking consent | Date | Signature |

**Principal Investigator**

Dr Clarissa Giebel

University of Liverpool

Waterhouse Building Block B

Brownlow Hill,

**Student Investigator**

Thais Caprioli

University of Liverpool

Thais.Caprioli@liverpool.ac.uk

**Other investigators**

Dr Stephen Mason

University of Liverpool

maceo@liverpool.ac.uk

Prof. Siobhan Reilly

University of Bradford

s.reilly@bradford.ac.uk

## Participant consent form – Person living with dementia participant

**Version 3,** 13.04.2022

**Title:** Exploring the facilitators and barriers in accessing and delivering dementia-related social-support services during the COVID-19 pandemic in the UK

**Name of researcher(s):** Thais Caprioli, Dr Clarissa Giebel, Dr Stephen Mason, Prof. Siobhan Reilly

Please initial box

1. I confirm that I have read and have understood the information sheet dated **13.04.2022** for the above study, or it has been read to me. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that taking part in the study involves completing a one-to-one interview that will last no longer than 45 minutes. The interview can be conducted over Zoom or through the telephone. ☐
3. I understand and agree that my participation will be audio recorded, and I am aware of and consent to your use of these recordings for the following purpose: to analyse the data. Once the data has been transcribed, the audio recordings will be securely destroyed. ☐



☐

4. I understand and agree that field notes will be taken, and I am aware of and consent to your use of the field notes for the following purpose: to analyse the data. The field notes will be anonymised, not be disseminated and stored on the University of Liverpool's M drive.

5. I understand that my participation is voluntary and that I am free to stop taking part and can withdraw from the study at any time without giving any reason and without my rights being affected. In addition, I understand that I am free to decline to answer any particular question or questions. ☐

6. I understand that I can ask for access to the information I provide, and I can request the destruction of that information if I wish at any time prior to anonymisation. I understand that following anonymisation (one week after the completing the interview) I will no longer be able to request access to or withdrawal of the information I provide. ☐

7. I understand that the information I provide will be held securely and in line with data protection requirements at the University of Liverpool until it is fully anonymised and then deposited in the Archive. ☐

8. I understand that signed consent forms, transcriptions and field notes will be retained on the University of Liverpool's M Drive and Dr Clarissa Giebel, Dr Stephen Mason and Thais Caprioli will have access to the data for ten years, after which the data will be deposited in the Archive. ☐

9. I understand that study data and materials may be looked at by individuals from the University of Liverpool for monitoring and ☐

auditing purposes. Only authorised persons of this organisation would be able to see the data and would have a duty of confidentiality to anyone taking part in the study ☐

10. I understand that the research team might contact the local authorities if some of the answers might need to be disclosed. ☐

11. I understand and agree that anonymised quotes from the interview may be used in reports and published materials. ☐

12. I agree to take part in the above study.

**Participant name**: _____ **Date**: _____

**Participant signature**: _____

Name of person taking consent: _____ Date: _____

Name of person taking consent signature: _____

**Principal Investigator**

Dr Clarissa Giebel

University of Liverpool

Waterhouse Building Block B

Brownlow Hill,

Liverpool

**Other investigators**

Dr Stephen Mason

University of Liverpool

maceo@liverpool.ac.uk

Prof. Siobhan Reilly

University of Bradford

**Student Investigator**

Thais Caprioli

University of Liverpool

Thais.Caprioli@liverpool.ac.uk

**Unpaid carers**

**Participant consent form – Carer participant**

**Version 3,** Date 13.04.2022

**Title:** Exploring the facilitators and barriers in accessing and delivering dementia-related social-support services during the COVID-19 pandemic in the UK

**Name of researcher(s):** Thais Caprioli, Dr Clarissa Giebel, Dr Stephen Mason, Prof. Siobhan Reilly

Please initial box

1. I confirm that I have read and have understood the information sheet dated **13.04.2022** for the above study, or it has been read to me. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that taking part in the study involves completing a one-to-one interview that will last no longer than 45 minutes. The interview can be conducted over Zoom or through the telephone. ☐
3. I understand and agree that my participation will be audio recorded, and I am aware of and consent to your use of these recordings for the following purpose: to analyse the data. Once the data has been transcribed, the audio recordings will be securely destroyed. ☐
4. I understand and agree that field notes will be taken, and I am aware of and consent to your use of the field notes for the following purpose: to analyse the data. The field notes will be anonymised, not be disseminated and stored on the University of Liverpool's M drive. ☐
5. I understand that my participation is voluntary and that I am free to stop taking part and can withdraw from the study at any time without giving any reason and without my rights being affected. In addition, I understand that I am free to decline to answer any particular question or questions. ☐
6. I understand that I can ask for access to the information I provide, and I can request the destruction of that information if I wish at any time prior to anonymisation. I understand that following anonymisation (one week after completing the interview). I will no longer be able to request access to or withdrawal of the information I provide. ☐
7. I understand that the information I provide will be held securely and in line with data protection requirements at the University of Liverpool until it is fully anonymised and then deposited in the Archive ☐



☐

8. I understand that signed consent forms, transcriptions and field notes will be retained on the University of Liverpool's M Drive and Dr Clarissa Giebel, Dr Stephen Mason and Thais Caprioli will have access to the data for ten years, after which the data will be deposited in the Archive.
9. I understand that study data and materials may be looked at by individuals from the University of Liverpool for monitoring and auditing purposes. Only authorised persons of this organisation would be able to see the data and would have a duty of confidentiality to anyone taking part in the study. ☐
10. I understand that the research team might contact the local authorities if some of the answers might need to be disclosed. ☐
11. I understand and agree that anonymised quotes from the interview may be used in reports and published materials ☐
12. I agree to take part in the above study. ☐

| _____ | _____ | _____ |
|---|---|---|
| Participant name | Date | Signature |
| _____ | _____ | _____ |
| Name of person taking consent | Date | Signature |


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**Appendix I** Summary of the public health measures across the UK at T1 and T2

(Summaries obtained from: England (DHSC, 2021a; Institute for Government analysis, 2021); Scotland: (Scottish Parliament Information Centre, 2022); Wales: (Welsh Parliament, 2021; 2022); Northern Ireland: (The Executive Office 2021a-e).

| **Survey timepoint** | **Months** | **Implemented COVID-19 public health measures** | | | |
|---|---|---|---|---|---|
| | **2021** | **England** | **Scotland** | **Wales** | **Northern Ireland** |
| T1 | March | **29th March**: Outdoor gatherings of either six people or two households allowed. Removal of stay at home order. | | **25th March:** Stay local restrictions removed. | |
| | April | **12th April:** Non-essential retail, hairdressers and public buildings reopen. Outdoor venues reopen. No indoor mixing between different households allowed. | **2nd April:** Local non-essential journeys allowed.<br><br>**5th April**: Hairdressers, garden centres re-open.<br><br>**16th April**: Travel within Scotland for outdoor socialising, recreation and exercise allowed. Outdoor meetings of groups of up to six adults from up to six households. | **12th April: N**on-essential retail opens. Travel from Wales to UK allowed.<br><br>**24th April:** Six people allowed to meet outdoors.<br><br>**26th April:** re-opening of outdoor hospitality and indoor entertainment. Organised outdoor activities for up to 30 people | **23rd April**: Close-contact services and and outdoor attractions re-open.<br><br>**30th of April**: Non-essential retail and outdoor hospitality reopen. Up to 15 people from three households allowed to gather in outdoor domestic settings. |
| | May | **17th May:** A maximum of 30 people allowed to mix outdoors. 'Rule of six' or two households allowed to mix indoors. Indoor venues reopen. | **17th May:** Eased restrictions on hospitality, entertainment and education. In level 2 areas, indoor gatherings of six people from three households allowed. | **3rd May:** Reopening of gyms and leisure centres.<br><br>**17th May**: Six people from six households meet indoors. Re-opening of indoor hospitality and indoor entertainment. Increase number of people who can attend | **24th May:** Indoor hospitality reopens. Six people from two households can mix indoors in domestic settings. Up to 15 people from three households can meet outdoors in a domestic garden. Face |

| | | | | | |
|---|---|---|---|---|---|
| | | | | organised indoor / outdoor activities. | coverings mandatory in indoor public settings. |
| | June | | | **7th June:** Up to 30 people can meet outdoors. Up to three household can form an extended household. Increase number of people allowed to attend organised outdoor gatherings.<br><br>**17th June:** Four weeks pause in easing of restrictions due to new delta variant. | |
| T2 | July | **19th July:** Most legal limits on social contact removed. Final closed sectors of the economy re-open. | **19th July:** Scotland moves to level 0. Physical distancing reduced to one meter indoor / outdoor places. Outdoor gatherings of up to 15 people from five households allowed without physical distancing. Face coverings remain. | **17th July:** Up to six people meet indoors. Increase in the number of people who can attend indoor events. Limit of people attending outdoor events removed. Face coverings remain mandatory in most indoor public places. | **27th of July:** Up to ten people from three households will be allowed to meet indoors in a domestic setting. |
| | August | **16th August:** Fully vaccinated adults no longer required to self-isolate following contact with COVID-19 case | **9th August:** Legal requirement for physical distancing and limits on gatherings removed. Two-meter physical distancing remains in place in health and care settings. Use of face coverings indoors remains. Removal of self-isolation rules for fully vaccinated people who test negative to COVID-19. Work from home advice remains. | **7th August:** Removal of the limit of people meeting indoors. All businesses re-open. Face coverings no longer required in most hospitality nut required in health and care settings and public transport. Fully vaccinated people only need to self-isolate if they develop symptoms or test positive to COVID-19. Work from home advice remains. | **16th August:** People who are fully vaccinated will no longer require to self-isolate for 10 days following contact with a positive COVID-19 case. The limit of people meeting in domestic outdoor settings was removed. |

| | |
|---|---|
| September | **10th September:** Indoor gatherings in domestic settings of 15 people from four households allowed. Removal of table service in indoor / outdoor places. |

## **Appendix J** Longitudinal quantitative survey - measuring tool

**Section 1: Informed consent**

*NOTE: This section explains the aim of this survey and lists the survey criteria you need to meet to be able to participate. Thank you.*

| No. | Questions | Comments | Coding | Answers |
|---|---|---|---|---|
| 1.01 | **Participation information sheet and consent questions copied in full here on JISC Online Surveys** | | | |
| 1.02 | What is the date today? | | *Date format field* | 1. _____ (DD/MM/YYYY) |
| 1.03 | What is your email address?<br><br>*(This will remain confidential. It is only for us to contact you about a further study or to receive the lay summary of the findings from this study – you can indicate your preferences at the end of this survey)* | | | 1. _____ |
| 1.04 | What is the name of the social support service organisation within the paid or voluntary sector you work or help/ volunteer for?<br>*(This will be anonymised and remain confidential; it is just to understand how many social support providers from different organisations are participating)* | | | 1. _____ |

**Section 2: Background information**

| No. | Questions | Comments | Coding | Answers |
|---|---|---|---|---|
| 2.02 | How old are you? | | *Numerical field*<br>*Select one field* | 1. 18 – 24<br>2. 25 – 34<br>3. 35 – 44<br>4. 45 – 54<br>5. 55 – 64<br>6. 65 and over<br>7. Prefer not to say |
| 2.03 | What gender do you identify as? | ***Please select a drop-down option*** | *Select one field* | 1. Female<br>2. Male<br>3. Other<br>4. Prefer not to say |

| | | | | |
|---|---|---|---|---|
| 2.04 | What is your ethnic background? | ***Please select a drop-down option*** | *Select one field*<br>*Text field* | 1. White<br>2. Mixed / Multiple ethnic groups<br>3. Asian / Asian British<br>4. Black / African / Caribbean / Black British<br>5. Prefer not to say<br>6. Other (specify): _____ |
| 2.05 | How many years of full-time education have you completed? *(Add up any part-time education you may have completed)* | ***Please select a drop-down option*** | *Select one field*<br>*Text field* | 1. _____ years<br>2. Prefer not to say |
| 2.06 | How many years have you worked or helped / volunteered as a social support provider? If less than a year, please write '0'. *(This question relates to the overall number of years you have worked and helped/ volunteered to deliver social support services– this can be in different organisations, sectors and services for various care recipients)* | | *Numerical field* | 1. _____ |

