

The development of good practice guidance for community dementia services: a collaboration with the World Health Organization

Short title: Human rights in dementia care

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“Dementia is not the end, it’s a new lease of life” – Dr. Jennifer Bute, Alzheimer’s Disease International and World Health Organization webinar ‘ADI hosting WHO: Rehabilitation and dementia: global, national, and personal perspectives’, 21st January 2025.

“Support means help to live an independent life while coping with my dementia” – person with dementia, 24th September 2025.

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Abstract

Introduction: Within community dementia services and systems, there are major concerns over the human rights of people with dementia and their families. Many countries have ratified the Convention on the Rights of Persons with Disabilities (CRPD), a human rights standard that works to respect, protect, and promote the human rights of people with disabilities, including dementia. The World Health Organization (WHO) is working to improve human rights for persons with dementia by developing good practice guidance for community dementia services. This thesis aimed to conduct research and develop robust methodology to inform the development of good practice guidance for community dementia services including recovery-oriented, person-centred, and rights-based care practices.

Methods: This thesis comprises of a group of related research studies: 1) a historical review of human rights within dementia care to contextualise current issues in dementia care, 2) a survey of attitudes to dementia and human rights using an adapted version of the WHO QualityRights Attitudes scale (QRAD), 3) a preliminary psychometric evaluation of the QRAD, 4) a policy review of human rights in national dementia plans, 5) a scoping exercise and literature search to identify dementia care services across the globe, and 6) an evaluation of good practice in human rights in a selection of dementia care services.

Results: 1) Philosophical thoughts and ethical decisions of dementia in ancient history have informed the legislation and care practices reported today. For example, in Ancient Greece, people thought to have weakened minds due to old age were legally unable to make wills. 2) Attitudes towards human rights in dementia today were related to older age, being female, and being a professional working in dementia care. 3) The QRAD was found to have adequate psychometric properties, showcasing good internal consistency and validity through convergent, divergent, and construct validity. 4) National dementia plans often covered basic human rights, particularly the right to be included in the community; however, there was a lack of acknowledgement

and actions to ensure the enjoyment of freedom from coercion and the right to participate, meaning more must be done to ensure that plans align with human rights standards such as the CRPD. 5) Over 1000 services were identified through the scoping exercise and 636 of these were removed through screening processes. 6) Twenty community dementia services were identified as showcasing good recovery-oriented, person-centred, and rights-based care practices that uphold the human rights of people with dementia and their families and supporters.

Implications: This work has endorsed the need for comprehensive guidance on recovery-oriented, person-centred, and rights-based care for community dementia services worldwide. Future work can focus on the global attitudes towards human rights in dementia and evaluate the human rights content of future national dementia plans and their implementation. This work will be continued in the development of the WHO good practice guidance on human rights in dementia due to be published in 2026. The guidance will inform governments, non-governmental organisations, and service providers how they can make improvements to ensure the full enjoyment of human rights for people with dementia.

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Disclaimer

The views in this thesis are mine and do not necessarily reflect those of the University of Nottingham, the World Health Organization, or the funder. The thesis may be used for the purposes of research or private consultation. No part of this thesis may be reproduced or used without full acknowledgement of the author.

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Presentations

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Abbreviations

AAQ: Attitudes to Ageing

ADI: Alzheimer's Disease International

ANOVA: Analysis of Variance

BPSD: Behavioural and psychological symptoms of dementia

CASP: Critical Appraisal Skills Programme

CFA: Confirmatory Factor Analysis

CHIME: Connectedness, Hope, Identity, Meaning and purpose, and Empowerment

CI(s): Confidence Interval(s)

CRPD: Convention on the Rights of Persons with Disabilities

DAI: Dementia Alliance International

DAS: Dementia Attitudes Scale

DIAN: The Dementia International Advisory Network for Human Rights

HICs: High-income countries

JDR: Join Dementia Research

LMICs: Low- to middle-income countries

LICs: Low-income countries

NIHR: National Institute of Health and Care Research

PDF: Portable document format

PPI: Patient and public involvement

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analysis

QRA: The QualityRights Attitudes scale

QRAD: The QualityRights Attitudes towards Dementia scale

QRCoerciveD: QualityRights attitudes towards involuntary and coercive practices in dementia (subscale 2)

QRServicesD: QualityRights attitudes towards the mental health/dementia service approach (subscale 1)

QRDecisionsD: QualityRights attitudes towards people with dementia as decision-makers and full members of society (subscale 3)

SD: Standard deviation

WHO: World Health Organization

WHO-CC: World Health Organization Collaborating Centre for Mental Health, Disability, and Human Rights

UDHR: Universal Declaration of Human Rights

UK: United Kingdom

UMICs: Upper- to middle-income countries

UN: United Nations

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1. Introduction – Dementia, dementia care, and human rights

1.1 Overview

At present, just under 60 million people have dementia worldwide (World Health Organization [WHO], 2023), but this number is expected to rise rapidly over the next few decades due to increasing life expectancy and population growth (Global Burden of Disease 2019 Dementia Forecasting Collaborators, 2022). Many services and support systems provide care throughout the trajectory of the condition. It is essential that these services are of high quality, but there are significant challenges to ensure this is the case. Not only is there pervasive global stigma towards people with dementia and their family members (Alzheimer's Disease International [ADI], 2024), but systemic barriers, such as a lack of funding, limited dementia literacy, and insufficient resources, mean there are considerable concerns over the human rights of people with dementia and their family members and supporters. Moreover, there is a lack of guidance about the respect, protection, and promotion of human rights within dementia services worldwide. Therefore, work is needed to ensure dementia care moves to a more recovery-oriented, person-centred, and rights-based approach.

1.2 Dementia

Dementia is an umbrella term for several diseases usually of a chronic and progressive nature (WHO, 2023). It is typically defined by a clear impairment of at least two cognitive functions that have declined beyond the expected levels at the individual's age and general cognition (WHO, 2023). The diseases that underlie dementia generally follow a triad of clinical expressions (Grand et al., 2011): 1) a wide range of cognitive impairments, including memory deficits, attentional difficulties, agnosia, and executive functioning impairments, 2) behavioural and psychological symptoms of dementia (BPSD), including depression, hallucinations, and aggression, and 3) difficulties completing activities of daily living. Examples of these activities

include eating, dressing, personal hygiene, and common household tasks. While these are the typical symptoms, their presentation varies depending on several factors, including the type of dementia, the individual's personal history, social circumstances, and any comorbid conditions (Aranda et al., 2021; Dempsey et al., 2015). Additionally, not all people with dementia will exhibit the typical symptoms described.

There are over 200 subtypes of dementia (Dementia UK, 2021), but the most common form is Alzheimer's disease, contributing to approximately 60% of dementia diagnoses (WHO, 2023). Other common forms of dementia include Lewy Body Dementia (also known as Dementia with Lewy bodies), Frontotemporal dementia, Vascular dementia, and Mixed dementia. There are also much rarer forms of dementia, including Posterior Cortical Atrophy and Primary Progressive Aphasia. The term 'young-onset dementia' is used to describe people who develop dementia below the age of 65 (ADI, 2023a). With the number of people with dementia predicted to increase, and therefore the number of people affected by dementia increasing alongside, access to various health and social care services will be necessary.

1.3 Support for people with dementia and their families

People with dementia, as well as their families and supporters, usually want to stay as independent and autonomous for as long as possible (Donnelly et al., 2016; Stephan et al., 2018), but many increasingly need help and support to maintain these wishes (Nunn et al., 2025). Dementia care has typically followed the medical model of disability (Walmsley & McCormack, 2016). While this model of care has made substantial contributions to discoveries regarding dementia and medications to reduce symptoms and possibly slow the progression of dementia, it ignores the influence of other factors, such as the environment or social factors, in the onset and resultant experience of the condition.

The social model of disability has gained more significance over the last few decades. This model argues that society disables individuals, and societal change is therefore recommended to make any positive impact on the

lives of people with disabilities (Spector & Orrell, 2010). The psychosocial model later expanded on this, asserting that disability is the result of societal factors negatively impacting on the psychological wellbeing of individuals (Bruns & Warren, 2011). However, the model of disability considered by many as the most holistic is the biopsychosocial model (Engel, 1977; Spector & Orrell, 2010). This model acknowledges the aspects of what makes a person a person, bringing attention to the physical, cognitive, behavioural, and psychological impacts of dementia and illustrating how excess disability can occur.

1.3.1 Types of community-based services for dementia

People with dementia, as well as their families and supporters, often have complex needs that span the health and social sector, necessitating a strong and collaborative effort to provide effective psychological, social, and health care (WHO, 2018). But because most people with dementia live in the community, primarily in their own homes, and receive care and support from family members (Hochgraeber et al., 2017), this places considerable responsibility on people with dementia to care for themselves or for family members to provide all levels of appropriate care and, therefore, other care options are required. Consequently, community dementia services are becoming more commonplace to provide these alternatives, as well as alternatives to institutionalisation (Ploeg et al., 2009).

Panagiotidou et al. (2021) conducted a scoping review and identified eight categories of services: 1) peer support services, 2) social, cultural, and recreational services, 3) hospital-based services, 4) support and respite services, 5) crisis services, 6) community health services, 7) supported living accommodation, and 8) palliative and end-of-life services. The activities provided by each type can be found in chapter 6 (page 140). Although there are distinct categories of services, there is an overlap of the support provided, albeit with some key differences (Panagiotidou et al., 2021). It should be stated that these community services are based on westernised ideas about dementia and how care for the condition should be provided, and there are challenges in the development and implementation of these services in

collectivist cultures, particularly in low- to middle-income countries (Murali et al., 2025).

1.4 How dementia can be experienced by different groups of people

The impact of dementia is not only felt by those diagnosed, but also their families, supporters, healthcare professionals, and the health, social, legal, and financial systems (Akinyemi et al., 2022; Clarke & Bailey, 2016). Factors that can affect the experience of dementia for all groups include personal histories, beliefs about dementia, what the diagnosis means for them, and prior experiences of dementia (Scott, 2022). While the literature and media tend to focus on negative aspects of dementia, there are positive experiences too. However, the impact of dementia is different for everyone; as a person diagnosed with dementia stated, "I may be an expert by experience, but I am only an expert in *my* experience" (personal communication, 20th February 2025, emphasis added by BH).

1.4.1 People with dementia

The impact of dementia is often felt long before a diagnosis is ever made, with the journey to obtaining a diagnosis described as arduous and long (Stephan et al., 2018; Stokes et al., 2014). There have been many instances of people with dementia being misdiagnosed as having depression, particularly when in the earlier stages (Martin et al., 2013). This means that when the diagnosis is given, dementia is often in the later stages (Christie, 2020). During a diagnostic session, people with dementia describe feeling overwhelmed, not just by the diagnosis, but the amount of information provided to them (Handley et al., 2024). Any information tends to be generic information about dementia as a condition, rather than diagnosis-specific, provided in the form of leaflets, which can cause distress and further upset due to difficulties in relating to the information (personal communication, 6th November, 2024). Not only that, but individuals with dementia have reported that they are told what they can no longer do due to the diagnosis (personal communication, 4th November 2024), being told to give up their life as they knew it, sort out legalities, and prepare for death. Swaffer (2015) termed this 'prescribed

disengagement™'. This could be explained by the tragedy and biomedical discourses of dementia, which emphasise losses of insight, personality, and capacity (McParland et al., 2017; Scales et al., 2017).

Post-diagnostic life can also present several challenges. People with dementia can find it difficult to maintain relationships, experience lower levels of self-esteem and empowerment, feel they lose both opportunities and abilities to stay in control of their lives, and lose a sense of belonging (Brown, 2017; Clarke & Bailey, 2016; Peoples et al., 2023; Popok et al., 2022). People with dementia have reported fears of losing their independence and the social consequences of their diagnosis, resulting in self-isolation and withdrawal to alleviate fears of being shunned by others and to project a picture of independence (Brown, 2017; Clarke & Bailey, 2016; Fletcher, 2021; Mitchell, 2018).

People diagnosed with young-onset dementia can experience additional difficulties purely due to their younger age. At the time they are diagnosed, they are more likely to be navigating employment, younger families, more active lives, and greater financial responsibilities (Fox et al., 2023; Giebel et al., 2020; Ottoboni et al., 2021; Popok et al., 2022). Additionally, services tend to be aimed at older people with dementia, meaning people with young-onset dementia can feel less heard, less supported, and bounce around from service to service more frequently than those of an older age in search of appropriate support (Giebel et al., 2020; Rabanal et al., 2018). With dementia typically thought of as an 'older person's disease', people with young-onset dementia can feel dismissed and often experience increased difficulty obtaining a diagnosis and subsequent relevant information afterwards, as most information is aimed at older people (Fox et al., 2023; Ottoboni et al., 2021).