**Section 3: Your social support service organisation within the paid or voluntary sector**

| No. | Questions | Comments | Coding | Answers |
|---|---|---|---|---|
| 3.01 | In which sector do you work or help /volunteer as a social support provider? | ***Please select all that apply*** | *Select multiple field* | 1. Private<br>2. Governmental / Public<br>3. Non-governmental organisation<br>4. Not-for-profit organisation<br>5. Prefer not to say<br>6. Other (specify) _____ |
| 3.02 | Please choose an option that best describes your current arrangement with the social support service organisation you work or help /volunteer for | ***Please select a drop-down option*** | *Select one* | 1. Paid work<br>2. Helping /Volunteering (unpaid)<br>3. Other (specify): _____ |

| | | | | |
|---|---|---|---|---|
| 3.03 | In which region are you working or helping / volunteering as a social support provider? | ***Please select a drop-down option*** | *Select one* | 1. East Midlands<br>2. East of England<br>3. Greater London<br>4. North East<br>5. North West<br>6. South East<br>7. South West<br>8. West Midlands<br>9. Yorkshire and the Humber<br>10. Scotland<br>11. Northern Ireland<br>12. Wales<br>13. Other (specify): _____ |
| 3.04 | What is (are) the address (es) where you 'usually' work or help/ volunteer as a social support provider?<br><br>*(By 'usually' we mean the address (es) where you work or help / volunteer as a social support service provider before the COVID-19 pandemic)* | ***This can be the address (es) of a local centre / branch or the place you deliver support services*** | *Text field* | |

**Section 4: Delivery of social support services within the paid or voluntary sector before the COVID-19 pandemic**

*NOTE: This section asks about the social support services you were delivering **BEFORE** the COVID-19 pandemic impacted the delivery of services*

*By 'delivering' we mean social support services you were involved in delivering or organising care to recipients, to either people living with dementia and / or unpaid carers.*

| No. | Questions | Comments | Coding | Answers |
|---|---|---|---|---|
| 4.01 | Were you delivering social support services before the COVID-19 pandemic? | ***Please select a drop-down option*** | *Select one field*<br><br>If '2. No' selected -> Q. 5.1 | 1. Yes<br>2. No |
| 4.02 | How many hours a week did you work or help /volunteer as a social support provider before the COVID-19 pandemic? | ***Please estimate*** | | 1. _____ hours |
| 4.03 | Which types of social support services were you | ***Please select all that apply*** | *Select multiple* | 1. Paid home care<br>2. Support groups<br>3. Respite care |

| | | | | |
|---|---|---|---|---|
| | delivering before the COVID-19 pandemic? | | | 4. Day care centre<br>5. Home meal delivery<br>6. Transport<br>7. Accompanying / befriending<br>8. Social activities<br>9. Other (specify): _____ |
| 4.04 | Which type of social support service were you <u>primarily</u> delivering before the COVID-19 pandemic? | ***Please select a drop-down option*** | *Select one field* | 1. Paid home care<br>2. Support groups<br>3. Respite care<br>4. Day care centre<br>5. Home meal delivery<br>6. Transport<br>7. Accompanying / befriending<br>8. Social activities<br>9. Other (specify): _____ |

NOTE: The following questions relate to the type of social support service you were <u>primarily</u> delivering **BEFORE** the COVID-19 pandemic impacted the delivery of services.

Please combine your answers if you were delivering multiple social support services within the type of social support service you were <u>primarily</u> delivering

| | | | | |
|---|---|---|---|---|
| 4.05 | Who were the care recipients of this social support service? | ***Please select a drop-down option*** | | 1. People living with dementia<br>2. Current / former informal carers<br>3. Both - people living with dementia and current / former informal carers |
| 4.05 | How was this social support service delivered before the COVID-19 pandemic? | ***Please select all that apply*** | *Select multiple* | 1. In person – one-to-one<br>2. In person – group format<br>3. Remotely (e.g., telephone / online etc) - one-to-one format<br>4. Remotely (e.g., telephone / online etc) - group format<br>5. Other (specify) _____ |
| 4.06 | On average, how many care recipients attended each in-person session before the COVID-19 pandemic? *(if the social support service* | ***Please estimate*** | *Numerical field* | 1. _____ |

| | | | | |
|---|---|---|---|---|
| | *not delivered in-person, please write '0')* | | | |
| 4.07 | On average, how many care recipients attended each remote session before the COVID-19 pandemic? *(if the social support service was not delivered remotely, please write '0')* | ***Please estimate*** | *Numerical field* | 1. _____ |
| 4.08 | During a regular month, how many care recipients accessed this social support service before the COVID-19 pandemic? | ***Please estimate*** | *Numerical field* | 1. _____ |
| 4.09 | During a regular month, how often was this social support service delivered before the COVID-19 pandemic? | ***Please estimate*** | | 1. _____ times |
| 4.10 | During a regular month, how often was this social support service delivered remotely before the COVID-19 pandemic? | ***Please select a drop-down option*** | *Select one field* | 1. Never – service was not delivered remotely<br>2. Sometimes<br>3. Often<br>4. All the time |
| 4.11 | Which formats were used to deliver this social support service remotely before the COVID-19 pandemic? | ***Please select all that apply*** | *Select multiple* | 1. N/A - Service not delivered remotely<br>2. Telephone calls<br>3. Videoconferencing calls (e.g. Zoom / Skype)<br>4. Letters<br>5. e-mail<br>6. Text messaging<br>7. Resources on a website<br>8. E-Learning<br>9. Social Media<br>10. Mobile Applications (Apps)<br>11. Internet portals<br>12. Internet forums<br>13. Other (specify): _____ |
| 4.12 | Before the COVID-19 pandemic, how satisfied were you with the delivery of this social support service? | ***Please select a drop-down option*** | | 1. Very satisfied<br>2. Fairly satisfied<br>3. Not satisfied |

**Section 5: Delivery of social support services within the paid or voluntary sector during the COVID-19 pandemic**

*NOTE: This section asks about social support services you are delivering, at the time of completing this survey,* ***DURING*** *the COVID-19 pandemic impacted the delivery of the services*

*By 'delivering' we mean social support services you are involved in delivering or organising care to recipients, to either people living with dementia and / or informal carers.*

| No. | Questions | Comments | Coding | Answers |
|---|---|---|---|---|
| 5.01 | At the time of completing this survey, are you delivering any social support services? | ***Please select a drop-down option*** | *Select one field*<br><br>*If '2. No' selected -> Q. 6.1* | 1. Yes<br>2. No |
| 5.02 | How many hours a week do you work or help /volunteer as a social support provider during the COVID-19 pandemic? | ***Please estimate*** | | 1. _____ hours |
| 5.03 | Was there a period during the COVID-19 pandemic when you were not delivering any social support services? | ***Please select a drop-down option*** | *Select one field* | 1. Yes<br>2. No |
| 5.04 | How many weeks were you not delivering any social support services during the COVID-19 pandemic? | ***Please estimate*** | *If selected '1. Yes', in Q 5.03* | 1. _____ (weeks) |
| 5.05 | At the time of completing this survey, which types of social support services are you delivering? | ***Please select all that apply*** | *Select multiple* | 1. Paid home care<br>2. Support groups<br>3. Respite care<br>4. Day care centre<br>5. Home meal delivery<br>6. Transport<br>7. Accompanying / befriending<br>8. Social activities<br>9. Other (Specify): _____ |
| 5.06 | At the time of completing this survey, which type of social support service are you primarily delivering? | ***Please select a drop-down option*** | *Select one field* | 1. Paid home care<br>2. Support groups<br>3. Respite care<br>4. Day care centre<br>5. Home meal delivery<br>6. Transport<br>7. Accompanying / befriending<br>8. Social activities<br>9. Other (specify): |

_____

NOTE: The following questions relate to the social support service you are **primarily** delivering at the time of completing this survey, **DURING** the COVID-19 pandemic.

Please combine your answers if you are delivering multiple support services within the type of support service you are **primarily** delivering

| | | | |
|---|---|---|---|
| 5.07 | Who are the care recipients of this social support service? | ***Please select a drop-down option*** | 1. People living with dementia<br>2. Current / former informal carers<br>3. Both people living with dementia and current / former informal carers |
| 5.08 | At the time of completing this survey, how is this social support service delivered? | ***Please select all that apply*** | 1. In person – one-to-one<br>2. In person – group format<br>3. Remotely (e.g., telephone / online etc) - one-to-one format<br>4. Remotely (e.g., telephone / online etc) - group format<br>5. Other (specify):<br>_____ |
| 5.09 | At the time of completing this survey, are any additional COVID-19 measures in place whilst delivering this social support service? | ***Please select all that apply*** | 1. N/A - Service only delivered Remotely<br>2. Care recipients to provide contact details (track and trace)<br>3. Wearing PPE<br>4. Minimise contact with care recipient<br>5. Shorter time spent with care recipient<br>6. Social distancing<br>7. Care recipients to bring their own food / drink<br>8. Organising different activities<br>9. Support service providers have received the COVID-19 vaccine<br>10. Care recipients have received the COVID-19 vaccine<br>11. Other (specify):<br>_____<br>12. No additional measures |
| 5.10 | At the time of completing this survey, how many care | ***Please estimate*** | 1. _____ |

| | | | | |
|---|---|---|---|---|
| | recipients, on average, attend each in-person session? *(If the social support service not currently delivered in-person, write '0')* | | | |
| 5.11 | At the time of completing this survey, how many care recipients, on average, attend each remote session? *(If the social support service not currently delivered remotely, write '0')* | ***Please estimate*** | | 1. _____ |
| 5.12 | At the time of completing this survey, how many care recipients access this social support service during a regular month? | ***Please estimate*** | | 1. _____ |
| 5.13 | At the time of completing this survey, how often is this social support service delivered during a regular month? | ***Please estimate*** | | 1. _____ times |
| 5.14 | At the time of completing this survey, how often is this social support service delivered remotely during a regular month? | ***Please select a drop-down option*** | *Select one field* | 1. Never – service not delivered remotely<br>2. Sometimes<br>3. Often<br>4. All the time |
| 5.15 | At the time of completing this survey, which formats are used to deliver this social support service remotely? | ***Please select all that apply*** | *Select multiple*<br>*Text field* | 1. N/A - Service not delivered remotely<br>2. Telephone calls<br>3. Videoconferencing calls (e.g. Zoom / Skype)<br>4. Letters<br>5. e-mail<br>6. Text messaging<br>7. Resources on a website<br>8. E-Learning<br>9. Social Media<br>10. Mobile Applications (Apps)<br>11. Internet portals<br>12. Internet forums<br>13. Other (specify): _____ |
| 5.16 | At the time of completing this survey, how satisfied are you with the delivery of this social support service? | ***Please select a drop-down option*** | | 1. Very satisfied<br>2. Fairly satisfied<br>3. Not satisfied |

**Section 6: Receiving further information**

| No. | Questions | Comments | Coding | Answers |
|---|---|---|---|---|
| 6.01 | We are planning to conduct interviews to explore the views and experiences in delivering social support services during the COVID-19 pandemic.<br><br>Would you like to be contacted to receive further information on our upcoming study? | ***Please select a drop-down option*** | *Select one field* | 1. Yes – I am happy to receive information on the upcoming study<br>2. No – I would not like to receive information on the upcoming study |
| 6.02 | Would you like to receive a lay summary of the findings from this study via email? | ***Please select a drop-down option*** | | 1. Yes – I would like to receive a lay summary of the findings via email<br>2. Yes – I would like to receive a lay summary of the findings via post<br>3. No – I would not like to receive a lay summary of the findings |

*NOTE: Thank you very much for completing this survey!*

*The shopping voucher prizes will be drawn once all the data has been collected - we will contact the winner!*

## **Appendix K** Semi-structured interviews – topic guides

### Social care and support providers

Q1. Tell me a little bit about yourself, how did you start working or helping to deliver support services for people living with dementia and carers?

Q2. Could you tell me about the types of support services you were delivering before the COVID-19 pandemic? How were these support services delivered?

Q3. And what about during the COVID-19 pandemic, could you tell me about the types of support services you delivered during the pandemic?

Q4. Throughout the COVID-19 pandemic, has the delivery method of the support services you delivered changed? If so, how?

Q5. What were some of the positive aspects, if any, of delivering support services during the COVID-19 pandemic, and what were the downsides and barriers?

Q6. As the public health restrictions ease, how have the support services you deliver re-started? How do you plan to deliver support services in the future?

Q7. What advice would you give to someone delivering support services in dementia care in a future public health crisis?