However, people with dementia are capable of learning, adapting, and advocating for themselves and others (Popok et al., 2022; Swaffer, 2020; Talbot & Coulson, 2023). One such example of adaptation is the notion and practice of accepting their diagnosis. This has helped to make sense of their new circumstances and how to navigate their lives and enabled them to find

enjoyment in their present rather than worrying consistently about their future (Talbot & Coulson, 2023; Volkmer et al., 2023). People with dementia have also described using humour to help them cope and regulate emotional difficulties (Merrick et al., 2013; Popok et al., 2022). Those in advanced stages of dementia can also continue to express their humanity, needs, and wishes through everyday actions and expressions (Bøgmose et al., 2025).

1.4.2 Family members and supporters

The majority of care for people with dementia is provided by family members, often known as informal carers, family carers, care partners, or supporters, primarily by spouses, adult children, and sometimes children-in-law (Merrilees, 2016). As with people with dementia, the impact of the condition and caring duties are often felt before a diagnosis is obtained (Liu et al., 2020). It is reported that family members and supporters of people with dementia are more likely to feel a more negative impact of providing care than those of other chronic illnesses and mental health conditions (Merrilees, 2016; Nay et al., 2015). Possible reasons for this include the fact that assistance is needed for a wider variety of tasks, depending on the capabilities of the person with dementia, and more time tends to be spent caring for people with dementia in comparison to other conditions (Liu et al., 2021). One of the main concepts researched regarding the impact of dementia is 'caregiver burden', defined as stress carried by supporters who provide care for those with chronic illnesses (Merrilees, 2016). However, the term 'caregiver burden' has negative connotations for people with dementia, and therefore I shall be referring to the impacts of providing care, which are reportedly positive and negative.

Family members and supporters have reported increased levels of depression, increased mental and physical health problems, and decreased time for themselves (Gilsenan et al., 2022; Liu et al., 2021; Mahomed & Pretorius, 2022; Stokes et al., 2014). In addition, they also report a strong feeling of guilt, with research suggesting this is due to the thoughts or actions of moving their loved ones to residential or more formal care settings, any miscommunications or misunderstandings with their loved ones, and reorganising their priorities in their lives (Fletcher, 2021; Popok et al., 2022;

Quinn et al., 2010; Varik et al., 2020). An example of reorganising priorities could be reducing the time they provide support to their family member with dementia in order to meet deadlines and standards set at their workplace (Fletcher, 2021). There are also high levels of social isolation disclosed by family members and supporters of people with dementia, as they either remove themselves from social gatherings or are left out by others (Britton & Zimmermann, 2022; Bruinsma et al., 2022; Popok et al., 2022; Smith & Newbury, 2019).

Another complex phenomenon associated with providing care for loved ones with dementia is anticipatory grief, also known as 'living grief' (Scottish Intercollegiate Guidelines Network, 2023). This concept occurs in response to the known future death of a loved one, as well as other losses experienced due to demands relating to care (Dehpour & Koffman, 2023). For example, family members and supporters might grieve over a potential loss of freedom, considerable worry about the future, and anticipated changes over roles and competing priorities (Blandin & Pepin, 2017; Cheung et al., 2018; Fletcher, 2021). It can also be experienced through waiting for the next change and worrying about what that will bring (Brear et al., 2024). Although commonly linked to family members and supporters, anticipatory grief can be felt by people with dementia too (Waddington et al., 2025).

It is highly important to recognise that there are positive impacts of caring too. Providing care to family members with dementia has been reported to be associated with increased role satisfaction and emotional rewards due to fulfilling a sense of duty, as well as maintaining or improving relationships with the persons they are caring for (Lindeza et al., 2020; Lloyd et al., 2016; Quinn & Toms, 2018). They also report a sense of personal growth, with family members and supporters describing opportunities to learn more about themselves and an increasing confidence in their abilities (Lloyd et al., 2016). Resilience, adaptability, acceptance of the circumstances, and having coping strategies were found to be influential factors in positive experiences of dementia caregiving (Dias et al., 2015; Lloyd et al., 2016; Mahomed & Pretorius, 2022).

Family members and supporters are essential to ensuring and enabling people with dementia to live in their own homes as long as possible and often go to great lengths to do this (Redley et al., 2024). However, to maintain this, they need community services to meet their needs too, otherwise dementia would have a bigger impact on the healthcare system and its workers than it already does due to increasing reliance on residential care settings (McQueen, 2022; Rahja et al., 2020). In addition, negative health outcomes, both physical and mental, can diminish the abilities of families and supporters to provide the continuous support required, leading to increased demand for support for these experiences, including general health services as well as specific respite services (Dehpour & Koffman, 2023; Gilsenan et al., 2022; Roberts & Struckmeyer, 2018). This can add to the already intense workload of a stretched healthcare workforce and system.

1.4.3 Health and social care professionals

Primary doctors, healthcare providers, and specialists in dementia have a significant responsibility to strengthen and maintain the resilience of family members and supporters. These responsibilities include: providing opportunities for both people with dementia and their family members to be involved in the decision-making processes regarding the most appropriate steps to be taken after diagnosis, providing access to services, and offering educational resources and information necessary for family members to enhance their knowledge and understanding of their new role in caring for their loved one (Mwendwa et al., 2022; Roberts & Struckmeyer, 2018). Community healthcare workers also work to educate family members about the condition, and many describe feeling overwhelmed and helpless when family members, who undoubtedly knew their loved one, would not accept symptoms or the education provided (Hu et al., 2024).

Additionally, the diagnostic process, while difficult for people affected by dementia, can also be difficult for healthcare professionals. Yates et al. (2021) reported that healthcare professionals may experience uneasiness when disclosing the diagnosis and therefore use synonyms and descriptive language to talk about symptoms and terminology rather than being clear and explicit.

In addition, the workload of staff within care homes and hospital settings, for example, dealing with intense and extensive paperwork for each resident and the necessary conversations and formulations of care plans, meant that care staff could not provide the care they would wish to, due to a lack of time (Courtright et al., 2020), leading to excessive feelings of guilt (Midtbust et al., 2018). Healthcare workers often cited their desires to provide person-centred care and treat each person as the individual they are, but there were many systemic barriers to fulfilling their desires, including a lack of resources, lack of funding, and lack of workforce (Gil & Capelas, 2022; Øye et al., 2017; Rodgers et al., 2012; Steele et al., 2020). It is also reported that there was a lack of understanding by staff who did not care for people affected by dementia, and sometimes, even managers of care homes and hospitals. Scales et al. (2017) wrote that healthcare workers stated that managers would dismiss concerns or overlook them, leading to worsening dementia care and negativity around their own roles. Walmsley and McCormack (2016) reported that health professionals who did not work with people affected by dementia also invalidated and professionally disregarded the work provided by those caring for people affected by dementia. Furthermore, systemic stigma was noted through the names of the wards and pay structures of healthcare workers providing dementia care in comparison with other healthcare professionals (Walmsley & McCormack, 2016).

Providing end-of-life care for people with dementia is fraught with its own challenges for healthcare professionals. End-of-life care requires significant flexibility and adaptability due to the constantly fluctuating needs of not only the person with dementia, but their family members and supporters too (Abrams et al., 2019). As a result, staff developed boundaries to use as a protective factor, for themselves, the people they care for, and the organisation (Abrams et al., 2019). However, these boundaries can become difficult to maintain and lines can become blurred due to the unpredictable and ever-changing needs (Abrams et al., 2019). When working in end-of-life care, staff reported having difficulties detaching themselves from the people they cared for, having built close bonds with them throughout a difficult period in their lives, which added to any emotional difficulties experienced (Livingston et al.,

2012; Vandrevala et al., 2017). They often had to place significant boundaries and risk being seen as cold to protect themselves from the feelings of grief and the emotions and comfort-seeking of family members (Abrams et al., 2019; Vandrevala et al., 2017). Some staff have also described how care home residents were surrogate family and the loss of the resident reminded them of their own personal loss, exacerbating the impact of the death of someone with dementia (Livingston et al., 2012).

1.4.4 Health, social, legal, and financial systems

Dementia poses a great challenge to society (Osman et al., 2016; Wolters & Ikram, 2018). In 2019, approximately 57.4 million people had dementia around the globe (Global Burden of Disease 2019 Dementia Forecasting Collaborators, 2022). However, with the expanding global population and increasing life expectancy, it is predicted that 152.8 million will have dementia by 2050 (Global Burden of Disease 2019 Dementia Forecasting Collaborators, 2022). The number of people with dementia in low- to middle-income countries is increasing more rapidly than the numbers in high-income countries due to surges in life expectancy and a greater chance of risk factors (Alshahrani et al., 2024). As a result, it is expected that two-thirds of people with dementia will live in low- to middle-income countries by 2050 (Wimo et al., 2023; Wolters & Ikram, 2018).

The costs of dementia are huge; the annual global costs in 2019 were estimated to be US $1313.4 billion for 55.2 million people with dementia, equating to just under US $24,000 per person with dementia (Wimo et al., 2023). The cost breakdown was found to be as follows: 16% on direct medical costs, 34% on direct social sector costs, including long-term care services, and 50% on informal care costs. Despite the higher number of people with dementia in low- to middle-income countries, the overall spending for dementia was significantly higher in high-income countries, both total costs and per-person costs (Pedroza et al., 2022; Wimo et al., 2023). As the number of people with dementia increases, the financial cost is likely to rise substantially and it risks becoming an overwhelming societal issue (Pedroza et al., 2022; Winblad et al., 2016). To reduce the impact of dementia on persons

with the condition, their families, and the wider community, the WHO launched the 'Global action plan on the public health response to dementia 2017-2025' (WHO, 2017).

1.4.5 WHO's Global action plan on the public health response to dementia

The WHO global action plan was unanimously adopted by all 194 WHO Member States at the 70th World Health Assembly in 2017. The plan was grounded in seven cross-cutting principles, including the human rights of people with dementia, empowerment and engagement of people affected by dementia, and multisectoral collaboration on the public health response to dementia (WHO, 2017). It emphasises the need to integrate health and social care approaches and align actions taken with the developments in mental health, ageing, and non-communicable diseases (Burns & Robert, 2019). The goal of the plan is "to improve the lives of people with dementia and their families, while decreasing the impact of dementia on them as well as on communities and countries" (WHO, 2017, p.4). There are seven action areas complete with targets for the WHO Member States, among other stakeholders and partners, to implement in order to achieve the goal of the global action plan. Non-WHO Member States are also encouraged to follow the objectives of the plan. The action areas are:

1. Dementia as a public health priority
2. Dementia awareness and friendliness
3. Dementia risk reduction
4. Dementia diagnosis, treatment, care, and support
5. Support for dementia carers
6. Information systems for dementia, and
7. Dementia research and innovation

However, due to a lack of movement to achieve these targets by stakeholders and WHO Member States, it was decided that the WHO global action plan

would be extended to 2031 at the 78th World Health Assembly in May 2025 (WHO, 2025a).

1.5 Human rights

Human rights are basic to all individuals, regardless of individual and/or group status (United Nations [UN], 1948). The UN adopted the Universal Declaration of Human Rights (UDHR) in 1948, and it was the first document to set out fundamental rights that should be universally protected (UN, 1948). Examples of the rights to be protected include: 'the right to life, liberty, and security of person' (Article 3), 'no one shall be held in slavery or servitude…' (Article 4), and 'everyone has the right to recognition everywhere as a person before the law' (Article 6; UN, 1948). These rights can be categorised as negative and positive rights – in the UDHR, Articles 3-21 refer to negative rights, or civil and political rights, that require protection from infringements, whereas positive rights, or social, cultural, and economic rights, require not only protection, but realisation and fulfilment (Cahill, 2018). The UN declared that respect for human rights must be shown by the development and subsequent passing of rights laws at both national and international level (UN, 1948). By completing these actions and becoming parties to international treaties relating to human rights, States adopt obligations to respect, protect, and promote the human rights of their citizens.

Several conventions and legislations have been based on the UDHR. One such convention is The European Convention of Human Rights (ECHR). It was created by the Council of Europe and adopted in 1953 (Equality and Human Rights Commission, 2017) and protects the rights of persons living in countries that are Member States of the Council of Europe (Equality and Human Rights Commission, 2017). Alongside this, many countries in Europe have passed their own Human Rights Acts, including the United Kingdom. The Human Rights Act 1998 incorporates the rights described in the ECHR into UK law (Equality and Human Rights Commission, 2018). Outside of Europe, other countries and regions have formed their own treaties. For example, in Africa, the regional human rights treaty, the African Charter on Human and People's Rights, was adopted in 1981 and entered into force in

1986 (African Union, 2025). By 2000, Africa housed the largest number of governmental human rights commissions, although these commissions tended to only focus on civil and political rights, rather than include economic and social rights (Human Rights Watch, 2001). Despite the number of rights commissions, human rights violations are commonplace (Amnesty International, 2022; Human Rights Watch, 2001).

1.5.1 Convention on the Rights of Persons with Disabilities

Despite a significant number of signatories and ratifications of the UDHR, there are still numerous human rights infringements, particularly for people with disabilities. In response to this, the UN adopted the Convention on the Rights of Persons with Disabilities (CRPD; UN, 2006). People with disabilities were involved throughout the development and drafting of the CRPD, and are included within the CRPD Committee who receive reports from countries who ratify the Convention (Mittler, 2015). This human rights standard was the first to recognise people with disabilities as rights holders and that their disabilities and impairments cannot be used as a justification for denying them their human rights (Degener, 2016). In fact, Article 4 of the CRPD declares that 'State Parties undertake to ensure and promote the full realisation of all human rights and freedoms for all persons with disabilities without discrimination of any kind on the basis of disability' (UN, 2006). The UN's definition of disability appears in Article 1 of the CRPD and is as follows: 'persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (UN, 2006). Crowther (2016) argues that this definition undoubtedly includes people with dementia as beneficiaries of the CRPD. The Convention states that all persons despite disability or difference have the right to access health and social care that meets their preferences, needs, and experiences (Young et al., 2019).

As of the 22nd September 2025, the CRPD had been signed by 164 countries and ratified by 193 (UN, 2025). By signing the CRPD, countries agree to respect several of its obligations, whereas countries that ratify the

Convention enter an agreement in international law that the CRPD principles will be implemented in both policy and practice (Cahill, 2018). There are no new rights in the CRPD; the UN has reconfigured the rights from the UDHR to relate specifically to people with disabilities. It also includes ways in which States can demonstrate their work to uphold, protect, and promote the human rights of persons with disabilities. The Articles of the CRPD include 'equality and non-discrimination' (Article 5), 'freedom from exploitation, violence and abuse' (Article 16), 'living independently and being included in the community' (Article 19), 'habilitation and rehabilitation' (Article 26), and 'participation in political and public life' (Article 29). The CRPD principles have recently been endorsed by an expert panel of dementia stakeholders as quality standards for community dementia services (Panagiotidou et al., 2024).

However, it must be noted that people with dementia are not typically seen as members of the disability community. This is by other members of the disability community, healthcare professionals, and the general public (Shakespeare et al., 2019; Thomas & Milligan, 2018). Moreover, some people with dementia believe they do not belong in the disability community (Shakespeare et al., 2019). For the purposes of this research, we follow the argument that dementia is a condition that causes disability (Cahill, 2018).

1.6 Human rights in international dementia care

Around the world, there are concerns reported regarding the protection of human rights for people with dementia within dementia care (Steele et al., 2023). With the predicted life expectancy and global population increase, these issues will only get worse. In this section, I will provide some context for these human rights denials within care in relation to the CRPD principles.

1.6.1 The right to receive person-centred care

Person-centred care is an approach that focuses on the holistic needs of the individual requiring care (Love & Femia, 2015). It involves placing the person at the centre of their care, taking note of and incorporating their personal histories, culture, lifestyles, preferences, likes, and dislikes into care plans (Foth & Leibing, 2022). This approach to care demonstrates a move away

from the medical model of dementia to the more holistic biopsychosocial model (Love & Pinkowitz, 2013), deviating from the one-size-fits-all approaches previously used (Love & Femia, 2015). People with dementia, as well as their family members and supporters, should be included in all elements of their care (Mitchell & Agnelli, 2015). While not explicitly recognised by the CRPD, it could be said that person-centred care is a human right under Article 3 ('general principles'), which calls for respect for inherent dignity and individual autonomy of persons with disabilities, as well as their full and effective participation in society (UN, 2006).

Person-centred care follows the instrumental work of Carl Rogers, who argued that people with mental health conditions and psychosocial disabilities possess significant qualities, and they can draw from these qualities to find ways to help themselves, but only if they are provided with a supportive environment (Rogers, 1951). Tom Kitwood then related personhood to dementia, defining it as "a standing or status that is bestowed upon one human being, by others, it implies recognition, respect and trust" (Kitwood, 1997, p.8). Key to the principles of person-centred care is the concept of the person. However, what constitutes a person is under considerable debate, especially in the field of dementia.

The 'personhood and self' debate

The concept of 'person' is significant, because it has ramifications for human rights and other legalities (Foth & Leibing, 2022), although this is also deliberated (Ohlin, 2005). People with dementia, as discussed, are regularly positioned by others as 'lesser people' because of their impairments, particularly those of a cognitive nature (Caddell & Clare, 2010; Higgs & Gilleard, 2017; Strikwerda-Brown et al., 2019; Swaffer, 2014). The work of Kitwood to relate personhood to dementia is also subject to debate. Kitwood's definition of personhood places power onto those around the person with dementia to maintain and support personhood. Therefore, the social positioning of people with dementia by others then, by his definition, means that personhood is lost (Swinton, 2021), particularly with westernised views that cognition is essential for people to be considered 'persons' (Dewing,

2008). Additionally, if personhood is something that can be altered and varies depending on how others treat them, Higgs and Gilleard (2016) argue that the rights that people with dementia claim must also be subject to conversation and negotiation.

Intertwined with personhood, and often used synonymously, is the concept of the 'self'. The self is difficult to define, as emphasised by Caddell and Clare (2010). Sabat and Harré (1992) argued that there are different types of selves which contribute to overall selfhood; 'self one', where people take responsibilities for their own actions and are able to tell stories and relate experiences and feelings to others primarily using first-person pronouns (for example, 'I', 'myself', and 'mine'); 'self two', which comprises of a person's mental, physical, and emotional characteristics as well as the person's beliefs and desires, and; 'self three', the publicly presented version of ourselves, our roles, how we behave in social situations, and how others perceive and position us (Sabat & Harré, 1992).

From this view of what constitutes selfhood, it is possible to see where the argument that dementia contributes to a loss of self materialises, especially regarding 'self three'. However, as Sabat and Harré (1992) argue, dementia itself does not cause a loss of self, and only indirectly contributes to this. Following the work of Kitwood and personhood, 'self three' appears to be more susceptible to change than selves one and two. Hedman et al. (2013) reported that, in their study, people with dementia had no issues in expressing first-person pronouns and their 'self one', regardless of language deficits. They also found that some aspects of 'self two' had changed, but not necessarily for the worse as usually assumed; people with dementia were able to describe their traits and values, but that they had also been able to develop coping strategies and adapt to life with dementia. Rodgers (2018) reiterates this; the person diagnosed with dementia will remain the same valuable person with the same attributes, even if their mood and behaviours change throughout the trajectory of the disease.

People with dementia have reported experiencing treatment and behaviours from others that depersonalised and devalued them (Hedman et al.,

2013; Scales et al., 2017; Talbot et al., 2024). These behaviours were termed ‘malignant social psychology’ by Kitwood (1997), and includes behaviours such as infantilisation, disempowerment, stigmatisation, and invalidation (Mitchell & Agnelli, 2015). Malignant social psychology and its related behaviours tend to derive from negative attitudes and prejudices about dementia, particularly that nothing can be done about dementia and depictions that people with the condition are lesser humans (Higgs & Gilleard, 2017; Strikwerda-Brown et al., 2019; Swaffer, 2014, 2015). There is evidence to suggest that care providers want to use person-centred care practices and believe in the values of such care approaches, but the actual implementation is difficult, particularly in short-staffed, busy healthcare environments (Love & Femia, 2015), and therefore, care tends to be collectively informed rather than individualistic (Evans et al., 2018).

1.6.2 The right to legal capacity

Legal capacity refers to the right to make decisions about treatment, legalities, and everyday life and to have these decisions respected by others regardless of agreement (WHO, 2021a). It also refers to the capacity to “be both a holder of human rights and an actor under the law” (UN Committee on the Rights of Persons with Disabilities, 2016, p.3). Arstein-Kerslake and Flynn (2017) state that exercising legal capacity refers to also being a ‘legal agent’; that is, someone who can create, adapt, or erase legal relationships and make legally-binding decisions. The right to legal capacity is primarily protected by Article 12 of the CRPD (‘equal recognition before the law’; UN, 2006) and it underpins other human rights (Flynn & Arstein-Kerslake, 2014). Being diagnosed with dementia does not directly lead to a loss of the right to legal capacity (Halonen et al., 2024). However, there is a considerable misconception that having dementia means mental capacity is lost, and therefore people with dementia cannot decide things for themselves, and as a result, denials of legal capacity can occur (Steele et al., 2020). Regardless of mental capacity, people with dementia have the right to make decisions and have those decisions respected.

People with dementia can be denied opportunities to participate in decisions regarding their care plans and preferences (De Sabbata, 2020; Largent et al., 2023; Peel et al., 2016; Read et al., 2020; Smebye et al., 2012). This contravenes Article 17 of the CRPD, which states that people with disabilities have the right to make medical decisions and refuse treatments as everyone does (Davidson, 2025). If a decision is made by a person with dementia which others do not agree with, or a mistake is made during or because of the decision-making process, there is sometimes an assumption that the individual lacks capacity (Nedlund & Taghizadeh Larsson, 2016). People with dementia have reported that family members, supporters, and healthcare professionals have been reluctant to include them in the decision-making process (Donnelly et al., 2016; Read et al., 2020), denying the individual a chance to communicate their wills and preferences (De Sabbata, 2020). In some cases, decisions about people with dementia can be made for them, not with or by them, in a process labelled substitute decision-making, primarily by family members and supporters (Read et al., 2020). As a result, not necessarily deliberately, these decisions might be in direct conflict with the individual's wishes.

Decisions in dementia vary in context, importance, and complexity, ranging from decisions about day-to-day activities to decisions regarding potential research participation to significant treatment decisions, including health crises (Harrison Dening et al., 2016). And yet, it is noted that the more complex a decision becomes, the less support there is available for people with disabilities, including dementia, to help make the decision (Harding & Taşcıoğlu, 2018). Article 12 of the CRPD requires that when a person struggles to make an informed decision, they should be provided with support and measures that respect, protect, and promote their rights and wishes (De Sabbata, 2020; UN, 2006). These measures could include decision aids, such as videos, booklets, or tools which detail the decision to be made and possible outcomes, more in-depth guidance by healthcare professionals, supported decision-making, and/or advance care planning (Davies et al., 2019; Harrison Dening et al., 2016; Porteri, 2018; Sinclair et al., 2021).

Supported decision-making is one of the more thorough options to ensure that the legal capacity of people with dementia is upheld (Keeling, 2016). It involves taking time and care to explain the concepts, decisions, and potential outcomes, clarifying information if and when asked, and not rushing the individual into making the decision (Sinclair et al., 2021). Advance care planning, also known as advance care directives, is a process by which individuals can express their wishes and values for future care and treatment (Eisenmann et al., 2020; Piers et al., 2018). The process is seen as key to ensuring the most appropriate care for people in the future, including end-of-life care (Eisenmann et al., 2020), although there is a debate regarding their use in healthcare, particularly dementia care, as the wills and preferences of the individual may be different in the present compared to the wishes expressed in the past (Porteri, 2018). Therefore, it is recommended that advance care plans are reviewed regularly (Monnet et al., 2024).

1.6.3 The right to freedom from coercion

Coercive practices, or coercive methods, can be defined as any action that goes against the wishes of the person receiving care (Mengelers et al., 2019). From this definition, it is clear to see that denials of legal capacity contribute to denials of the right to non-coercive practices. The most reported coercive practices are restraints, seclusion, segregation, involuntary admission, and involuntary treatment (Atee et al., 2023; Gjerberg et al., 2016). Coercive practices have been classed as 'formal' and 'informal' within research; formal coercive methods are those typically regulated by legislation while informal coercive practices are not (Elmer et al., 2018). The right to non-coercive practices is protected by Articles 14, 15, and 16: 'liberty and security of person', 'freedom from torture or cruel, inhuman or degrading treatment or punishment', and 'freedom from exploitation, violence and abuse' respectively (UN, 2006).