Q8. Either before or during the COVID-19 pandemic, have you used technology to deliver support services? If so, how have you used technology and for which types of services?

Q9. Is there anything else you would like to add?

IF APPLICABLE:

Q10. How did you find transitioning from delivering in-person to remote support services? And how long did it take to initially set up the remote support services?

Q11. What were some of the positive aspects, if any, of using technology to deliver support services, and what were the downsides and barriers?

Q12. What are your thoughts on using technology to deliver support services in dementia care in the future?

**Service recipients**

Q1. Tell me a little about yourself, what type of support service do you find most helpful?

Q2. Could you tell me a little bit about the types of support services you accessed before the COVID-19 pandemic? How were you accessing these?

Q3. And what about during the COVID-19 pandemic, what types of support services are you accessing? How are you accessing these? How has this changed throughout the COVID-19 pandemic?

Q4. How have you found accessing support services during the COVID-19 pandemic? Was it easier, harder, or like before the COVID-19 pandemic?

Q5. What changes would you like so see in the delivery of support services in future public health crises or pandemics?

Q6. Have you ever accessed support services remotely, for example by the using the telephone or the computer?

Q7. Is there anything else you would like to add?

IF APPLICABLE

Q8. How have you found accessing support services remotely? What are the good and the not so good aspects of accessing support services remotely?

## **Appendix L** Longitudinal quantitative survey – data management protocol

The online survey was set-up on Jisc Online Survey. Data was downloaded from Jisc Online Surveys and exported into Microsoft Excel (version 2308). A raw copy of the dataset was stored, on a password-controlled Microsoft Excel (version 2308) spreadsheet on the University of Liverpool's storage system (M Drive). Once a raw copy of the dataset was stored, all data from Jisc Online Surveys was securely deleted. A clean copy of the dataset, including a summary of all changes made and rationales to making them, is stored in a password-controlled Microsoft Excel (version 2308) spreadsheet on the M Drive. Each participant was given an individual code, and all identifiable information was removed in the analysis, published paper, and lay summary.

Only study members from the University of Liverpool had access to participants' data. Study data and materials may be looked at by individuals from the University of Liverpool for monitoring and auditing purposes. Only authorised persons of the University of Liverpool were able to see the data and have a duty of confidentiality to anyone taking part in the study.

Data will be stored on the M Drive for ten years, after which it will be deposited into the University of Liverpool's Archive. Data obtained and may be shared and used by other authorised researchers to support future research. The University of Liverpool will keep identifiable information about participants for 10 years after the study has finished, after which it will be securely destroyed.

## **Appendix M** Semi-structured interviews – data management protocol

When recording a meeting on Zoom, the function automatically creates two files, one audio and visual recording, and one solely audio recording. The combined audio and visual recording were securely deleted from Zoom. The audio recordings were downloaded from Zoom and stored onto the Liverpool University's storage platform (M Drive). Once downloaded, all audio recordings were securely deleted from Zoom. When an audio recording device was used (Philips Voice Tracker), the audio file was transferred onto a University of Liverpool computer using a USB cable and saved on the M Drive. Once transferred, the audio file was securely deleted from the audio recording device.

All interviews were transcribed verbatim. I transcribed a third of the interviews, and the remainder were transcribed by a known professional transcription agency. Once transcribed, all audio-recordings were securely deleted from the M Drive. Transcripts and field notes were anonymised and stored on a password-controlled word document on the M Drive. These will be stored on the M Drive for ten years, after which it will be deposited into the University of Liverpool's Archive and securely deleted from the M Drive. Each participant was given an individual code, and all identifiable information was removed in the analysis, written paper, and lay summary.

Only study members of this study from the University of Liverpool had access to the data. Study data and materials may be looked at by individuals from the University of Liverpool for monitoring and auditing purposes. Only authorised persons of this organisation was able to see the data and have a duty of confidentiality to anyone taking part in the study.

## **Appendix N** Semi-structured interviews - debriefing protocol

If a participant becomes distressed or upset during the interview, the interview will pause. The PhD student will provide support, and the interview will only resume if the participant is happy to do so. If not, the participant will be given the opportunity to continue the interview at a later date. The debriefing forms will be shared and if the participants continue to feel distressed, the Ph.D. student will advise them to contact their GP at the first instance. The debriefing forms include the contact details of dementia related organisations / associations.

**Detailed distress protocol**

1. If a participant should become distressed during the interview, the interview will pause and the audio recorder / Zoom recording will be turned off. The Ph.D. student will suggest for the participant to take 5-10-minute break and offer to talk through any issues that have been raised.
2. The interview will only continue if the participant is happy to do so.
3. After the interview, either stopped prematurely or after completion, the Ph.D. student will direct the participant to the participant information sheet again as well as a stand-alone debriefing sheet which contains details of dementia related organisations / associations. This is so the participant can contact organisations and support networks.
4. The Ph.D. student will offer to schedule a follow-up call the next day to talk through any issues which have been raised during the interview.

The Ph.D. student will have the opportunity to debrief with senior members of the research team if they should feel upset or distressed following an interview and can contact their primary supervisor directly. The Ph.D. student has shadowed a post-doctoral researcher conduct remote interviews and had discussed with several experienced researchers how they have diffused situations when participants became distressed during interviews.

**Appendix O** Semi-structured interview - debriefing forms

**Social care and support providers**

**Title:** Exploring the facilitators and barriers in accessing and delivering dementia-related social-support services during the COVID-19 pandemic in the UK

**DEBRIEFING DOCUMENT – social support provider participants**

**Version 1,** Date 05.01.2022

If you feel distressed or concerned after taking part in the interview, or if you have any further questions, please do not hesitate to contact me or the principal investigdetor.

**Thais Caprioli (PhD student)**

**Email: Thais.caprioli@liverpool.ac.uk**

**Dr Clarissa Giebel (Principal Investigator)**

**Tel.: 01517949966, Email: clarissa.giebel@liverpool.ac.uk**

For more general concerns or issues raised relating to delivering social support services during the COVID-19 pandemic, please contact your GP.

**Service recipients**

**Version 1,** Date 05.01.2022.

**Title:** Exploring the facilitators and barriers in accessing and delivering dementia-related social-support services during the COVID-19 pandemic in the UK

## DEBRIEFING DOCUMENT – People living with dementia and carer participants

If you feel distressed or concerned after taking part in the interview, or if you have any further questions, please do not hesitate to contact me or the principal investigator.

**Thais Caprioli (PhD student)**

**Email: thais.caprioli@liverpool.ac.uk**

**Dr Clarissa Giebel (Principal Investigator)**

**Tel.: 0151 794 9966, Email: Clarissa.giebel@liverpool.ac.uk**

For more general concerns relating to your dementia or your caring role, or about any issues raised concerning access to social support services during the COVID-19 pandemic, please contact your GP, or any of the services listed below:

**National Dementia Helpline** (Mon-Fri 9am – 5pm, Sat & Sun 10am – 4pm):Tel.: 0300 222 1122

**Dementia Information Line** (Mon-Sun 8am – 7pm):

Tel.: 0844 887 0005

**TIDE Carers:**

Tel.: 0151 237 2669; Email: carers@tide.uk.net; Website: https://www.tide.uk.net/

**Alzheimer's Society Dementia Connect support line:**

Tel.: 0333 150 3456

**NHS Carers Direct Helpline** (Mon – Fri 9am – 8pm, Sat & Sun 11am – 4pm): Tel.: 0300 123 1053

**Carers UK Advice Line**:

Tel.: 0800 808 7777

## **Appendix P** Initial analysis of the longitudinal quantitative survey

### Survey completion

A total of 75 participants completed the survey at T1, and 58 participants completed the survey at both timepoints. As outlined in **Figure 8**, following the cleaning of the data sets, a total of 27 (36.0%) participants had complete data entries at T1, and 11 (18.7%) participants at all survey timepoints. Only participants with complete data entries were included in the analysis.

The uppermost boxes indicate the number of participants who completed the survey at each timepoint.

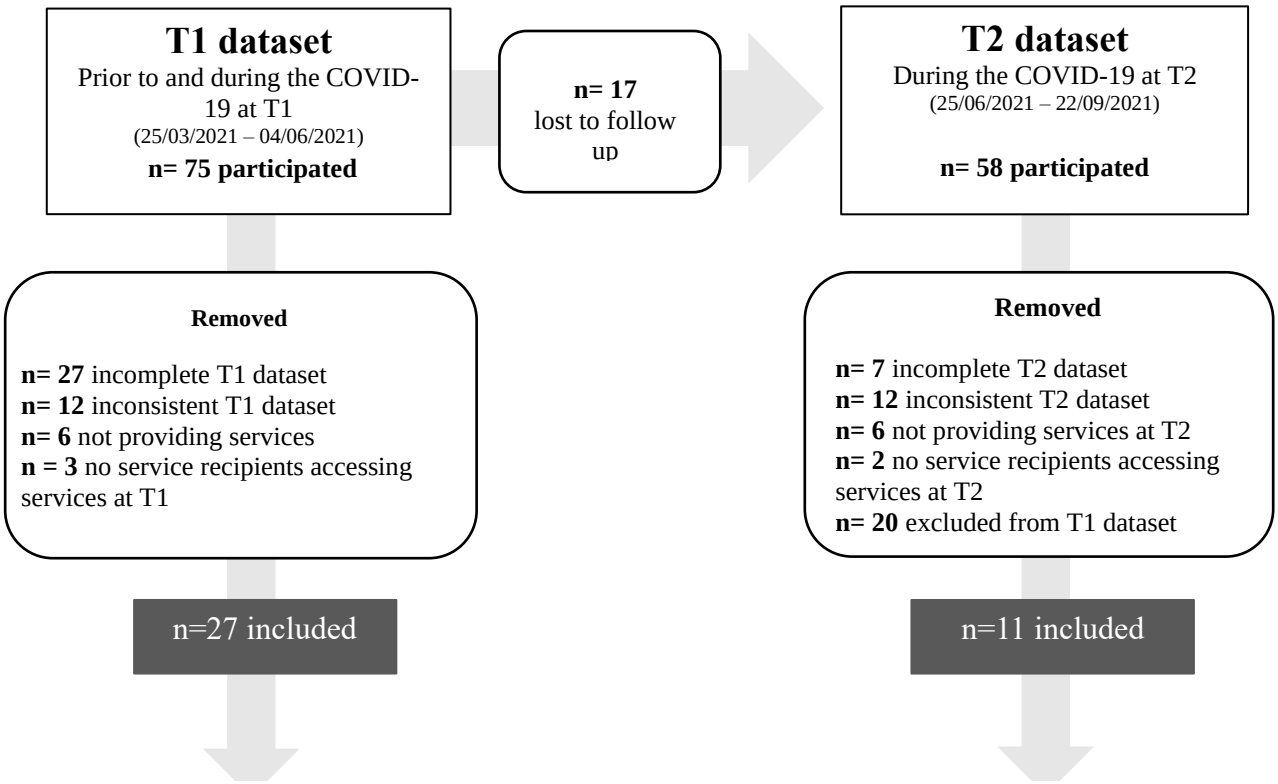



**Figure 8** Flowchart depicting participation flow and completion rates during the longitudinal study in the initial analysis

Following the removal of (1) incomplete data entries (missing responses), (2) inconsistent data entries (contradicting responses within the same data entry), (3) participants not delivering social support services, (4) no service recipients accessing social support services (5) losses to follow up (participants who did not complete the survey at both time points), a total of 27 participants has complete data at T1 and 11 participants had complete data at both survey timepoints.

### Participant and provider characteristics

Most participants identified as female, White and at least thirty-five years old. Participants mainly delivered services in a paid capacity, within the Third sector and in areas classified within the third and fifth IMD quintiles (**Table 30**).