The evidence suggests that coercive practices, particularly restraints, are used in response to BPSD. BPSD, also denoted as 'expressions of unmet needs' or 'changes in behaviour' (Alzheimer's Society, 2018), are symptoms which include delusions, hallucinations, anxiety, depression, verbal

aggression, and sleep disturbances (Cloak et al., 2024). Numerous forms of restraints have been identified in both literature and policies: physical, mechanical, technological surveillance, psychological, and chemical (Royal College of Nursing, 2008). People with dementia across the globe have been subjected to restrictions in their movements with the use of force by healthcare staff, locked doors, spongy chairs and a removal of wheelchairs and walking frames to make it difficult for people with dementia to get up (Gjerberg et al., 2016; Øye & Jacobsen, 2020; Pu & Moyle, 2022; Steele et al., 2020). Family members and supporters have been reported to sometimes participate in coercive practices to get their loved one to do something they did not want to do, including lying to the person with dementia (Gjerberg et al., 2016; MacKenzie, 2021). An example of this from the study was that an adult child lied to their mother with dementia to get her to shower and allow staff to help her maintain hygiene, by telling her that she was coming to visit despite no plans to (Gjerberg et al., 2016). This suggests that family members may participate not to harm their loved one, but to maintain their quality of life.

In addition to restraints, people with dementia have been known to encounter seclusion not only from the wider community, but from other persons within residential settings who do not have dementia (Graham, 2021; Steele et al., 2020; Steele et al., 2019). By using restraints such as locked doors, segregation can also materialise from a lack of communal activities and areas (Steele et al., 2019). People with dementia have expressed wishes to not be confined to residential facilities or be segregated, but these types of restrictions are not typically perceived as denials of their human rights (Steele et al., 2020). Forced admissions and treatment decisions have also been experienced by people with dementia. Decisions to admit and/or treat people with dementia against their will are primarily made by healthcare professionals, such as physicians and nurses, with family members occasionally consulted (Gjellestad et al., 2021). One example of forced or involuntary treatment is the use of antipsychotic medication and benzodiazepines. These are typically used as chemical restraints and for the convenience of healthcare workers (Ralph & Espinet, 2019). They can be

prescribed to control behaviour without the knowledge and consent of the individual taking them (Hegde & Ellajosyula, 2016).

Not all restrictive practices are used coercively; for example, it could be that a person with dementia has asked for a bedrail or medication to reduce the risk of falls from their bed (Farrell et al., 2025). However, when subject to coercive practices, and any other human rights infringements, people with dementia can struggle to make their voices and complaints heard, either because the impairments caused by dementia, such as language deficits, hinder them from being able to communicate, or because they may not be taken seriously (Cahill, 2018). According to the biopsychosocial model, BPSD are the result of interactions between a person's biology, previous experiences, and the current environment (Cloak et al., 2024), and therefore, it could be that the use of coercion exacerbates these symptoms. Sabat et al. (2011) write that protestations against their care by people with dementia tend to be seen as another symptom rather than the individual being unhappy and uncomfortable with the inappropriate care. Furthermore, people with dementia who attempt to live in the community, communicate with residents without dementia in the same residential setting, resist care, or participate in any communal activities have been labelled 'absconders', which in turn can cause more restrictions on movement (Steele et al., 2020).

1.6.4 The right to being included within the community

People with dementia have the right to live independently and have the same choices and opportunities as others. They should be allowed and encouraged to choose where they live, who they want to live with, and access a wide range of community services, both health-related and otherwise (WHO, 2017). This right is protected by Article 19 of the CRPD: 'living independently and being included in the community' (UN, 2006). Human beings, not just people affected by dementia, have a basic instinct and need to belong and be members of a community (Terras et al., 2019), and being excluded from the community has been linked to excess disability and lower levels of wellbeing (Jose & Cherayi, 2016).

As previously mentioned, the segregation of people with dementia in residential facilities influences community involvement within both the facility and the wider community outside (Steele et al., 2020). The lack of communal activities within residential settings leads to decreased social inclusion and interactions; Gebhard et al. (2024) conducted an observational study within 12 care homes in Germany and noted that most interactions that people with dementia had were with staff, otherwise they spent most of their time without social interactions. Locked doors and other environmental restrictions, both at home and in long-term care facilities, were other methods of denying the right to community inclusion. A further denial of community inclusion is the revoking of driving licences, which additionally denies freedom of movement, autonomy, and independence (Sanford et al., 2020). A lack of access to community services also contributes to infringements of the right to be included in the community (Giebel et al., 2023).

1.6.5 The right to participate in societal and political decisions

Participation, in relation to human rights, refers to people affected by dementia, particularly those with the condition, being involved in societal decisions, helping to design and deliver services and inform policies and procedures in their community, regardless of whether they are the direct recipients (Breuer et al., 2022; WHO, 2021a). It encompasses the concept of citizenship: having rights and responsibilities in the wider community (O'Connor et al., 2022). The right to participation is protected in the CRPD by Articles 29 and 30: 'participation in political and public life' and 'participation in cultural life, recreation, leisure, and sports' respectively (UN, 2006).

The importance of people with dementia and their family members participating in societal and political decisions cannot be understated and it is gaining more support from healthcare providers (Breuer et al., 2022). But in a recent review, the only European country examined where the participation of people affected by dementia in the development of care services was common was Finland, although there were efforts to increase participation in Greece and Sweden identified (Schmachtenberg et al., 2022). Additionally, they are not involved in discussions around other issues that affect and relate to them

(Oksnebjerg et al., 2018). Being unable to participate in the development and delivery of services and societal decisions goes against the desires of people with dementia and their supporters to be heard and involved (Prince, 2017; Rahja et al., 2020).

Moreover, there are instances where being enabled and encouraged to participate is seen as tokenistic, missing genuine engagement and want from the people in authoritative positions (Halonen et al., 2024). It was recently described by a couple with significant participatory experience that they felt that sometimes researchers and policy makers only approached them because ethics applications and journals seek patient and public involvement before research proposals and papers can be considered (personal communication, 20th February 2025).

1.6.6 The right to receive recovery-oriented care

Recovery-oriented care approaches refer to personal recovery. This type of recovery focuses on adapting to an illness and working to rebuild life to gain and maintain a good quality of life (Daley et al., 2013). One of the most widely accepted models of personal recovery is the CHIME framework (Bejerholm & Roe, 2018; Leamy et al., 2011). Within this framework, dementia services should provide holistic care that meets the differing needs of people affected by the condition, enabling them to stay connected to others both in their care and the wider community, have hope for the future, maintain their identity, live a life meaningful to them, and empower them to gain or regain control over their lives (Leamy et al., 2011).

Under this approach, people with dementia should be provided with rehabilitative interventions and care that aims to reduce the impact of dementia and support their optimal functioning – this is a human right itself protected by Article 26 of the CRPD (‘habilitation and rehabilitation’; UN, 2006). Recovery and dementia are not seen to be compatible due to dementia currently being incurable (Kristensen et al., 2024; Lowen et al., 2019), but this refers to clinical recovery, that is, the alleviation of symptoms. It is necessary to provide personal recovery-oriented care that enables and empowers people

with dementia to maintain optimism and find positive ways to meet their needs and preserve their sense of self (Daley et al., 2013; Gavan, 2011; Wolverson et al., 2024). There are increases in offers of rehabilitative support in post-diagnostic dementia services, even though the progress is slow and unequal across different income countries (ADI et al., 2025).

1.7 Understanding human rights infringements

Duffy et al. (2024) argue that care practices that deny human rights and are abusive exist on a spectrum, and inadequate standards of care emerge from systemic flaws. For example, residential care facilities tend to be run on very tight/small budgets which are controlled by operators who prioritise cost-effectiveness and returns in finances (Rodgers et al., 2012; Steele et al., 2020). Moreover, these owners might not be involved in the day-to-day operations and therefore do not see the realities of the care provided (Scales et al., 2017). Healthcare professionals, as well as family members and supporters, may also have to fight with and against a lack of resources, including a lack of time to spend with people with dementia and competing priorities (Courtright et al., 2020; Midtbust et al., 2018).

Other barriers to the full realisation of human rights for people with dementia and their families include economic, cultural, and organisational restrictions (Kupeli et al., 2018; Steele et al., 2020). Furthermore, there is a significant difficulty in maintaining the balance between the safety of the person receiving care and fully respecting, protecting, and promoting the individual's human rights (Backhouse et al., 2018; Evans et al., 2018). This is exacerbated by liability policies in residential care settings (Backhouse et al., 2018). Furthermore, the situation and barriers vary depending on cultures and regions around the globe. Many low- to middle-income countries, for example, are unable to benefit from improvements in pharmacological, psychological, and social developments in dementia care that high-income countries take advantage of (Uwakwe, 2000). It may also be that malignant social psychology occurs as a result of families and professionals trying to be kind; for example, by trying to make information clear, family members and supporters might talk as though they would to a young child in attempts to

make it easier for the person to understand, which can lead to infantilisation and ‘elderspeak’ (Zhang et al., 2020).

Approaches in dementia care must be adapted to respect, protect, and promote the full realisation of human rights for people with dementia as well as their supporters. Obtaining and sustaining an understanding of human rights, how they relate to people affected by dementia, and how these rights can be respected and protected within dementia care settings will ensure people affected by dementia are provided with care that will uphold their dignity, agency, and autonomy (Kelly & Innes, 2013).

1.8 Summary

People with dementia are one of the most vulnerable groups of people, subject to misconceptions about the condition, stigma, and discrimination (Mattsson & Giertz, 2020). As a result, they, as well as family members and supporters, can experience infringements on their basic human rights. This occurs despite legislation, both national and international, and human right standards such as the CRPD and the Glasgow Declaration launched in 2014 by Alzheimer Europe with strong endorsement from the European Working Group of People with Dementia (Alzheimer Europe, 2014), that specify rights to be upheld by countries. Following the global movement towards recovery-oriented, person-centred, and rights-based approaches to care within healthcare systems, and the WHO’s global action plan reiterating this to community dementia services, the scrutiny regarding rights denials for people with dementia has significantly grown. To ensure that the human rights of people affected by dementia are respected, protected, and promoted, a substantial international and intersectional effort is required to implement the WHO global action plan (Prince, 2017). Community dementia services must provide the most appropriate care to guarantee the full enjoyment of human rights for people affected by dementia. Therefore, there is critical work to be done to show services how they can implement recovery-oriented, person-centred, and rights-based care within a variety of legal frameworks.

1.8.1 Thesis aims

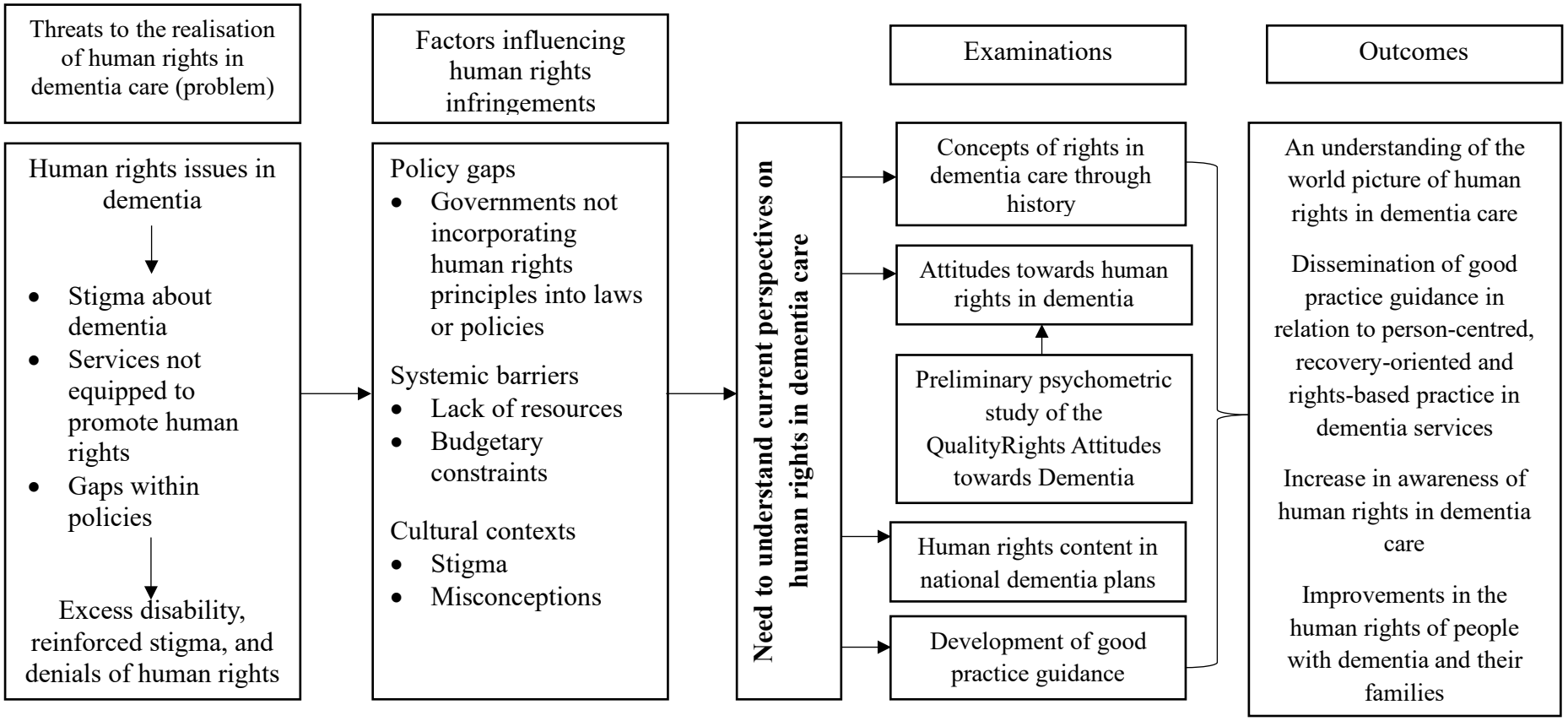
This doctoral research aimed to contextualise human rights in dementia care worldwide, working to produce a framework on which WHO guidance on recovery-oriented, person-centred, and rights-based care in community dementia services will be produced. To ensure a holistic overview of human rights in dementia is achieved, this research aimed to answer the following research questions:

1. How were human rights for people with dementia conceptualised in care throughout history?
2. What are attitudes towards human rights in dementia today?
3. Do governments around the world incorporate human rights principles in their national dementia plans?

This work, taken together, will provide a framework and methodology for the development of the good practice guidance. The thesis will thus provide context regarding past perspectives of human rights in dementia, before examining current attitudes and policies. Finally, this research will investigate the current care practices around the world to determine how well human rights are respected, protected, and promoted in community dementia services. Figure 1.1 shows how the current knowledge and PhD research will come together and produce the desired outcomes of an understanding of human rights in dementia, reductions and preferably eliminations of stigmatising attitudes and discriminatory behaviour towards people with dementia, and improvements in the respect, protection, and promotion of human rights.

Figure 1.1

Logic model demonstrating how the PhD informs the good practice guidance



2. A conceptual history of human rights in dementia care

2.1 Introduction

The concept of dementia as we know it today is relatively new. It is only in the last 125 years that dementia has been explained as a brain disease (Bosco et al., 2019). Before this, people with dementia have been seen as 'madmen' due to a loss of reason and cognition (Albert & Mildworf, 1989; Bosco et al., 2019). Consequently, the care and treatment of these people reflected these societal views and could deny them what we now consider basic human rights (Jenkins, 2017). It could be that previous attitudes and practices in dementia care have influenced care approaches in the present. Therefore, there is a need to explore the care of people with dementia and vulnerable older people throughout history to understand how past perspectives on rights inform current practices and policies.

A major reform occurred in 1948 with the development of the Universal Declaration of Human Rights (UDHR; UN, 1948), which was the first document to set out fundamental rights to be protected. Following on were the developments and subsequent adoptions of the European Convention on Human Rights and the African Charter for Human and People's Rights in 1953 and 1981 respectively (African Union, 2025; Equality and Human Rights Commission, 2017), However, people with disabilities were still subject to denials of their human rights within care services and wider communities, and as a result, the Convention on the Rights of Persons with Disabilities (CRPD) was adopted (UN, 2006). The CRPD was developed with disability activists, and it reconfigured the rights in the UDHR to relate specifically to people with disabilities, including dementia, and stated that physical, mental, intellectual, and sensory impairments are not reasons to deny human rights (Mittler, 2015; UN, 2006).

Despite ratifications of the CRPD, people with dementia can still experience infringements on their human rights today (Øye & Jacobsen, 2020;

Steele et al., 2023; Steele et al., 2020). These infringements occur due to barriers including societal attitudes, policies, legislations, and systemic obstructions (Backhouse et al., 2018; Duffy et al., 2024; Kupeli et al., 2018). Because these challenges to enabling the full enjoyment of human rights for people with dementia and their families may have arisen from historical attitudes and practices in dementia care, there is a need to better understand how past perspectives on human rights in dementia may have informed current policy, attitudes, and practices.

2.1.2 Aim

To examine historical concepts and the developments of ideas of human rights in dementia care.

2.2 Methods

2.2.1 Design

This broad, narrative, historical, and conceptual review investigated human rights in dementia care throughout history. A protocol for the methodology was developed and followed. All data were qualitative to allow an in-depth examination of the material. Content analysis was used to effectively analyse the large quantity of data (Elo & Kyngäs, 2008), with both deductive and inductive approaches utilised to incorporate all relevant information identified.

2.2.2 Data collection

Search strategies

Purposive searching was used to obtain empirical and secondary documentation to enable the most relevant information for this review to be identified and retrieved. A systematic search strategy was developed in consultation with an expert librarian (ED; see section 2.6). The search strategy (appendix 1) was employed on four databases (MedLine, PsycINFO, Scopus, and ASSIA), while BH conducted searches on Google Scholar and the University of Nottingham's library database (NUSearch) to find full-texts, grey literature, and hard-copies, including textbooks. These searches were

conducted with no publication date or language limitations. On Google Scholar and NUSearch, only the first 10 pages of results were examined for relevant documentation.

Eligibility criteria

As the enquiry had an extensive scope, the inclusion criteria were deliberately broad. Documents were to be included if they:

- were about dementia or 'senility' (or similar ageing-related decline suggestive of dementia in documents before 1950)
- were a primary or secondary[1] historical document about dementia and/or the care of persons with dementia
- reported on the history of dementia care and/or the care of the vulnerable elderly/older people and/or terms and conditions synonymous with dementia
- focused on the human rights or similar concepts of people with dementia and/or vulnerable older people and/or terms and conditions synonymous with dementia
- reported on milestones in dementia care, such as reforms in dementia care and/or dementia care legislation
- were in English or were amenable to translation into English

Documents were to be excluded if they only focused on the aetiology of dementia. We identified several tertiary[1] documents that did not add any new information, such as letters to the editor or commentaries on papers/symposiums. However, because the primary sources of information were either not identified within our searches or accessible, BH, in agreement with OM and MO, decided that tertiary documents that only provided a personal opinion would be excluded from analysis.

[1] Primary documents are those that are a first-hand, original source created at the time of the event, such as original literature or diaries; Secondary documents are those that analyse primary documents, such as academic articles interpreting primary documents; Tertiary documents are those which offer no original information or analysis, instead summarising information from primary and secondary sources, and they can include documents such as textbooks, timelines, and letters to an editor.

2.2.3 Data analysis

A deductive content analysis approach with flexible, inductive approaches included (Elo & Kyngäs, 2008) was chosen for this review. These authors suggest three phases of preparation, organisation, and reporting of deductive content analysis so that the rigour and robustness of the research process is ensured. One of these phases is to develop a categorisation matrix of codes and key words to look for in the data. BH produced an unconstrained categorisation matrix using CRPD principles and conceptual constructs in dementia such as 'the self' to streamline data extraction (appendix 2). Unconstrained matrices enable different, additional categories to be included within extraction through the use of inductive principles, allowing a broader analysis of the data (Elo & Kyngäs, 2008). To code the data in accordance with the matrix, BH used coloured post-it notes to give each code a colour (for example, light blue meant 'coercive practices' and bright orange meant 'milestones in care movements'). Initially, the coding was designed to be similar to the CRPD principles, but after several discussions, it was decided that using broader terms (as above) would enhance the quality of the data collected and achieve a more in-depth review.

Appraisal of secondary and tertiary sources

Quality appraisal was conducted on the secondary and tertiary sources using selected questions from an appraisal checklist for reviews on historical documents. The checklist was used in Bosco et al.'s (2019) review of the concept of dementia through time, which they adapted from the Critical Appraisal Skills Programme (CASP) appraisal checklists (CASP, 2025). The questions used to appraise the documents were:

1. did the authors look for the right type of documents? (hint: studies should be relevant to the scope of the study, and be a primary source [or consult different secondary sources to compare and contrast the validity and accuracy of the information reported])

2. did the authors favour the use of primary sources? (hint: see if the document reports the current contextual factors and if the document reports first-hand accounts)
3. does the review clearly discuss the findings in reference to the context within which it is situated? (hint: look for implication for policy and practice, and for historical determinants influencing current socio-political decisions)

Answers for these screening questions were 'yes', 'cannot tell', and 'no'. No sources were removed from analysis for clarity or lack of quality.

2.3 Results

An initial search was conducted on 16th March 2023 by ED, with an updated search completed on the 10th July 2024. BH completed the Google Scholar and NUSearch searches on the 23rd March 2023 and again on the 11th July 2024. A total of 11,471 documents were identified on the databases (Medline=6516; PsycINFO=3233; Scopus=1285; and ASSIA=437), with an additional 23 documents identified through the grey literature searches. After the removal of duplicates, 5227 documents were put forward for screening. See the PRISMA study flow diagram (figure 2.1).

2.3.1 Quality appraisal of sources

Overall, the documents included in the review were found to be of good quality in relation to authors looking for the right type of documents for their reviews and reports (table 2.1). Additionally, sources were of good quality regarding the discussion of their findings in reference to the context it was situated in. We did not use the appraisal questions for primary documents because it was not feasible.

2.3.2 Content analysis and themes

This section discusses the overall concept identified in the literature and the human right it refers to in accordance with the CRPD and the WHO's groupings used today (legal capacity, non-coercive practices, participation, community inclusion, and recovery-oriented & person-centred care; WHO,

2021a). Overall, three main themes were identified during the analytic process: 1) philosophical and ethical concepts of dementia, 2) lawmaking and the right to legal capacity and freedom from coercion, and 3) the self, personhood, citizenship, and the right to participation, community inclusion, and person-centred care.

Philosophical and ethical concepts of dementia

One of the main views of the Classical Antiquity period (eighth century BC to sixth century AD) was that cognitive decline was inevitable as people reached older age, with Pythagoras deeming people between the ages of 63-81 as 'senile' (Berchtold & Cotman, 1998; Poulakou-Rebalakou et al., 2012). In the fourth century BC, in Ancient Greece, Aristotle argued that reason is the primary characteristic of being a person, suggesting logical thinking and problem solving were some of the main attributes of being human (Jenkins, 2017). As the attitude was that older people inevitably declined cognitively and mentally, they were viewed as being insane or out of their minds (Berchtold & Cotman, 1998). Roman satirist Juvenal in the first century AD even branded cognitive and mental decline as severely degrading (Moog & Schafer, 2007). Being labelled senile had significant consequences, as people over the age of 63 were deemed no longer legally responsible for their actions (Moog & Schafer, 2007; Poulakou-Rebelakou et al., 2012). This philosophical thinking of the symptoms commonly associated with dementia nowadays led to ethical and legal debates about how best to care for those with dementia and the wider society.