**Table 30** Participant socio-demographic characteristics in the initial analysis (T1: n=27; T2: n=11)

| n (%) | **T1 dataset n=27** | **T2 dataset n=11** |
|---|---|---|
| **Gender** | | |
| Female | 21 (77.8) | 9 (81.8) |
| Male | 6 (22.2) | 2 (18.2) |
| **Age group** | | |
| 25-34 | 1 (3.7) | 1 (9.1) |
| 35-44 | 5 (18.5) | 2 (18.2) |
| 45-54 | 4 (14.8) | 1 (9.1) |
| 55-64 | 9 (33.3) | 3 (27.3) |
| 65 and over | 8 (29.6) | 4 (36.4) |
| **Ethnicity** | | |
| White | 25 (92.6) | 10 (90.9) |
| Mixed / multiple ethnic groups | 2 (7.4) | 1 (9.1) |
| **Sector** | | |
| Public | 2 (7.4) | 2 (18.2) |
| Private | 1 (3.7) | - |
| Third sector | 24 (88.9) | 9 (81.8) |
| **Contractual arrangement** | | |
| Paid | 18 (66.7) | 7 (63.6) |
| Unpaid | 9 (33.3) | 4 (36.4) |
| **Region** | | |
| East of England | 3 (11.1) | 2 (18.2) |
| Greater London | 3 (11.1) | 1 (9.1) |
| North East | 1 (3.7) | 0 (0.0) |
| North West | 5 (18.5) | 1 (9.1) |
| South East | 3 (11.1) | 0 (0.0) |
| South West | 5 (18.5) | 3 (27.3) |
| West Midlands | 4 (14.8) | 2 (18.2) |
| Yorkshire and Humber | 3 (11.1) | 2 (18.2) |
| **IMD quintile of service provision area** | | |
| 1 | 5 (18.5) | 1 (9.1) |
| 2 | 5 (18.5) | 2 (18.2) |
| 3 | 5 (18.5) | 4 (36.4) |
| 4 | 4 (14.8) | 1 (9.1) |
| 5 | 8 (29.6) | 3 (27.3) |
| **Years full-time education** | | |
| Median (range) | 15 (4-21) | 15 (7-20) |
| **Years working/ volunteering as a social support provider[α]** | | |
| Median (range) | 10 (1.5-42) | 12 (1.5-35) |

[α] Refers to the cumulative number of years working / volunteering to deliver social support services to any service recipients, not necessarily within dementia care.

Compared to prior to the pandemic, the number of hours worked / volunteered decreased during the pandemic at T1 (median (range): prior COVID-19: 24 (2-50); T1: 18 (1-50)). The hours worked / volunteered at T1 and T2 remained similar (median (range): prior COVID-19: 30 (2-38); T1: 28 (2-37.5); T2: 28 (1.5-45)). A total of 9 participants (33.3%) paused service delivery at the beginning of the pandemic (median:6 weeks, range:2-45weeks).

### Service provision prior to and during the pandemic

Participants delivered a median of two services across all survey timepoints. Social activities and support groups were most delivered services (**Table 32**).

*Types of primary services delivered*

A total of 21 participants (77.8%) delivered the same primary service prior to the pandemic and at T1. Eight participants (72.7%) delivered the same primary services across all survey timepoints. Support groups, day care centres and social activities were the most delivered primary services across survey timepoints. Services were mainly delivered to people with dementia and unpaid carers ( **Table 31** and **Table 32**).

*Delivery methods and formats employed to deliver primary services*

Prior to the pandemic, most services were delivered in-person, in a group format. However, some services, either as part of hybrid or remotely delivered service delivery methods, did deliver one-to-one services remotely. During the pandemic at T1, a shift from in-person to remote or hybrid service delivery methods was observed. Either as part of hybrid or remotely delivered services, the delivery of remote group-based services increased at T1 (**Table 31**). At T2, the number of in-person services slightly increased, but most services were hybrid (**Table 32**).

Prior to the pandemic, some participants delivered services by telephone calls (n=4 (36.4%)), emails (n=4 (36.4%)), and resources on a website (n=3 (27.3%)) (**Figure 9**). The number of participants using formats to remotely deliver services increased at T1, notably the use of videoconferencing software (Prior COVID-19: n=1 (9.1%); T1: n=7 (63.6%)). At T1, hybrid or remote services mostly delivered by videoconferencing software were support groups, advice, information and support and social activities (**Table 33**). Telephone calls (n=6 (54.5%)) and videoconferencing software (n=4 (36.4%)) remained the most employed formats at T2 (**Figure 9**).

**Table 31** A summary of primary services delivered, service recipients and usage per delivery method prior to the pandemic and at T1 (n=27) in the initial analysis

| | Prior COVID-19 n=27 (n (%)) | | | | T1 n=27 (n (%)) | | | |
|---|---|---|---|---|---|---|---|---|
| | **In person (n=19)** | **Hybrid (n=7)** | **Remotely (n=1)** | **Total (n=27)** | **In person (n=3)** | **Hybrid (n=11)** | **Remotely (n=13)** | **Total (n=27)** |
| **Primary services delivered** | | | | | | | | |
| Accompanying/ befriending | - | 1 (14.3) | - | 1 (3.7) | - | 2 (18.2) | 1 (7.8) | 3 (11.1) |
| Advice, support and information | - | 3 (42.9) | 1 (100.0) | 4 (14.8) | - | 2 (18.2) | 1 (7.8) | 3 (11.1) |
| Day care centre | 6 (31.6) | - | - | 6 (2.4) | 3 (100) | 2 (18.2) | - | 5 (18.5) |
| Social activities | 5 (26.3) | 2 (28.6) | - | 7 (25.9) | - | 2 (18.2) | 6 (46.2) | 8 (29.6) |
| Support groups | 8 (42.1) | 1 (14.3) | - | 9 (33.3) | - | 3 (16.7) | 5 (38.5) | 8 (29.6) |
| **Service recipients of primary services** | | | | | | | | |
| Unpaid carer (current / former) | - | - | - | - | - | - | 1 (7.7) | 1 (3.7) |
| Person with dementia | 6 (31.6) | - | - | 6 (22.2) | 1 (33.3) | 1 (9.1) | 1 (7.7) | 3 (11.1) |
| Both | 13 (68.4) | 7 (100.0) | 1 (100.0) | 21 (77.8) | 2 (66.7) | 10 (90.1) | 11 (84.6) | 23 (85.2) |
| **Format of primary services** [α] | | | | | | | | |
| In-person – one-to-one | 2 (10.5) | 5 (71.4) | - | 7 (25.9) | 1 (33.3) | 6 (54.5) | - | 7 (25.9) |
| In-person – group format | 19 (100.0) | 5 (71.4) | - | 24 (88.9) | 3 (100.0) | 6 (54.5) | - | 9 (33.3) |
| Remote – one-to-one | - | 7 (100.0) | 1 (100.0) | 8 (29.6) | - | 10 (90.1) | 7 (53.8) | 17 (63.0) |
| Remote – group format | - | 2 (28.6) | - | 2 (7.4) | - | 7 (63.6) | 10 (76.9) | 17 (63.0) |
| **How often primary services were delivered remotely** [β] | | | | | | | | |
| Never | 19 (100.0) | - | - | 19 (70.4) | 3 (100.0) | - | - | 3 (11.1) |
| Sometimes | - | 6 (85.7) | - | 6 (22.2) | - | 5 (45.6) | 2 (15.4) | 7 (25.9) |
| Often | - | 1 (14.3) | - | 1 (3.7) | - | 6 (54.5) | 1 (7.7) | 7 (25.9) |
| All of the time | - | - | 1 (100.0) | 1 (3.7) | - | - | 10 (76.9) | 10 (37.0) |
| **Satisfaction with primary service delivery** | | | | | | | | |
| Very satisfied | 16 (84.2) | 5 (71.4) | 1 (100.0) | 22 (81.5) | 1 (33.3) | 3 (16.7) | 4 (30.7) | 8 (29.6) |
| Fairly satisfied | 3 (15.8) | 2 (28.6) | - | 5 (18.5) | 2 (66.7) | 8 (72.7) | 8 (61.5) | 18 (66.7) |
| Not satisfied | - | - | - | - | - | - | 1 (7.8) | 1 (3.7) |
| **Average number of times primary services were delivered** [β] | | | | | | | | |
| Median (range) | 8 (1-40) | 4 (1-25) | 24 | 6 (1-40) | 20 (20-21) | 4 (1-20) | 4 (1.5-30) | 4 (1-30) |
| **Average number of service recipients accessed primary services** [β] | | | | | | | | |
| Median (range) | 30 (6 -800) | 35 (12 – 100) | 100 | 30 (6-800) | 13 (7-24) | 25 (3-100) | 30 (4-300) | 24 (3-300) |

[α] Participants could select multiple options. [β] During a regular month

**Table 32** An overall longitudinal summary of primary services delivered, service recipients and usage prior to the pandemic, T1 and T2 (n=11) in the initial analysis

| | **Prior COVID-19 (n=11) (n (%))** | **T1 (n=11) (n (%))** | **T2 (n=11) (n (%))** |
|---|---|---|---|
| **All services delivered** [α] | | | |
| Accompanying/ befriending | 3 (27.3) | 3 (27.3) | 3 (27.3) |
| Advice, support and information | 1 (9.1) | 1 (9.1) | 1 (9.1) |
| Day care centre | 4 (36.4) | 3 (27.3) | 3 (27.3) |
| Home meal delivery | - | - | - |
| Paid home care | 1 (9.1) | 1 (9.1) | - |
| Respite care | 2 (18.2) | - | - |
| Social activities | 8 (72.7) | 8 (72.7) | 6 (54.5) |
| Support groups | 8 (72.7) | 7 (63.6) | 9 (81.8) |
| Transport | 1 (9.1) | - | 1 (9.1) |
| **Average number of services delivered per participant** | | | |
| Median (range) | 2 (1-5) | 2 (1-4) | 2 (1-4) |
| **Primary services delivered** | | | |
| Accompanying/ befriending | - | - | 1 (8.3) |
| Advice, support and information | 1 (9.1) | 1 (9.1) | - |
| Day care centre | 3 (27.3) | 3 (27.3) | 3 (27.3) |
| Social activities | 3 (27.3) | 3 (27.3) | 3 (27.3) |
| Support groups | 4 (36.4) | 4 (36.4) | 4 (36.4) |
| **Service recipients of primary services** | | | |
| Unpaid carer (current / former) | - | - | - |
| Person with dementia | 3 (27.3) | 1 (9.1) | 2 (18.2) |
| Both | 8 (72.7) | 10 (90.9) | 9 (81.8) |
| **Primary services delivery methods** | | | |
| In person | 7 (63.6) | 1 (9.1) | 3 (27.3) |
| Hybrid | 4 (36.4) | 7 (63.6) | 6 (54.5) |
| Remotely | - | 3 (27.3) | 2 (18.2) |
| **How often primary services were delivered remotely** [β] | | | |

| | | | |
|---|---|---|---|
| Never | 7 (63.6) | 1 (9.1) | 3 (27.3) |
| Sometimes | 3 (27.3) | 3 (27.3) | 1 (9.1) |
| Often | 1 (9.1) | 5 (45.5) | 5 (45.5) |
| All of the time | - | 2 (18.2) | 2 (18.2) |
| **Overall satisfaction with primary service delivery** | | | |
| Very satisfied | 7 (63.6) | 2 (18.2) | 6 (54.5) |
| Fairly satisfied | 4 (36.4)) | 9 (81.8) | 5 (45.5) |
| Not satisfied | - | - | - |
| **Average number of times primary services were delivered** [β] | | | |
| Median (range) | 7 (1-25) | 6 (2-20) | 8 (2-46) |
| **Average number of service recipients accessed primary services** [β] | | | |
| Median (range) | 40 (6-180) | 25 (4 –120) | 26.5 (5-104) |

[α] Participants could select multiple options. [β] During a regular month

**Table 33** Formats employed per hybrid or remote primary service at T1 (n=24) in the initial analysis (overall dataset n=27)

| | Accompanying/ Befriending | Advice, information and support | Day care centre | Social activities | Support groups | Total |
|---|---|---|---|---|---|---|
| | n=3 | n=3 | n=2 | n=8 | n=8 | n=24 |
| **Formats employed to deliver primary services remotely** [α] | | | | | | |
| e-learning | 1 (33.3) | - | - | - | - | 1 (4.2) |
| e-mail | 2 (66.7) | 3 (100.0) | - | 6 (75.0) | 3 (37.5) | 14 (58.3) |
| Internet forum | - | - | 1 (50.0) | - | - | 1 (4.2) |
| Internet portal | - | - | 1 (50.0) | - | - | 1 (4.2) |
| Mobile application | - | - | - | - | 1 (12.5) | 1 (4.2) |
| Post | 2 (66.7) | 3 (100.0) | - | 2 (25.0) | 1 (12.5) | 8 (33.3) |
| Social media | - | 1 (33.3) | - | 1 (12.5) | 1 (12.5) | 3 (12.5) |
| Telephone calls | 3 (100.0) | 3 (100.0) | 2 (100.0) | 7 (87.5) | 4 (50.0) | 19 (79.2) |
| Text messaging | 2 (66.7) | 2 (66.7) | 1 (50.0) | - | 2 (25.0) | 7 (29.2) |
| Videoconferencing | 1 (33.3) | 3 (100.0) | 1 (50.0) | 6 (75.0) | 8 (100.0) | 19 (79.2) |
| Website resources | 2 (66.7) | 2 (66.7) | - | 3 (37.5) | - | 7 (29.2) |
| **Average number of formats employed per participant** | | | | | | |
| Median (range) | 6 (1-6) | 5 (5 -7) | 3 (3 -6) | 3 (2-5) | 1.5 (1-7) | 3 (1-7) |

[α] Participants could select multiple options.