Figure 2.1

PRISMA flow diagram of the search and screening process

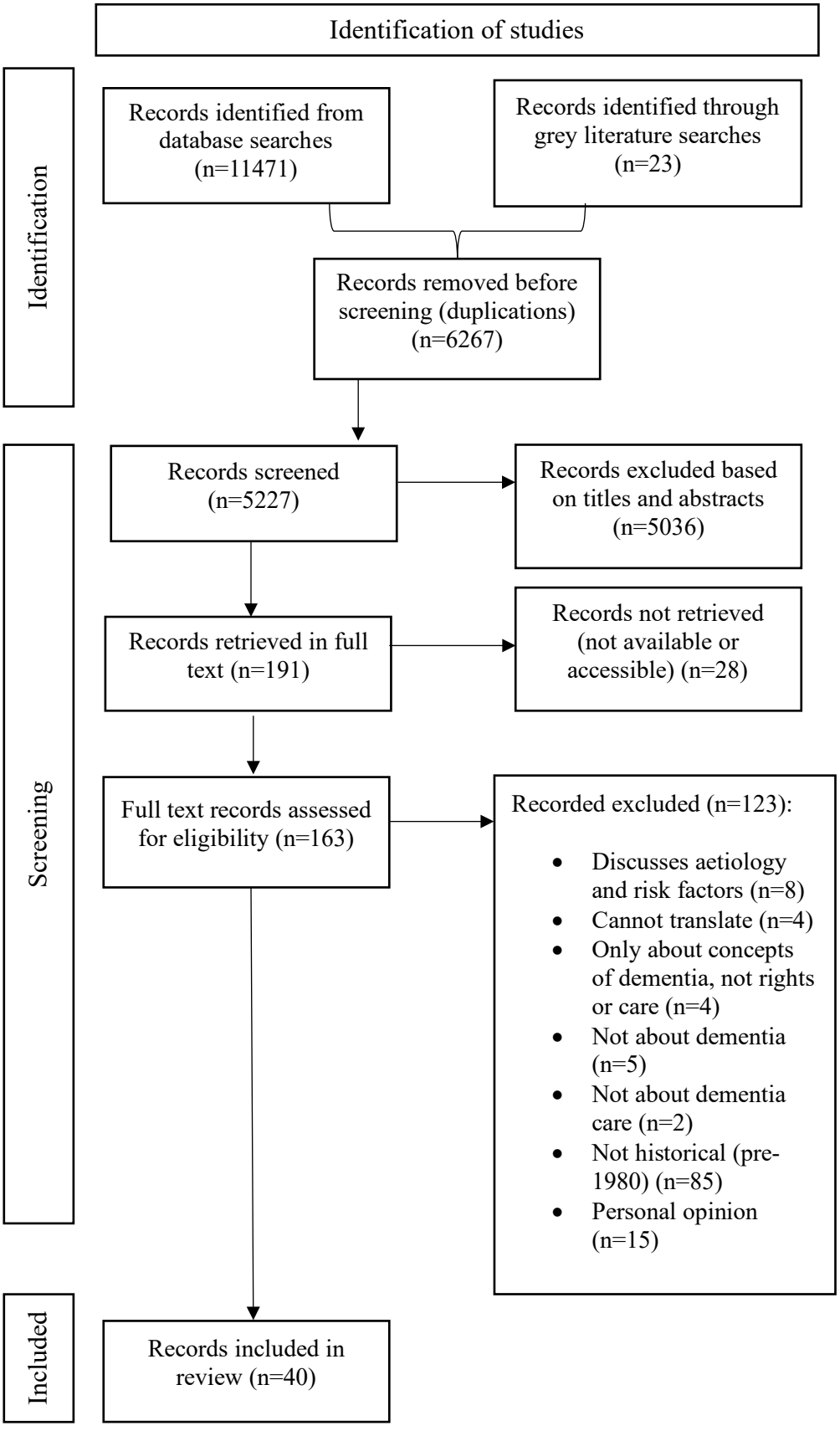


Table 2.1

Quality appraisal of the secondary and tertiary sources included in the analysis

		Screening questions		
Sources	Type of document	Did the authors look for the right type of documents?	Did the authors favour the use of primary sources?	Does the review clearly discuss the findings in reference to the context within which it is situated?
Andrews (2017)	Secondary	Yes	Yes	Yes
Appelquist et al. (2019)	Secondary	Yes	Yes	Yes
Berchtold & Cotman (1998)	Secondary	Yes	Yes	Yes
Callahan et al. (2013)	Tertiary	Yes	Cannot tell	No
Cohen & Kruschwitz (1997)	Secondary	Yes	Yes	Yes
Cokayne (2003)	Tertiary	Yes	No	No
Conolly (1830)	Primary	N/A	N/A	N/A
De Smet & Spautz (1989)	Secondary	Cannot tell	Cannot tell	No
Dudovitz (1985)	Secondary	Cannot tell	Yes	No
Engstrom (2007)	Secondary	Yes	Yes	Yes

Evans & Strumpf (1989)	Secondary	Yes	No	Yes
Federspiel & Keipes (2014)	Tertiary	Cannot tell	Cannot tell	Yes
Goffman (1961)	Primary	N/A	N/A	N/A
Hill & Laugharne (2003)	Secondary	Yes	Yes	No
Hilton (2015)	Secondary	Yes	Yes	Yes
Hilton (2016)	Secondary	Yes	Yes	Yes
Hilton (2014)	Secondary	Yes	Yes	Yes
Jenkins (2017)	Secondary	Yes	Yes	Yes
Kärrström (1986)	Secondary	Yes	Yes	No
Lacey (1999)	Secondary	Yes	Yes	Yes
Lauritsen (1988)	Secondary	Cannot tell	Cannot tell	Yes
Leão & Rhodes (2016)	Primary	N/A	N/A	N/A
Metzler (2016)	Secondary	Yes	Cannot tell	Yes
Montigny (1994)	Secondary	Yes	Yes	Yes
Moog & Schafer (2007)	Secondary	Yes	Cannot tell	Yes
More (1533)	Primary	N/A	N/A	N/A
Myers (1998)	Secondary	Yes	Yes	Yes
Nelson & Bernat (1989)	Secondary	Yes	Cannot tell	Yes

Papavramidou (2018)	Secondary	Yes	Cannot tell	No
Pinel (1806)	Primary	N/A	N/A	N/A
Poulakou-Rebelakou et al. (2012)	Secondary	Yes	Cannot tell	No
Roth (1955)	Primary	N/A	N/A	N/A
Scull (1981)	Secondary	Yes	Yes	Cannot tell
Thamby et al. (2021)	Secondary	Yes	Yes	Yes
Townsend (1962)	Primary	N/A	N/A	N/A
Vollmann (2001)	Secondary	Yes	No	Yes
Willis (1684)	Primary	N/A	N/A	N/A
Woodrow (1998)	Tertiary	Yes	Yes	Yes
Woodward (1850)	Primary	N/A	N/A	N/A
Yang et al. (2016)	Secondary	Yes	Yes	Yes

Lawmaking and the right to legal capacity and freedom from coercion

In the sixth century BC, Athenian lawmaker and judge Solon declared that wills were to be decreed valid unless the person making that will had impaired judgement through old age (Berchtold & Cotman, 1998; Leão & Rhodes, 2016; Papavramidou, 2018). This was echoed in the imperial decree Codex Justinianus, a collection of Roman laws and legal principles developed in sixth century BC, stating that old age alone was not a reason to invalidate a will, unless the person was of unsound mind (Moog & Schafer, 2007), and was further emphasised during the reigns of Diocletian and Maximian in the Roman Empire in the third and fourth centuries BC (Moog & Schafer, 2007). At the same time, the age of 60 or 65 was considered the age to be exempt from particular public and legal obligations, such as jury duties and mandatory attendance in the senate (Cokayne, 2003). However. during the Roman empire, the heads of families, known as 'pater familias', typically the oldest man, held significant legal powers over their families, and regardless of potential senility, were not primarily within the thoughts of legislators due to their high status in Roman society (Moog & Schafer, 2007).

Additionally, during the Roman empire, the Twelve Tables, which codified legal processes up to 450 BC, appeared to separate the individuals who would automatically be subject to paternal authority, particularly minors, and those who required care and guardianship due to the loss of mental abilities and a subsequent loss of independence (Moog & Schafer, 2007). Poulakou-Rebelakou et al. (2012) reports that these laws were in effect, particularly during the Byzantine empire (330-1453 AD), and people with dementia, or similar symptoms, were often provided with a legal curator, who would take control over their property and legal rights (Poulakou-Rebelakou et al., 2012). This can also be seen in the places people with cognitive decline were cared for. People with dementia, in the Byzantine Empire, were hospitalised in institutions known as 'morotropheia', which differed from the usual Byzantine hospitals, 'xenons', which served the poor, homeless, and sick (Poulakou-Rebelakou et al., 2012). The term 'morotro'

appears similar to that of ‘morosis’, a word used throughout history to describe ‘imbecility and mental slowness’ (Barrough, 1583). Interestingly, Barrough made distinctions between memory loss and loss of reason but still referred to dementia as ‘madness’, while ‘imbecile/ity’ was another word used to describe people with dementia, along with the term ‘madmen’ (Willis, 1684).

People who were seen as ‘mad’, including those with dementia, were often placed in lunatic asylums, madhouses, and workhouses, but only after their families could no longer look after them (Andrews, 2017). Moreover, people with dementia and older people could be committed to the asylums and madhouses without their consent or against their will (Townsend, 1962). These institutions were very custodial in nature, and people with dementia and vulnerable older people could be subject to chains, shackles, strikings, and harsh punishments (Montigny, 1994; More, 1533; Willis, 1684). Despite these institutions becoming the common place of formal care for people with dementia, particularly during the industrialisation period in the Victorian era, asylums and madhouses were seen as inappropriate places for people with dementia due to the belief that decline was incurable and symptoms of dementia were unmanageable (Andrews, 2017).

However, following the period of Enlightenment in Europe (17th-18th century), a time of intellectual and philosophical movements which emphasised reason, science, and humanity, the idea of ‘moral treatment’ was gaining more prominence. In the late 1700’s to early 1800’s, William Tuke and Dr Philippe Pinel called for more humanitarian treatments of people in asylums and hospitals, including the removal of chains, strikings, and beatings in favour of gentler forms of mechanical restraint, such as the straitjacket (Jenkins, 2017; Pinel, 1806; Tuke, 1813). Pinel was successful in arguing that madness was not a crime, but instead was a disease (Andrews, 2017), which was confirmed by Alois Alzheimer in 1906 (Alzheimer, 1906). Tuke and Pinel favoured treating the patients with compassion and respect, providing meaningful activities, and working with them to discover the difficulties each individual faced (Jenkins, 2017; Pinel, 1806; Scull, 1981;

Tuke, 1813). Vincent Chiarugi, an Italian physician of the late 1700's, also opposed the use of restraints and argued for more humanitarian reforms in the care of the mentally ill, encouraging occupational therapy, sanitary measures, and humane treatment of people within the mental hospitals (Cohen & Kruschwitz, 1997). In addition, John Conolly, a psychiatrist working in the Middlesex County Asylum in England, advocated for further benevolent reform, including the removal of mechanical restraints, writing that treating people with dignity, respect, quality medical care, providing liberal recreations and a therapeutic physical environment was key to their recovery (Cohen & Kruschwitz, 1997; Conolly, 1830).

However, in 1903, the Tooting Bec Asylum (which had the status of a workhouse) opened as a result of the complaints from other asylums that they were receiving too many patients who were only dealing with the senility of old age (Metropolitan Asylums Board, 1882-1883, as cited in Andrews, 2017). Tooting Bec became an institution primarily for those of older people with an unsound mind (Andrews, 2017), but here, people with dementia could still experience significant chemical and physical restraints, a common practice seen up to the 1950's (Hilton, 2014, 2015; Lacey, 1999).

The self, personhood, citizenship, and the right to participation, community inclusion, and person-centred care

Pinel's approach to dementia, alongside other humanitarian advocates, helped galvanise socially progressive approaches in dementia care (Jenkins, 2017). Carl Rogers, an American psychologist who was one of the founders of humanistic psychology, and particularly person-centred therapy, demonstrated a monumental shift in the care practices of people with dementia (Bartlett & O'Connor, 2007; Jenkins, 2017; Rogers, 1951). The concept of personhood, that is, the status of being a person, led to further models of care, including the social citizenship approach, which brought into focus the human rights of people with physical and mental health conditions and dementia (Jenkins, 2017). After the second world

war, the social citizenship model strengthened concepts of personhood, promoting the status of marginalized groups of people to that of other citizens (Bartlett & O'Connor, 2007). While citizenship has its roots in Roman society, it was reconceptualised to be inclusive of civil, political, and social rights (Bartlett & O'Connor, 2007). The citizenship model also emphasises the relationship an individual has with the State, so that while people have responsibilities to the State, the State also has responsibilities to its people (Council of Europe, 2025).

In 1948, the UDHR was adopted by the UN, listing 30 human rights to be fully protected for all persons. These rights included '[freedom from] torture or … cruel, inhuman and degrading treatment or punishment' (Article 5; UN, 1948). Despite this, in the 1950's, staff at institutions were still reported to patronise and 'speak down to' the vulnerable elderly in their care, depersonalising the people there (Hilton, 2015; Lauritsen, 1988; Townsend, 1962). In addition, staff were described as ignoring or nullifying the capacities and skills of people with dementia in their wards, often not recognising them (Townsend, 1962). Consequently, the self and identity of the person in these institutions is degraded further, as Goffman describes the boundaries placed between a person and their environment are disrespected (Goffman, 1961). After experiencing depersonalising treatment and the effects of institutionalisation, people with dementia were associated with taking the 'passive, sick role', suggesting disempowerment and a dwindling sense of self (Parsons, 1951, cited in Woodrow, 1998).

People with dementia were also segregated from not only the wider community, but other people within the institution. It has been described how people with dementia were 'discarded' to the back, hidden wards of hospitals, where people with 'no hope of recovery' were placed (Hilton, 2015; Lacey, 1999). They were chemically and physically restrained to their beds, and so-called 'parked' on the wards, and confined to wards due to locked doors (Lacey, 1999; Lauritsen, 1988). Chemical restraints were primarily used on those who refused treatments or were extremely agitated (Hilton, 2014). This was in spite of the

rising use of advance care directives and living wills, in which people with cognitive decline could record their wishes and preferences regarding future treatment while still able to make autonomous decisions (Nelson & Bernat, 1989; Vollmann, 2001). However, if the person was unable to make decisions, a guardian would be appointed to deal with matters of land and legal rights, as well as other rights regarding where the person lived (Dudovitz, 1985). In the 1960's and 1970's, in Denmark, it was legal for the doors of wards and other institutions to be locked under the Hospital Act and Mental Health Act (Lauritsen, 1988). Swedish legislation of the same time also stated that locked doors could be legally used, but only if the person being locked in was at risk of serious harm if they left the ward (Kärrström, 1986). Nevertheless, calls for more community-based care following biopsychosocial approaches (Engel, 1977) to dementia were increasing, and movements were made to ensure this occurred (Bosco et al., 2019; Innes, 2002).