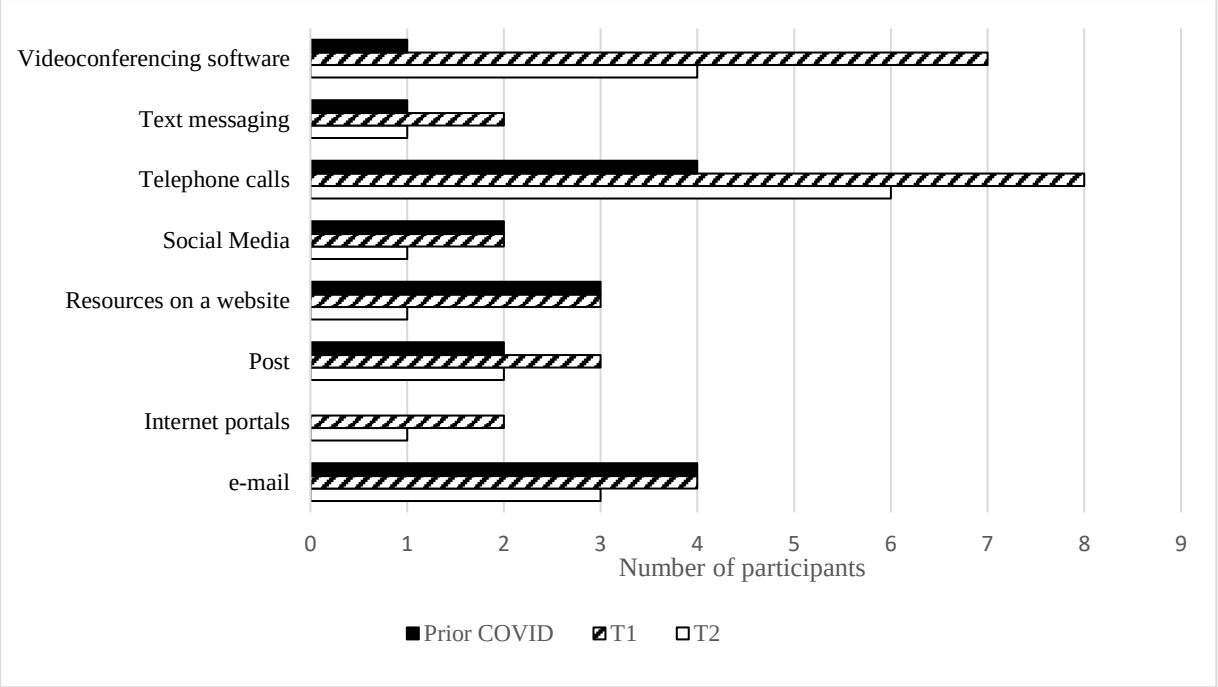



**Figure 9** Formats employed to deliver primary services prior to the pandemic, at T1 and T2[α] (n=11) in the initial analysis

[α]Participants could select multiple options

*Frequency of service delivery and usage of primary services*

Compared to prior to the pandemic, the frequency of service delivery per regular month slightly decreased at T1 (**Table 31** and **Table 32**). At T2, services were delivered slightly more frequently per regular month than they were prior to the pandemic (**Table 32**).

Overall, compared to prior to the pandemic, fewer service recipients accessed services at T1 (**Table 31** and **Table 32**) per regular month. Delivered by any service delivery method, prior to the pandemic, each in-person group-based services were accessed by a median of 15 (6-72) service recipients. Prior to the pandemic, two participants delivered remote group-based services, that were each accessed by two and 14 service recipients. Delivered by any service delivery method, at T1, each in-person group-based service were accessed by fewer service recipients (median: n= 8 (5-12)). At T1, each remote group-based service was accessed by a median of 12 (2-59) service recipients. At T2, the number of service recipients accessing services remained similar to at T1 (**Table 32**).

**COVID-19 mitigation measures implemented to delivery primary services**

All participants implemented mitigation measures when delivering in-person services (either as part of fully in-person or hybrid delivery models) at T1 and T2. Social distancing, wearing personal protective

equipment (PPE), the COVID-19 vaccination of social care and support providers, and delivering different activities were the most implemented measures (**Table 34**).

**Table 34** COVID-19 mitigation measures implemented to deliver primary services in-person in the initial analysis

| | **T1 n=8 (n (%))** | **T2 n= 9 (n (%))** |
|---|---|---|
| **COVID-19 measures employed to deliver primary services** [α] | | |
| Service recipient vaccinated | 5 (62.5) | 5 (55.6) |
| Service recipient bring food/drink | 2 (25.0) | 2 (22.2) |
| Service recipient contact details (track and trace) | 4 (50.0) | 4 (44.4) |
| Different activities | 6 (75.0) | 5 (55.6) |
| Minimise contact with service recipients | 5 (62.5) | 3 (33.3) |
| Shorter time spent with service recipients | 2 (25.0) | - |
| Social distancing | 8 (100.0) | 7 (77.8) |
| Social care and support providers vaccinated | 7 (87.5) | 5 (55.6) |
| Wearing PPE | 6 (75.0) | 4 (44.4) |
| **Average number of measures employed per participant** | | |
| Median (range) | 6 (2-7) | 4 (3-5) |

[α] Participants could select multiple options. Abbreviation: personal protective equipment (PPE)

### Satisfaction with primary service delivery

Prior to the pandemic, participants were ‘very satisfied’ when delivering in-person and hybrid services (**Table 31**). At T1, most social care and support providers were ‘fairly satisfied’ with the delivery of primary services, but the number of providers who were ‘very satisfied’ increased at T2 (**Table 32**).

## **Appendix Q** A coded segment of a transcript

**P052:** The library service because w-that'd be one of our really big um sessions, they said would I make some videos of singings , like those sessions, that they would put on their health and well being website . And this was at the time of lockdown and, as I say, I sing, like a horse, and so there is me on my iPhone and my piano. Doing [chuckles] the whole thing starts off with warmups, you know, sort of getting them to do physical jokes and doing daft things, but they wanted that, and they wanted some of the songs, so I was making these half an hour videos which are toe curling the embarrassing for me . But I think they developed a sort of cult status and so they were [chuckles] sort of viewed hundreds of times a month, far greater than our clientele so obviously they've been viewed more widely . So we did this throughout and even after a little bit of lockdown because what we were finding was that people did not respond well to Zoom or Skype. They hated that. Even if they've been used to skyping with with their families

**Interviewer:** yeah

**P052:** and could perfectly well write an email

**Interviewer:** Mm

**P052:** they found that, the they found, having to rely on having a connection at a certain time, having the apparatus being able to nail somebody with memory loss to a small screen and engage with… a group activity at a distance. They just hated it. Th-they said it was um audio and visual, together with an overload, it made them feel, somebody said it made her feel, more lonely than ever . Because in normal singing she be able to turn around and smile at someone or put her arm around them, whereas you couldn't do that , obviously, the la-latency, you know, you don't all sing together the sound goes funny . And, you know, just the fact that they couldn't keep people engaged, it-it was a no hoper. But, with these videos they could access them on demand .

External stakeholders / partnerships

Adapting services – creativity and motivation

Remote - increase outreach / timely access

Did not like videoconferencing software

Some digital literacy

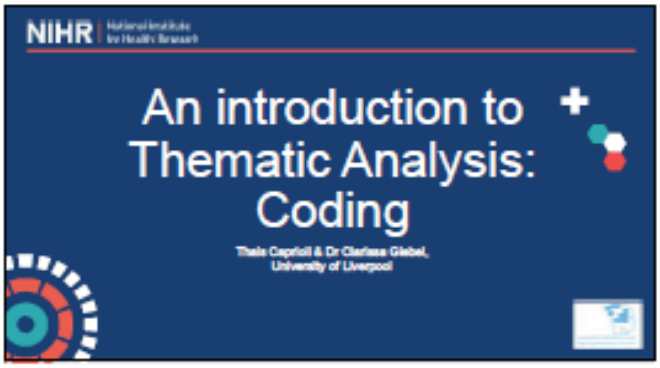
Prerequisites to access

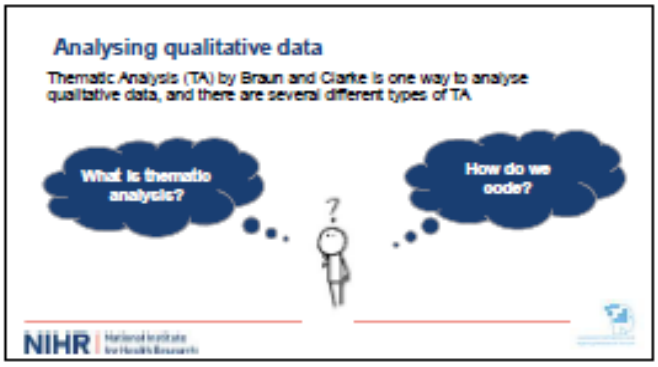
Sensory overload

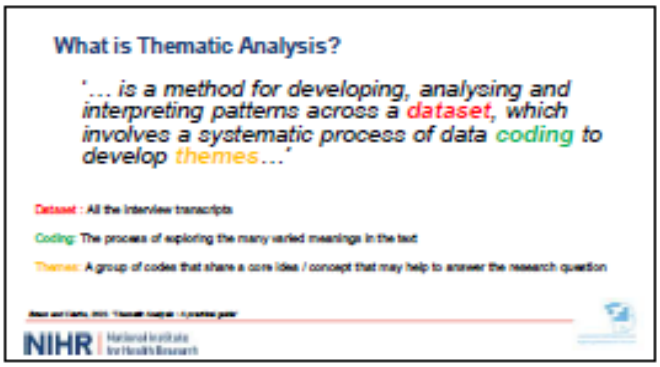
Not the same as in-person services - companionship

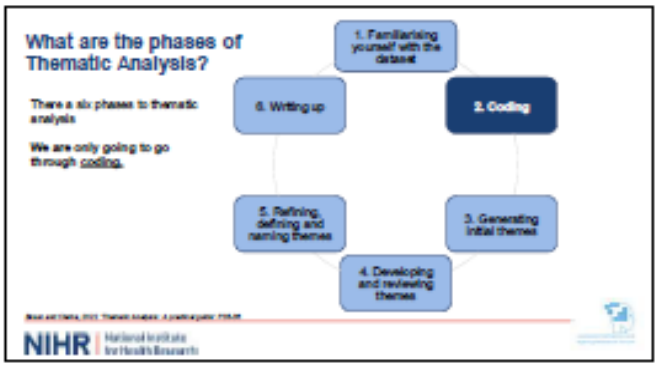
Technical glitches

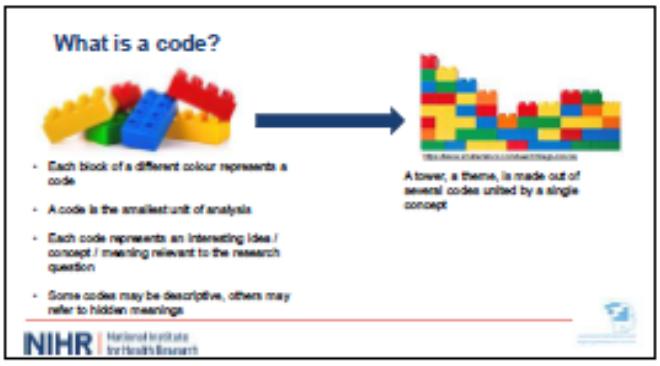
**Appendix R** Public advisor TA coding training power point slides

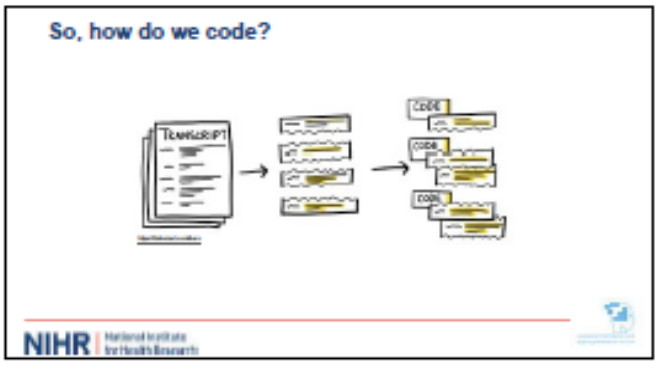


1. Familiarise yourself with your transcript
   - Make sure you have a copy of the research question (s)
   - Read through the transcript a couple of times
   - Take notes of any thoughts / overall impressions that come to mind
2. Start to code your transcript
   - Go through your transcript again, and highlight parts of the text which may be interesting / relevant / meaningful to answering the research question (s)
   - Label each code. One / couple of words to summarise the analytic idea or meaning captured within the code
   - Inductive, deductive or mixture of approaches can be applied when coding

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## Inductive vs deductive approaches to coding

**Inductive**

Data driven

May not reflect researcher's own beliefs / interest on the topic

Good to provides a broader / expansive analysis of the whole dataset

It's a continuum, and both approaches to coding can be used in a single analysis

**Deductive**

Uses a pre-existing theory, framework, or other researcher-driven focus to identify themes of interest

Good to focus on a specific part of the data set / finding that can be best understood within pre-existing theory

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## Things to remember…

There are no right or wrong answers. Coding is shaped by our own subjective experiences.

Codes may change the more you read and think about your transcript.

Some segments of text may have no codes attributed to it. Other segments may have multiple codes.

Some transcripts may not provide information to answer all the research questions. And that's ok!

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## Any examples?

Interviews with social support providers

**Research questions:**

1. To understand how the pandemic has affected the delivery and access of social support services in dementia care
2. To explore the experiences of delivering and accessing social support services during the pandemic
3. To understand the challenges and opportunities presented by the use of ICT in service delivery

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**Respondent:** Yeah, and that that, you know, kind of one of the big bits of learning, I think that we took away from it, that you know, as great as it was to be able to maintain that connection, it's just, it can never replace face to face work, you know. I hear a lot of ah statutory partners talking about how they may never go back to home visits again, it's like, well really, just sounds, sounds like an absolutely horrific route to go down, I think, as a tool it's fantastic, and and we are, we still, ran some blended sessions. Um so, our our clinic, for example, um which we ran virtually over lockdown, um some really interesting things developed during that, where we, because, because we weren't meet in person and we're doing virtually it meant that people can attend from anywhere, so we had people from all over [country] starting to come in like [city], [city], [city] would come and take part. [cough]. And we even had, we've been doing some work with a PhD student from Edinburgh who's, who was based in [city] in the US, and she would co-run the sessions with our clairvoyance, she's been a PhD around um music and dementia. So, we had this amazing situation where we had people from all over [country] and all over the world, going to take part in it. And we now run that session with, most of our, with our members in the rooms, we're maybe 50 members in the room, but we still Zoom in, so those people can still take part, if they want to. Um… the other time we switched back to Zoom, was um, we had some really heavy snow a few months ago, and we had to phone everybody up, and say the roads aren't safe travels today, don't come in. So, we just said, right, let's just switch back and do a Zoom session again instead. Not everybody was able to take part, but some people were able to come and engage in that, and it meant that, you know, there's definite potential there still around extreme weather situations like that or… There may be a situation where somebody may be too ill to come in, but still fit enough to take part in things so… We are always thinking about ways we can take and use this type of technology. [coughs].

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**Respondent:** Yeah, and that that, you know, kind of one of the big bits of learning, I think that we took away from it, that you know, as great as it was to be able to maintain that connection, it's just, it can never replace face to face work, you know. I hear a lot of ah statutory partners talking about how they may never go back to home visits again, it's like, well really, just sounds, sounds like an absolutely horrific route to go down, I think, as a tool it's fantastic, and and we are, we still, ran some blended sessions. Um so, our our clinic, for example, um which we ran virtually over lockdown, um some really interesting things developed during that, where we, because, because we weren't meet in person and we're doing virtually it meant that people can attend from anywhere, so we had people from all over [country] starting to come in like [city], [city], [city] would come and take part. [cough]. And we even had, we've been doing some work with a PhD student from Edinburgh who's, who was based in [city] in the US, and she would co-run the sessions with our clairvoyance, she's been a PhD around um music and dementia. So, we had this amazing situation where we had people from all over [country] and all over the world, going to take part in it. And we now run that session with, most of our, with our members in the rooms, we're maybe 50 members in the room, but we still Zoom in, so those people can still take part, if they want to. Um… the other time we switched back to Zoom, was um, we had some really heavy snow a few months ago, and we had to phone everybody up, and say the roads aren't safe travels today, don't come in. So, we just said, right, let's just switch back and do a Zoom session again instead. Not everybody was able to take part, but some people were able to come and engage in that, and it meant that, you know, there's definite potential there still around extreme weather situations like that or… There may be a situation where somebody may be too ill to come in, but still fit enough to take part in things so… We are always thinking about ways we can take and use this type of technology. [coughs].

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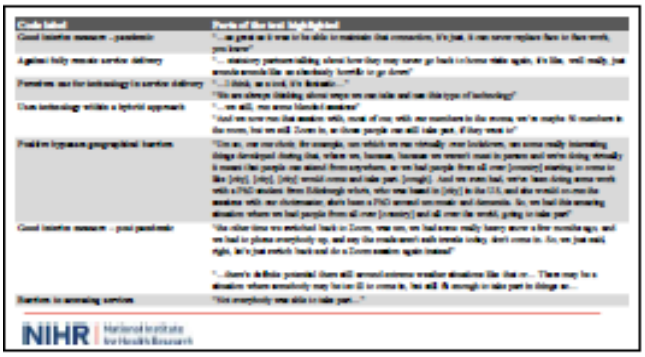
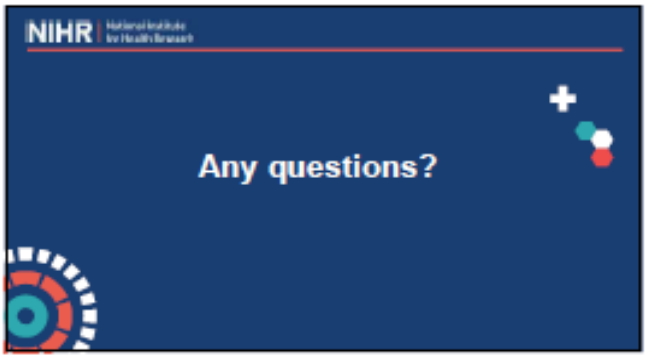


| Code label | Parts of the text highlighted |
|---|---|
| Good interim measure – pandemic | "...we give as it was to be able to maintain that connection, it's just, it can never replace face to face work, you know" |
| Against fully remote service delivery | "... stationary partners talking about how they may never go back to home visits again, it's like, well really, just sounds terrible to go down" |
| Positives use for technology in service delivery | "...I think, as a tool, it's fantastic..." |
| | "We are always thinking about ways we can take and use this type of technology" |
| User technology within a hybrid approach | "...we still, we were blended I mention" |
| | "And we now run this session with, most of our, with our members in the room, we're maybe 10 members in the room, but we still Zoom in, so those people can still take part, if they want to" |
| Positive bypasses geographical barriers | "Um so, one our clients, for example, um which we ran virtually over lockdown, um some really interesting things developed during that, where we, because, because we weren't meet in person and we're doing virtually it meant that people can attend from anywhere, so we had people from all over [country] starting to come to like [city], [city], [city] would come and take part, [rough]. And we even had, we've been doing some work with a PhD student from Edinburgh where, who was based in [city] in the US, and she would, so was the sessions with our clinicians, she's been a PhD around um covid, and dementia. So, we had this amazing situation where we had people from all over [country] and all over the world, going to take part" |
| Good interim measure – post pandemic | "the other time we switched back to Zoom, was um, we had some really heavy snow a few months ago, and we had to phone everybody up, and say the roads aren't safe inside today, don't come in. So, we just said, right, let's just switch back and do a Zoom session again instead" |
| | "...there's definite potential there will around extreme weather situations like that or... There may be a situation where somebody may be too ill to come in, but still fit enough to take part in things or..." |
| Barriers to accessing services | "Um everybody was able to take part..." |



**Appendix S** Health Inequalities Assessment Tool

NIHR | Applied Research Collaboration North West Coast

**Health Inequalities Assessment Tool (HIAT) Report**

**All outline and full proposals that want support from us must include a health inequalities assessment report. ARC NWC will use this report to decide whether your proposal 'fits' with our objective: to make sure that everything we do has the potential to reduce health inequalities and their causes.**

**In the form below, we ask you to briefly outline your response to each section of the toolkit at www.hiat.org.uk**

**In particular, we would like you to specify any change you have made to your planned activity as a result of your assessment or explain why you feel changes are not necessary.**

**You should use the toolkit with the members of the public involved in your activity. Please briefly outline how you have involved them or explain why you did not involve them at this stage.**

**1. Name of your project**

Facilitators and barriers to engaging with community support services in dementia: A mixed methods approach of addressing health inequalities

**2. Theme of your project**

Health Care Across the Life Course

**3. Who was involved in the assessment (include relevant members of the public)? If you did not involve the public, please say why not.**

This report has been updated through various discussions with both public advisors involved in the project

**4. Please summarise the results of your assessment under the section headings. For each stage, highlight the changes to your activity as a result of the assessment. If you did not make any changes, please give your reasons why.**

**What are the health inequalities that influenced or created this problem?**

There is currently no cure for dementia, and, as prioritised in the NHS Long Term Plan , further efforts are required to support PLWD and their informal carers to live well within their communities for as long as possible. Social care accounts for the largest costs in dementia post-diagnosis care . Community support and social care services are non-clinical services delivered to support PLWD and their informal carers to live well within their communities. These can, for example, include paid home care, support group and respite care. The COVID-19 pandemic

and associated public health measures caused changes in the delivery of community support services. Many services have temporarily withdrawn, operating at a reduce capacity or have turned towards information communications technologies (ICT) alternatives to deliver remote support. Prior to the COVID-19 pandemic, barriers in accessing community support services included lengthy diagnosis process, unsuitability of services, long waiting lists, identifying as ethnic minorities, financial issues, geographical discrepancies in service provision, and transportation difficulties . Accessing remote community support services is likely to require certain prerequisites such connectivity, access to technological devices, digital literacy and confidence in using the ICT. These prerequisites are likely to be influenced by offline factors, such as socio-economic factors, educational attainment, rurality and the ability to receive support. The term 'digital divide' refers to people who have and who do not have access to the internet. Nowadays, as the internet has become much more mainstream, the focus is often placed on the outcomes experienced from using the ICT. This will include being able to access devices when it is required and being able to use the ICT to achieve the intended outcomes. A recent systematic review identified that the discontinuity of telemedicine follow ups in dementia care were often associated with an increase in age, lower level of formal education and lower telemedicine satisfaction. Hearing or visual deficits may add an additional barrier in accessing or benefitting from remote support, nevertheless, this population are often excluded from research studies exploring remote interventions. A public advisor working on the project explained that the 2D image on screens tends to reduce the time the PLWD remains interested in remote services, and they prefer the interaction offered during in person services. The behavioural issues associated with some types of dementia may further compound the difficulties in engaging with remote services. Furthermore, depending on the services accessed, PLWD may be required to hold the device or the small screen on a phone may further contribute to fatigue and disinterest. Frailty and not be able to receive support from informal carers was associated with lower odds of attending and receiving a videoconference assessment. Other studies exploring the acceptability and feasibility of remote supportive interventions for PLWD identified that support from informal carers was at times required and PLWD with access to assistive technology and telecare more often had younger carers and who did not live with the PLWD. Albeit, receiving assistance from informal carers is likely to also depend on their knowledge and experience of using technology.