2.4 Discussion

This was the first review to explore concepts of human rights in the care of people with dementia and vulnerable older persons throughout history. There is sufficient evidence that as early as the Roman and Ancient Greece period, many philosophers were thinking of what constitutes a person and what should happen if a person's cognitive abilities decline and they are thought of as no longer capable of being independent. This led to the development of mechanisms to care for people with dementia and synonymous conditions, including legislations regarding wills, guardianship, and different approaches in care. From the 1800's onwards, the concepts of dignity and respect began to rise through the arguments of Tuke and others.

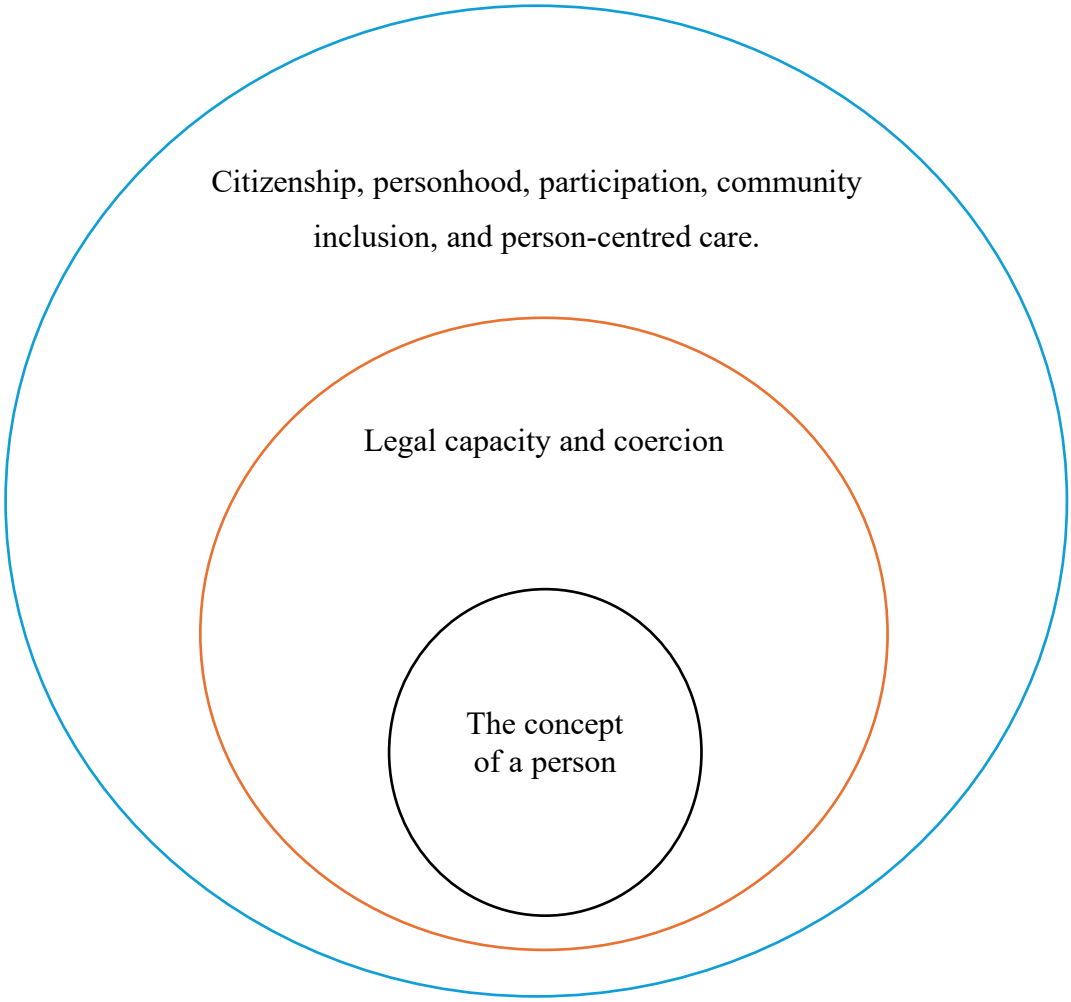
Today, there are still debates about the concept of a person and the self. Kitwood (1997) discussed that personhood is maintained by others around the person with dementia, and practices that stigmatise, disempower, and infantilise people with dementia reduce their personhood. Although there is evidence to

suggest that people with dementia are the same person regardless of their diagnosis, depictions and beliefs that a person with dementia is a lesser person have persisted (Strikwerda-Brown et al., 2019; Swaffer, 2014). Because of this, people with dementia can be denied the opportunity to make decisions regarding treatment and decisions can be made for them through substitute decision-making (Read et al., 2020). They can also be subject to coercive practices, exclusion from the wider community, and a lack of access to rehabilitative, recovery-oriented care approaches (Gebhard et al., 2024; Pu & Moyle, 2022; Steele et al., 2023) due to these stigmatising beliefs that have origins from ancient history. Therefore, this review has indicated how previous attitudes and practices have influenced the current human rights situation for people with dementia.

The review illustrates how philosophical thinking about what constitutes a person grew to ethical debates about how best to care for someone who is losing the attributes considered essential for being a person, such as rational thinking and problem solving. These debates progressed to work in the development of mechanisms that made care practices legal, such as the use of substitute decision-making, 'best-interest' actions, and the use of coercion. Finally, the idea that the state has a right and responsibility to their citizens and the concepts of participation, community inclusion, and person-centred care materialised. This led to further legislation and practices adopted to protect the human rights of people with dementia as it is known today. Figure 2.2 provides a visual representation of the progress described, demonstrating how each theme and concept changes to develop the next.

Figure 2.2

A visual representation of the development of human rights in dementia care



2.4.1 Methodological challenges

A major methodological problem of this study was how broad the search strategy had to be due to the different concepts of dementia and unknown terminology of human rights throughout history. For example, simply putting the term 'dementia' would have limited the relevant literature found because the condition as we know it today was only conceptualised in the early 1900's. Additionally, other conditions, such as schizophrenia, were referred to as 'dementia praecox'. A lot of sources initially found were removed during the screening process due to being about 'dementia praecox', and not dementia itself. In addition, the broad strategy

also meant a lot of other irrelevant literature was identified, leading to a longer screening process. Furthermore, the screening process was elongated due to the number of sources that did not have an abstract attached to the citation file provided by ED, and to ensure no relevant literature was incorrectly removed, BH searched for over 130 additional abstracts.

During the process, the eligibility criteria underwent several changes, meaning the screening and analysis had to be pushed back. However, additional criteria were needed after abstract screening was first completed in July 2023. This was because over 700 papers remained, either due to difficulties obtaining abstracts or limited information within the abstracts found, which led to concern over the potential of removing important sources. One example of the additional criteria was the removal of literature that focused on the aetiology of dementia only. Furthermore, full quality appraisal of the sources identified was not completed and not all sources included in the review, such as the tertiary sources, could be appraised using the full CASP guidelines with Bosco et al.'s (2019) adaptations.

2.4.2 Findings in the context of previous research

The findings of this review have provided a wide picture of the development of human rights in dementia, documenting how concepts of dementia and the care for people with the condition are interlinked and have changed throughout history. It is clear that the development of human rights for people with dementia has had a complicated history, as has the development of human rights in general (Mahlmann, 2023). Mahlmann reports that throughout the history of human rights, the attribute of reason and moral thought were the underpinnings of being afforded rights, a similar link to the attitudes of philosophers of Classical Antiquity. The idea that past attitudes and practices have shaped things today is not new. Bosco et al. (2019) argued that views and practices are maintained and emphasised through enculturation within different cultures.

The review has demonstrated how the care of people with dementia has led to denials of the human rights protected today by the UDHR and the CRPD. The CRPD was recently endorsed as a quality standard for dementia care (Panagiotidou et al., 2024), and therefore provides a good standard for our review to contextualise our findings. In Classical Antiquity, if someone was judged to be of unsound mind due to old age, that person could no longer make validated wills (Berchtold & Cotman, 1998; Leão & Rhodes, 2016). They were also subject to an appointed guardian who would take control over their civil rights and property (Moog & Schafer, 2007).

Guardianship, whereby a third party is appointed by a court to make financial and welfare decisions for someone deemed to lack capacity (Zietlow et al., 2022), is still a legalised practice today, but primarily as a last resort, for example, in the Mental Capacity Act of the UK (Mental Capacity Act, 2005). Additionally, the use of substitute decision-making is a common practice, whereby decisions are made for the person with dementia by healthcare professionals or family members (De Sabbata, 2020; Todd et al., 2021), usually based on ideas on the 'best interests' of the person. This means that resultant care and treatment could therefore go against the wishes and preferences of people with dementia, which in accordance with the CRPD, would deny them legal capacity and freedom from coercion. Supported decision-making is encouraged by the UN to reduce infringements of legal capacity; this process includes the provision of information and tools to help make informed decisions when help is needed (Cunha & Garrafa, 2023; UN, 2006).

Furthermore, coercive practices that have been used throughout history, such as mechanical restraints including being tied to beds (Andrews, 2017; Willis, 1684), and, later on, chemical restraints, including sedation (Scull, 1981; Townsend, 1962), have also been reported in recent years. Restrictions on movements have been identified in numerous care settings, with the use of technological surveillance, locked doors, spongy chairs, and the removal of walking aids reported in the 21st century (Gjerberg et al., 2016; Hofmann & Hahn,

2014; Pu & Moyle, 2022). Reasons for coercive methods include the pervasive stigma of dementia, particularly attitudes of healthcare workers, healthcare workers under pressure to complete tasks, and the safety of the person with dementia and others (Fetherston et al., 2024; Lejman et al., 2013; Moermans et al., 2022). Moreover, restraints and sedation were used to control the behaviour of people with dementia, particularly for those with increased behavioural and psychological symptoms of dementia (Atee et al., 2023; Ralph & Espinet, 2019; Steele et al., 2020). The controlling of behaviour was often also a reason for the forced admission to institutions (Scull, 1981).

The removal of people with dementia and vulnerable older people from the wider society to institutions constitutes a denial of the right to be included within the community as protected under the CRPD (UN, 2006). Additionally, the use of appointed legal guardians could exacerbate denials of community inclusion, as they could decide where the person with dementia would live, and hence with whom they can associate (Dudovitz, 1985). According to the CRPD, this decision should be made by people with dementia, either autonomously or with support. Moreover, we identified that people being cared for in institutions were treated as though they had no competences and skills, with staff ignoring these capabilities and depersonalising them. This can happen today, with the use of 'elderspeak' (using simplified language with older adults which sounds like how someone would talk to a baby; Shaw & Gordon, 2021); and patronising language used in community services (Zhang et al., 2020). 'Elderspeak' and treating them as children has a historical basis; Pythagoras likened the senium period of life (ages 60+) to the returning of childhood due to mental decline (Bosco et al., 2019).

2.4.3 Limitations

A strength of this review was the utilisation of a systematic literature search to enhance the quality of accumulated knowledge through three years of research. This has improved the reliability and validity of the review. Quality appraisal

assessments on the secondary and tertiary literature to determine the trustworthiness of the sources identified also helped to validate the conclusions drawn. Additionally, using an unconstrained matrix meant that a wider historical picture of the concepts of human rights in dementia care could be ascertained. But, due to the broad search strategy and differences between historical concepts and knowledge of human rights and dementia care today, extracting the exact relevant information was difficult. It required a lot of subjectivity and interpretation, a known limitation of qualitative research, meaning the conclusions cannot necessarily be called empirical.

Furthermore, the literature and sources identified in the searches primarily come from westernised and individualistic cultures, meaning the results may not be generalisable to those of collectivist, eastern cultures. Some of the sources removed due to an inability to translate them were from countries that could have bridged this gap. Also, no relevant information from the Middle Ages was obtained. Although dementia was seen as the consequence of sinning or witchcraft during this time period (Bosco et al., 2019; Yang et al., 2016), the care and treatment of people with dementia was not described. Berchtold and Cotman (1998) identified a similar problem for their review, stating that little is known about dementia and synonymous conditions during the Middle Ages, because the information appears to disappear after the Roman and Byzantine empires and becomes more prevalent again from the 18th century onwards. This means that the findings of this review are influenced by a significant gap in the historical timeline.