On the other hand, adopting ICT in practice can may be an enabling factor and increase opportunities to access support for some people. Whilst previous research has focused on the use of ICT to provide remote support that solely address the needs of the informal carers, some studies had demonstrated the use of ICT to delivery memory clinic services to rural and underserved communities. Advantages may include reduce costs, convenience (notably for those with mobility problems) and access to personalised support in a timely manner. Furthermore, as found in my longitudinal survey and interview study, following two years of confinement, some people with dementia and unpaid carers were anxious to resume engaging in in-person settings. Thus, the opportunity to access support remotely is important for some service recipients, and the use of ICT may facilitate and hinder the access to support.

Furthermore, whether community support services can provide a digital alternative is likely to depend on community support service providers' access to ICT and their digital skills and

ability to assist the care recipients to navigate the ICT. This is also likely to be influenced by factors associated with the social determinants of health. Through discussions with the public advisors, we also talked about the greater capacity of some community support service organisation to quickly and reactively, install remote service provision at the beginning of the COVID-19 pandemic. Capacity largely related to staff's access to equipment, digital literacy, and support.

**How will your proposed work tackle the socio-economic causes of the inequalities in health you identified in section 1?**

Firstly, to obtain a greater understanding of the use of ICT in the delivery of post-diagnostic support in dementia care, we are conducting a systematic review that seeks to summarise how remote post-diagnosis support that address the needs of PLWD or those of the dyad has previously been delivered, the types of services offered remotely and to explore the views of care recipients on accessing remote dementia-related post-diagnostic services. The systematic review provides an overview of previous research and summarise the views and any barriers experienced in accessing remote dementia-related post-diagnostic services. The review will help shape future work as part of the project. During the synthesis of the included studies, we have identified several factors which may relate to health inequalities, such as: having an unpaid carer to participate alongside the PLWD in the study, access to an ICT device / sufficient digital literacy formed part of the inclusion criteria of several studies. Some studies provided the necessary devices and training prior to the intervention. We found that remote service provision is likely to benefit some care recipients, but not all. Future research should systematically record the support provided by unpaid carers to facilitate the engagement of PLWD with remote services. This is important to capture as not all PLWD have an unpaid carer, or an unpaid carer who is able to provide ICT assistance.

Secondly, we devised a UK wide longitudinal study to understand how community support and social care services were delivered prior to and at two time points during the COVID-19 pandemic. We are interested in understanding how community services have adapted during the pandemic (if at all), and whether some services have turned towards ICT as a mean to provide remote support. The questionnaire captured participants socio-economic background information and postcodes of the community support and social care organisation. IMD quintiles will be calculated, which may help to undercover discrepancies in service provision across the UK. Findings may provide recommendations for policy to help to support and improve service delivery in future public health crises or possibly in circumstances when remote delivery will compliment face-to-face service provision. Input from the public advisors working on the project was sought when creating the questionnaire, ensuring that the tool captures pertinent information. As this project is occurring during the COVID-19 pandemic, data is being collected remotely and recruitment is conducted through emails and social media. The survey can be completed online or through the telephone.

Thirdly, to complement our findings from the above longitudinal study, we conducted remote (telephone or video conferencing software) qualitative interviews to further understand the delivery and access to community support services during the COVID-19 pandemic from the service provider and receiver point of view. Social support providers will be recruited from

those who have participated in the longitudinal study and who have expressed interest in taking part in future qualitative work. To increase the representativeness of our sample, an element of purposive sampling (socio-demographic information, types of services, IMD score of service provision area) will be introduced during sample selection. The topic guide was developed with the public advisor, who recommended to include a question relating to how quickly remote services were set up (if applicable). Furthermore, we plan to interview PLWD and carers, recruited through convenience sampling, to gain an understanding of their experiences in accessing support during the COVID-19 pandemic. Understanding the barriers and facilitators in access will hopefully assist policy in the development and delivery of appropriate services in future public health crises and help guide the use of ICT as part of the ongoing hybrid landscape. The topic guide was developed and piloted with the public advisor.

Due to the COVID-19 pandemic and the vulnerability of the study population, data collection had to be collected remotely, which may have discouraged participants who are more digitally excluded to participate – either through not hearing about the study, or not being able to participate remotely. We have tried to mitigate this by advertising the studies through multiple avenues, including engaging with social prescribing routes, and provided the option to collect data over the telephone. Some data recruitment was also done in person – e.g., advertising the study at the dementia information day in Liverpool.

**How will you make sure that your evaluation and monitoring shows the effect of your activity on health inequalities and their causes?**

The COVID-19 pandemic has increased the use of ICT in the delivery of community support services in dementia care. Whilst the use of ICT in service delivery may play a fundamental role in increasing access and achieving universal health coverage, it may not act as an enabling factor for all care recipients or be suitable for all types of services. Our work aims to help build an understanding of how ICT has been used in the delivery of community support services and to explore the potential facilitators and barriers in engaging with community support services during the COVID-19 pandemic from both the service provider and receiver point of view. Findings may feed into policies to help to assist the preparedness of service delivery in the event of future pandemics and help to guide the use of ICT in the current hybrid landscape.

**What wider effect might your activity have on health inequalities and their causes and how can this be delivered?**

A lay summary of the findings from this project will be provided and shared through different platforms. Participants taking part in the longitudinal study and the qualitative interview study can indicate if they would like to receive a lay summary of the findings, and if so, either via email or through the post. For the qualitative interview study, two separate lay summaries will be devised, one for social support participants and the other for PLWD and carer participants. Findings may also be shared during conferences or webinars attended by multiple stakeholders (service providers and care recipients). The public advisors working on the project have been involved while devising the lay summaries using the ARC Bite Size summary and are authors on the papers from my project. Furthermore, some findings have also been disseminated through blogs.

## **Appendix T** Overall reflexive piece

In the following paragraphs, I reflect on conducting and analysing data from my interviews. This piece is made up from combining entries from my reflexive research diary.

This study was my first experience in conducting qualitative research, and I undertook appropriate training beforehand. I also shadowed an experienced researcher interview unpaid carers and observed how they sensitively navigated emotional topics, which I found helpful. Moreover, I participated, as a participant, in several qualitative studies. This enabled me to further observe different interviewing techniques and place myself in the shoes of an interviewee. Furthermore, reading published papers reporting on studies I took part in was insightful, and, realising I had been quoted, made me appreciate the importance of carefully selecting my data extracts.

Prior to my interview, all participants had read the study information sheet, which included the aim of the study, expected knowledge dissemination measures, and their rights as participants, which were re-explained prior to the interview. Through the study information sheets and pre-interview discussions, participants were made aware that I was a student and that the work formed part of my Ph.D. thesis. The topic guides were developed with my public advisors. The wording of the questions was carefully chosen to ensure they were understood by most participants and avoided any technical terms. Moreover, I included a question at the end of the interview which enabled participants to discuss anything which they felt was relevant but omitted in my questions. I felt this was important, not only to include content I may have overlooked, but to give participants an opportunity to set the agenda of what was discussed.

I felt a mixture of anxiety and excitement prior to interviewing. Although I had exchanged several emails with participants beforehand, that was the extent to our established rapport prior to the interview. Thus, the first question focused on rapport building. Participants were forthcoming, and their answers to my rapport building question often took longer than anticipated, and at times, I wondered if I should intervene to re-focus the interview. Towards the start of data collection, a participant pre-empted my questions. Unsure how to manage this, I let them lead the interview. The questions covered were similar to the ones I had prepared, but the interview was far from smooth, and the transcript was quite jagged. As I gained experience, I felt more confident while interviewing and had a similar issue surfaced, I would have felt comfortable enough to try to moderate interview. Overall, some interviews were more fluid, yielded richer data and/or evoked greater emotional responses than others. Interviews with social care and support providers were generally longer, oftentimes quite poignant, and possibly, because I found it easier to relate to some of their experiences, left me tired, with a lot to process. Many social care and support providers were thankful for the opportunity to participate in my study as it created a space for them to reflect, which is something I felt privileged to have been a part of. Following each

interview, I wrote field notes on aspects that came to mind which I thought was (or could be) important. Most reflections I recorded related to my interviewing technique, and how it could be improved, notably while interviewing participants with dementia. Examples included talking slower and asking one question at a time.

The location of where the interview is conducted is important as it may provide additional insights and/or influence how participants' respond to questions (Elwood & Martin, 2000). For example, participants may respond differently while interviewed in their own homes, university campus or place of employment (Elwood & Martin, 2000). Choosing a location needs to include an aspect of pragmatism, but importantly, ensure confidentiality and participants should be involved while deciding on the location (Elwood & Martin, 2000). Due to the pandemic, my interviews were conducted remotely, and participants could decide from where they were interviewed. While I did not collect information regarding their location, some participants told me whether they were joining from their office or from home. I suppose with extensive homeworking during the pandemic, the line between areas of employment and personal homes have been somewhat blurred. However, during some interviews, I was unable to I see participants (interviewed by telephone / video icon disabled while interviewed by videoconferencing software). While the lack of non-verbal communication rendered it hard to gauge how participants felt, I found myself paying more attention to the language they employed, picturing parts of their narratives in my mind.

I transcribed a third of the transcripts, which helped me to engage with the data. Initially, conducting a reflexive TA felt somewhat intuitive, yet alien. Spending time familiarising myself with transcripts and field notes was helpful to emerge myself in the data. I found visually mapping concepts that initially stood out for me, which were refined as my understanding deepened, helped me to engage and make sense of the data. I trained one of my public advisors on how to code transcripts, and comparing and discussing our codes was helpful to ensuring that the analysis was grounded in lived experience. While we mostly shared similar thoughts, at times, they interpreted a segment of text differently, or part of a transcript stood out for them, but I had not considered it too relevant. This exposed me to different ways of thinking about the data and helped me reflect on my assumptions.

Lastly, while writing up the findings, I found selecting data extracts to demonstrate analytical claims, at times, challenging. I tried to use a mixture of long and short quotes, from an array of participants. On several occasions several quotes illustrated an analytical claim, and while somewhat mitigated by including a table with additional quotes, I found selecting the 'best' quote difficult.

## **Appendix U** Post code selection

A total of 14 postcodes were selected. Following discussions with my supervisory team, postcodes were selected by the following process.

1. Downloaded the rural and urban classification (based on the 2011 census) of LAs (Official Statistics, 2021). The three-tier classification was selected (predominantly urban, predominantly rural and urban with significant rural)
2. Downloaded the LA district summary of IMD (Ministry of Housing, Communities & Local Government, 2019b) and looked at the IMD average rank.
3. Three LAs within each rural and urban classification were selected based on the LA's IMD average rank and geographical area within England.
4. For larger LAs, local IMD maps (mySociety, 2019) was used to select one deprived and one affluent area.

## **Appendix V** Completed PRISMA checklist (Page et al., 2021)

**Table 35** PRIMA checklist (Page et al., 2021)

| Section and Topic | Item # | Checklist item | Location where item is reported |
|---|---|---|---|
| **TITLE** | | | |
| Title | 1 | Identify the report as a systematic review. | 50 |
| **ABSTRACT** | | | |
| Abstract | 2 | See the PRISMA 2020 for Abstracts checklist. | Table 36 |
| **INTRODUCTION** | | | |
| Rationale | 3 | Describe the rationale for the review in the context of existing knowledge. | 52-53 |
| Objectives | 4 | Provide an explicit statement of the objective(s) or question(s) the review addresses. | 53 |
| **METHODS** | | | |
| Eligibility criteria | 5 | Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses. | 56 |
| Information sources | 6 | Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted. | 55 |
| Search strategy | 7 | Present the full search strategies for all databases, registers and websites, including any filters and limits used. | 55 |
| Selection process | 8 | Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process. | 56 |
| Data collection process | 9 | Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process. | 56 - 57 |
| Data items | 10a | List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect. | 57 |
| | 10b | List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information. | 57 |
| Study risk of bias assessment | 11 | Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process. | 56-57 |
| Effect measures | 12 | Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results. | NA |

| Section and Topic | Item # | Checklist item | Location where item is reported |
|---|---|---|---|
| Synthesis methods | 13a | Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)). | NA |
| | 13b | Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions. | NA |
| | 13c | Describe any methods used to tabulate or visually display results of individual studies and syntheses. | 58 |
| | 13d | Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used. | 58 |
| | 13e | Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression). | NA |
| | 13f | Describe any sensitivity analyses conducted to assess robustness of the synthesized results. | NA |
| Reporting bias assessment | 14 | Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases). | NA |
| Certainty assessment | 15 | Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome. | NA |
| **RESULTS** | | | |
| Study selection | 16a | Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram. | 60 |
| | 16b | Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded. | 60 |
| Study characteristics | 17 | Cite each included study and present its characteristics. | 61-66. |
| Risk of bias in studies | 18 | Present assessments of risk of bias for each included study. | 67 |
| Results of individual studies | 19 | For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots. | NA |
| Results of syntheses | 20a | For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies. | NA |
| | 20b | Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect. | NA |
| | 20c | Present results of all investigations of possible causes of heterogeneity among study results. | NA |
| | 20d | Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results. | NA |
| Reporting biases | 21 | Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed. | NA |

| Section and Topic | Item # | Checklist item | Location where item is reported |
|---|---|---|---|
| Certainty of evidence | 22 | Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed. | NA |
| **DISCUSSION** | | | |
| Discussion | 23a | Provide a general interpretation of the results in the context of other evidence. | 78-80 |
| | 23b | Discuss any limitations of the evidence included in the review. | 80-81 |
| | 23c | Discuss any limitations of the review processes used. | 80-81 |
| | 23d | Discuss implications of the results for practice, policy, and future research. | 80-81 |
| **OTHER INFORMATION** | | | |
| Registration and protocol | 24a | Provide registration information for the review, including register name and registration number, or state that the review was not registered. | 53 |
| | 24b | Indicate where the review protocol can be accessed, or state that a protocol was not prepared. | 53 |
| | 24c | Describe and explain any amendments to information provided at registration or in the protocol. | NA |
| Support | 25 | Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review. | 81 |
| Competing interests | 26 | Declare any competing interests of review authors. | 81 |
| Availability of data, code and other materials | 27 | Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review. | NA |

**Table 36** PRISMA checklist – abstract (Page et al., 2021)

| Section and Topic | Item # | Checklist item | Reported (Yes/No) |
|---|---|---|---|
| **TITLE** | | | |
| Title | 1 | Identify the report as a systematic review. | 50 |
| **BACKGROUND** | | | |
| Objectives | 2 | Provide an explicit statement of the main objective(s) or question(s) the review addresses. | 51 |
| **METHODS** | | | |
| Eligibility criteria | 3 | Specify the inclusion and exclusion criteria for the review. | 51 |
| Information sources | 4 | Specify the information sources (e.g. databases, registers) used to identify studies and the date when each was last searched. | 51 |
| Risk of bias | 5 | Specify the methods used to assess risk of bias in the included studies. | 51 |
| Synthesis of results | 6 | Specify the methods used to present and synthesise results. | Missing |
| **RESULTS** | | | |
| Included studies | 7 | Give the total number of included studies and participants and summarise relevant characteristics of studies. | 51 |
| Synthesis of results | 8 | Present results for main outcomes, preferably indicating the number of included studies and participants for each. If meta-analysis was done, report the summary estimate and confidence/credible interval. If comparing groups, indicate the direction of the effect (i.e. which group is favoured). | 51 |
| **DISCUSSION** | | | |
| Limitations of evidence | 9 | Provide a brief summary of the limitations of the evidence included in the review (e.g. study risk of bias, inconsistency and imprecision). | Missing |
| Interpretation | 10 | Provide a general interpretation of the results and important implications. | 51 |
| **OTHER** | | | |
| Funding | 11 | Specify the primary source of funding for the review. | Only in main text |
| Registration | 12 | Provide the register name and registration number. | Only in main text |

**Appendix W** Completed CROSS checklist (Sharma et al., 2021)

| Section/topic | Item | Item description | Reported on page # |
|---|---|---|---|
| **Title and abstract** | | | |
| Title and abstract | 1a | State the word "survey" along with a commonly used term in title or abstract to introduce the study's design. | 116 |
| | 1b | Provide an informative summary in the abstract, covering background, objectives, methods, findings/results, interpretation/discussion, and conclusions. | 117 |
| **Introduction** | | | |
| Background | 2 | Provide a background about the rationale of study, what has been previously done, and why this survey is needed. | 118-119 |
| Purpose/aim | 3 | Identify specific purposes, aims, goals, or objectives of the study. | 119 |

| **Methods** | | | |
|---|---|---|---|
| Study design | 4 | Specify the study design in the methods section with a commonly used term (e.g., cross-sectional or longitudinal). | 99 |
| Data collection methods | 5a | Describe the questionnaire (e.g., number of sections, number of questions, number and names of instruments used). | 120-121 |
| | 5b | Describe all questionnaire instruments that were used in the survey to measure particular concepts. Report target population, reported validity and reliability information, scoring/classification procedure, and reference links (if any). | 109; 120-121; Appendix J |
| | 5c | Provide information on pretesting of the questionnaire, if performed (in the article or in an online supplement). Report the method of pretesting, number of times questionnaire was pre-tested, number and demographics of participants used for pretesting, and the level of similarity of demographics between pre-testing participants and sample population. | 121 |
| | 5d | Questionnaire if possible, should be fully provided (in the article, or as appendices or as an online supplement). | Appendix J |
| Sample characteristics | 6a | Describe the study population (i.e., background, locations, eligibility criteria for participant inclusion in survey, exclusion criteria). | 119-120 |
| | 6b | Describe the sampling techniques used (e.g., single stage or multistage sampling, simple random sampling, stratified sampling, cluster sampling, convenience sampling). Specify the locations of sample participants whenever clustered sampling was applied. | 120 |
| | 6c | Provide information on sample size, along with details of sample size calculation. | missing |
| | 6d | Describe how representative the sample is of the study population (or target population if possible), particularly for population-based surveys. | NA |
| Survey | 7a | Provide information on modes of questionnaire administration, including the type and number of contacts, the location where the survey was conducted (e.g., outpatient room | 120 |

| | | | |
|---|---|---|---|
| administration | | or by use of online tools, such as SurveyMonkey). | |
| | 7b | Provide information of survey's time frame, such as periods of recruitment, exposure, and follow-up days. | 120 |
| | 7c | Provide information on the entry process:<br>–>For non-web-based surveys, provide approaches to minimize human error in data entry. | NA |
| | | –>For web-based surveys, provide approaches to prevent "multiple participation" of participants. | 105 |
| Study preparation | 8 | Describe any preparation process before conducting the survey (e.g., interviewers' training process, advertising the survey). | NA |
| Ethical considerations | 9a | Provide information on ethical approval for the survey if obtained, including informed consent, institutional review board [IRB] approval, Helsinki declaration, and good clinical practice [GCP] declaration (as appropriate). | 120 |
| | 9b | Provide information about survey anonymity and confidentiality and describe what mechanisms were used to protect unauthorized access. | 97 |
| Statistical analysis | 10a | Describe statistical methods and analytical approach. Report the statistical software that was used for data analysis. | 121 |
| | 10b | Report any modification of variables used in the analysis, along with reference (if available). | NA |
| | 10c | Report details about how missing data was handled. Include rate of missing items, missing data mechanism (i.e., missing completely at random [MCAR], missing at random [MAR] or missing not at random [MNAR]) and methods used to deal with missing data (e.g., multiple imputation). | 122 |
| | 10d | State how non-response error was addressed. | missing |

| | | | |
|---|---|---|---|
| | 10e | For longitudinal surveys, state how loss to follow-up was addressed. | 122 |
| | 10f | Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for non-representativeness of the sample. | NA |
| | 10g | Describe any sensitivity analysis conducted. | NA |
| **Results** | | | |
| | 11a | Report numbers of individuals at each stage of the study. Consider using a flow diagram, if possible. | 120 |
| Respondent characteristics | 11b | Provide reasons for non-participation at each stage, if possible. | missing |
| | 11c | Report response rate, present the definition of response rate or the formula used to calculate response rate. | NA |
| | 11d | Provide information to define how unique visitors are determined. Report number of unique visitors along with relevant proportions (e.g., view proportion, participation proportion, completion proportion). | NA |
| Descriptive results | 12 | Provide characteristics of study participants, as well as information on potential confounders and assessed outcomes. | 123 |
| | 13a | Give unadjusted estimates and, if applicable, confounder-adjusted estimates along with 95% confidence intervals and p-values. | 123-131 |
| Main findings | 13b | For multivariable analysis, provide information on the model building process, model fit statistics, and model assumptions (as appropriate). | NA |
| | 13c | Provide details about any sensitivity analysis performed. If there are considerable amount of missing data, report sensitivity analyses comparing the results of complete cases with that of the imputed dataset (if possible). | NA |

| | | | |
|---|---|---|---|
| **Discussion** | | | |
| Limitations | 14 | Discuss the limitations of the study, considering sources of potential biases and imprecisions, such as non-representativeness of sample, study design, important uncontrolled confounders. | 138 |
| Interpretations | 15 | Give a cautious overall interpretation of results, based on potential biases and imprecisions and suggest areas for future research. | 138 |
| Generalizability | 16 | Discuss the external validity of the results. | 138 |
| **Other sections** | | | |
| Role of funding source | 17 | State whether any funding organization has had any roles in the survey's design, implementation, and analysis. | 139 |
| Conflict of interest | 18 | Declare any potential conflict of interest. | 139 |
| Acknowledgements | 19 | Provide names of organizations/persons that are acknowledged along with their contribution to the research. | NA |

**Appendix X** Completed COREQ checklist (Tong et al., 2007)

| Topic | Item No. | Guide Questions/Description | Reported on Page No. |
|---|---|---|---|
| **Domain 1: Research team and reflexivity** | | | |
| *Personal characteristics* | | | |
| Interviewer/facilitator | 1 | Which author/s conducted the interview or focus group? | 145 |
| Credentials | 2 | What were the researcher's credentials? E.g. PhD, MD | 140 |
| Occupation | 3 | What was their occupation at the time of the study? | 279 |
| Gender | 4 | Was the researcher male or female? | NA |
| Experience and training | 5 | What experience or training did the researcher have? | 279 |
| *Relationship with participants* | | | |
| Relationship established | 6 | Was a relationship established prior to study commencement? | 279 |
| Participant knowledge of the interviewer | 7 | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | 279 |
| Interviewer characteristics | 8 | What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | 107 |
| **Domain 2: Study design** | | | |
| *Theoretical framework* | | | |
| | 9 | | |

| | | | |
|---|---|---|---|
| Methodological orientation and Theory | | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | 143-144 |
| *Participant selection* | | | |
| Sampling | 10 | How were participants selected? e.g. purposive, convenience, consecutive, snowball | 144 |
| Method of approach | 11 | How were participants approached? e.g. face-to-face, telephone, mail, email | 146 |
| Sample size | 12 | How many participants were in the study? | 148 |
| Non-participation | 13 | How many people refused to participate or dropped out? Reasons? | missing |
| *Setting* | | | |
| Setting of data collection | 14 | Where was the data collected? e.g. home, clinic, workplace | 144 |
| Presence of non-participants | 15 | Was anyone else present besides the participants and researchers? | 145 |
| Description of sample | 16 | What are the important characteristics of the sample? e.g. demographic data, date | 146-147 |
| *Data collection* | | | |
| Interview guide | 17 | Were questions, prompts, guides provided by the authors? Was it pilot tested? | 145; Appendix K |
| Repeat interviews | 18 | Were repeat inter views carried out? If yes, how many? | NA |
| Audio/visual recording | 19 | Did the research use audio or visual recording to collect the data? | 145 |
| Field notes | 20 | Were field notes made during and/or after the interview or focus group? | 145 |

| | | | |
|---|---|---|---|
| Duration | 21 | What was the duration of the inter views or focus group? | 146 |
| Data saturation | 22 | Was data saturation discussed? | 94-95 |
| Transcripts returned | 23 | Were transcripts returned to participants for comment and/or corrected? | NA |
| **Domain 3: analysis and findings** | | | |
| *Data analysis* | | | |
| Number of data coders | 24 | How many data coders coded the data? | 145 |
| Description of the coding tree | 25 | Did authors provide a description of the coding tree? | 148 |
| Derivation of themes | 26 | Were themes identified in advance or derived from the data? | 145 |
| Software | 27 | What software, if applicable, was used to manage the data? | NA |
| Participant checking | 28 | Did participants provide feedback on the findings? | NA |
| *Reporting* | | | |
| Quotations presented | 29 | Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? E.g., participant number | 149-160 |
| Data and findings consistent | 30 | Was there consistency between the data presented and the findings? | 149-156 |
| Clarity of major themes | 31 | Were major themes clearly presented in the findings? | 149-156 |
| Clarity of minor themes | 32 | Is there a description of diverse cases or discussion of minor themes? | 149-156 |

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