2.4.4 Future directions and implications

This review has demonstrated how the rights of people with dementia have been denied throughout history, subsequently providing context for the infringements that can be experienced today. It has also shown how legislations and treaties have come into play, specifically the UDHR and CRPD. Stakeholders in dementia can use these results to train workforces on the rights of people with dementia and

reduce stigmatising attitudes within care settings. The WHO's QualityRights training (WHO, 2022b) has been found to be beneficial in reducing stigmatisation, increasing awareness of human rights in mental health conditions and psychosocial disabilities, including dementia and have improved commitment to improve practices to achieve a reduction and full removal of infringements of human rights (Poynton-Smith et al., 2023; Wang et al., 2025). In addition, policymakers can use the findings to contextualise new laws and policies which abide by the CRPD principles to respect, protect, and promote the human rights of people with dementia.

The results of the current review have shown how attitudes and beliefs about dementia and cognitive decline have influenced practices throughout history leading to the attitudes and practices seen today. As a result, work should be completed to investigate the current attitudes towards people with dementia and their human rights to see how this relates to practices now. Accordingly, with the finding that policies and legislations enabled human rights denials, particularly regarding legal capacity and the use of coercive methods, research should be conducted on policies today to examine the human rights content.

2.5 Conclusion

This historical review has provided an informed picture of human rights within dementia care. The work shows progress from the idea of ageing leading to senility to laws on legal capacity if judgements were impaired by old age. Attitudes towards dementia throughout history have sometimes placed people with dementia in the same bracket as those deemed insane. Moreover, coercive practices and institutionalisation further restricted freedoms. These care practices can be seen today, meaning people with dementia can still experience infringements on their fundamental human rights. The WHO launched their 'Global action plan on the public health response to dementia 2017-2025', which aims to reduce stigma, increase access to better quality care and policies, and provide actions for countries to follow to ensure the human rights of people with

dementia and their families are respected, protected, and promoted. The practices and beliefs about dementia identified in the review have provided context of the human rights denials seen today in dementia care.

2.6 Acknowledgement

I would like to extend thanks to Elizabeth Doney of Nottinghamshire Healthcare NHS Foundation Trust's Duncan Macmillan House Staff Library, who worked with me to develop the systematic search strategy and then conducted the search on the four databases twice to ensure the literature identified was updated.

3. Predictors of attitudes towards human rights in dementia

3.1 Introduction

Dementia-related stigma exacerbates the difficulties faced by people with the condition and their family members and can significantly impede efforts to both provide and receive the most appropriate care and support (Nguyen & Li, 2020). These negative perceptions of dementia have perpetuated throughout history and continue to spread throughout cultures and societies (Bosco et al., 2019) and often stem from a lack of awareness and knowledge of the condition. The consequences of stigma are far-reaching and often detrimental to the quality of life of people with dementia, resulting in excess disability and infringements on their human rights (Gronholm et al., 2024; Siette et al., 2023). In order to improve this situation, it is important to better understand attitudes towards human rights in dementia.

Historically, dementia has mistakenly been conceptualised as a normal part of ageing (Alzheimer's Disease International [ADI], 2024; Mussie et al., 2022; Young et al., 2019). Furthermore, in Western cultures where cognition, such as memory and rational thought, has been discussed as being a core value in what makes a person a person (Bosco et al., 2019), this being lost means that an individual could be seen as having lost their personhood and humanity (Higgs & Gilleard, 2016), and therefore, they can be denied their basic human rights (Low & Purwaningrum, 2020). People with dementia can be denied the right to make decisions and have those decisions respected by others, be recognised as a person before the law, participate in societal and structural decisions, such as the design and delivery of services, experience exclusion from the community, and be subject to practices that go against the wishes of the individual, including methods of restraint, segregation, and seclusion (Breuer et al., 2022; Giebel et al., 2023; Gjellestad et al., 2021; Halonen et al., 2024; Largent et al., 2023).

People with dementia are often fighting against a double-stigma; not only are they subject to dementia-related stigma, but due to misconceptions that dementia only affects older persons, they also face ageist attitudes. Ageism is defined as the stereotypes, prejudice, and discrimination towards people based on their age causing injustices and disadvantages across generations (WHO, 2025b). The ADI recently identified that 80% of the global population believed that dementia is a normal part of ageing, and more worryingly, 65% of healthcare professionals believed this too (ADI, 2024). To facilitate efforts to reduce dementia-related stigma and subsequent denials of human rights, it is important to understand any underlying factors of attitudes towards people with dementia as holders of human rights.

3.1.1 Aim

This United Kingdom (UK)-based study aimed to examine whether demographic factors, attitudes towards dementia, and attitudes towards ageing are related to and predict attitudes towards people with dementia as rights holders. It was hypothesised that demographic factors, such as age, gender, experience, and ethnicity, influenced these attitudes, and that attitudes towards dementia and attitudes towards ageing would be associated with attitudes towards people with dementia as rights holders.

3.2 Methods

3.2.1 Design

Utilising a cross-sectional, quantitative, online survey design, data about attitudes towards dementia, attitudes towards ageing, and attitudes towards human rights in dementia in a UK-based sample was collected between July-September 2024. Ethical approval for the study was given by the Unit of Mental Health and Clinical Neurosciences ethics committee at the University of Nottingham (ID: 3170) on 26th June 2024.

3.2.2 Participants

To obtain participants, the study was advertised on the Join Dementia Research (JDR) platform. The JDR platform is funded by the Department of Health and delivered by the National Institute for Health and Care Research (NIHR) in partnership with Alzheimer Scotland, Alzheimer's Research UK, and Alzheimer's Society. JDR is a platform for researchers to recruit participants and anyone in the UK can register to participate in ageing- and dementia-related research. JDR also allows for proxies to register on behalf of people with dementia. Although joining JDR suggests that volunteers have the capacity to provide consent for their participation in studies, a consent form and information sheet was included on the first page of the survey, and it was presumed that reading these documents indicated the capacity to provide informed consent. Furthermore, to register on JDR, all volunteers must be 18+. All registered volunteers on the platform were eligible to participate as there was no additional inclusion or exclusion criteria. The platform locates all volunteers in the UK by region, and the current study was opened to volunteers one region at a time to ensure a smooth operation, starting with the East Midlands.

3.2.3 Materials and measures

Questionnaires used in this study were added onto one online survey (appendix 3) created on JISC Online Surveys v3. The survey also included a lay information sheet with space for participants to provide informed consent. The information sheet detailed the survey and the objectives of the study, how the participants data would be used, and that they could withdraw at any time. There was also a glossary attached to the information sheet page to provide definitions of some of the concepts included in the survey (appendix 4). A 'finish later' button was incorporated due to the length of the included measures and subsequent length of the online survey. At the end of the standardised questionnaires, a debrief sheet was presented with the researcher's details. On this debrief sheet was a link to an additional survey which enabled participants to enter their details if they wished

to be entered into a prize draw for a chance to win a top prize of £1000 in the form of an Amazon voucher or a second prize of a £250 Love2Shop voucher.

Dementia Attitudes Scale (DAS; O'Connor & McFadden, 2010)

The DAS is a 20-item scale with a two-factor structure: 'dementia knowledge' and 'social comfort' (O'Connor & McFadden, 2010). 'Dementia knowledge' refers to knowledge and beliefs about people with dementia, while 'social comfort' refers to behaviours and feelings of comfort around people with dementia. The DAS was designed to reflect the affective, behavioural, and cognitive components of an attitude. The original questionnaire uses the phrase 'Alzheimer's disease and related dementias' or 'ADRD', but for clarity, we changed this to 'dementia'. The items in this scale after wording changes included 'people with dementia can be creative' (on the 'dementia knowledge' subscale) and 'I am not very familiar with dementia' (on the 'social comfort' subscale). Each item is scored by a 7-point Likert scale (1=strongly disagree to 7=strongly agree), with six items reverse-scored. The overall score can range between 20-140, and a higher score indicates more positive attitudes to dementia. The scale has been found to have good internal consistency (α=.85; O'Connor & McFadden, 2010).

Attitudes to Ageing Questionnaire (AAQ; Laidlaw et al., 2007)

The AAQ is a 24-item questionnaire that measures attitudes towards ageing in three domains: 'psychosocial loss' (focuses on old age being a negative experience in terms of psychological and social losses), 'physical changes' (relating to health, exercise, and the experience of ageing), and 'psychological growth' (positive gains for the self and others that could have been surprising; Laidlaw et al., 2007). These three domains form three factors, each with eight items, for example: 'old age is a time of loneliness' (psychosocial loss), 'I don't feel old' (physical change), and 'it is a privilege to grow old' (psychological growth). Each item is scored using a 5-point Likert scale. For items 1-7, the scale ranged from 1=strongly disagree to 5=strongly agree, and for items 8-24, the

scale ranged from 1=not at all true to 5=extremely true, with the 'psychosocial loss' subscale reverse scored. The overall score could range from 24-120, while the subscale scores could range from 8-40. Higher scores indicated more positive attitudes to ageing. Each subscale has been reported to have good internal consistency using the Person Separation Index (psychosocial loss=0.81, physical change=.81, psychological growth=.74; Laidlaw et al., 2007).

WHO QualityRights attitudes scale (QRA; WHO, 2022a)

The QRA is a 17-item measure that examines attitudes towards people with mental health conditions and psychosocial disabilities as holders of human rights (Moro et al., 2024). The attitudinal statements were based on the Convention on the Rights of Persons with Disabilities (CRPD) principles. There are three subscales: 1) 'attitudes towards mental health services approach' (QRServices), 2) 'attitudes towards involuntary and coercive practices' (QRCoercive) and 3) 'attitudes towards people with mental health conditions and psychosocial disabilities as decision-makers and full members of society' (QRDecisions; Moro et al., 2024). For this study, the survey was adapted so that the items were dementia specific. The 17-items were scored using a 5-point Likert scale (1=strongly disagree to 5=strongly agree) and included statements such as 'you can only inspire hope once a person is no longer experiencing symptoms *of dementia*' (QRServicesD), 'involuntary admission does more harm than good'(QRCoerciveD), and 'people with *dementia* should not be given important responsibilities' (QRDecisionsD). Italics demonstrate the adaptations made. Three items are reverse scored, and the overall score can range from 17-85. Scores for the three subscales could range from 5-25 for QRServicesD and QRDecisionsD, and 7-35 for QRCoerciveD. The lower the score, the more positive the attitude towards human rights in dementia. The original scale was found to have good internal consistency (α=.86; Moro et al., 2024).

3.2.4 Patient and public involvement contributions

To ensure the survey, glossary, and lay versions of the aims and information sheet were clear, the documents were sent to patient and public involvement (PPI) contributors: two couples, one with dementia and the other a family carer, and one previous family carer. It was important to include people with lived experience to ensure a smooth research process and obtain any feedback of the research design and documentation. One piece of feedback received was that some of the questions were worded in ways that could be confusing to volunteers on the JDR platform. However, due to the standardised nature of the measures used in the study, the wording could not be changed because it would potentially decrease the validity and reliability of the measures. To compensate, we suggested adding a note to the information sheet in bold writing to state that we could not change the measures beyond what had already been changed for the above reasons, which the PPI contributors agreed with. The PPI contributors were paid for their time in accordance with NIHR guidance (NIHR, 2024).

3.2.5 Procedure

The survey opened on the JDR platform on the 17th July 2024 and closed on the 6th September 2024, with eligible volunteers notified of the opportunity to participate if they wished. To complete the questionnaires, the participants had to sign the information sheet to indicate informed consent and then provide a code memorable to them so that they could quote this and enable BH to locate their answers if they wished to withdraw their data. Following this, the participants were asked demographic questions regarding age, gender, experience of dementia, and ethnicity. The DAS, QRAD, and AAQ came next. To submit their answers, the participants clicked ‘submit’ at the end of the final questionnaire, which then brought them to the debrief sheet. From here, the participants could either click the link on the page to enter their details in the separate survey for the prize draw or simply close the browser window to finish.

3.2.6 Analysis

All statistical analyses were completed on SPSS version 29. Sum and mean scores were calculated for each scale and subscale, and relevant demographic variables (gender, experience, and ethnicity) were coded into binary. Three bivariate Pearson's correlations were conducted between: 1) age and the total QRAD score, 2) total DAS score and the total QRAD score, and 3) the total AAQ score and the total QRAD score. Relationships were considered moderate if above 0.4 (Dancey & Reidy, 2007). Independent samples t-tests were also conducted to determine any gender differences in the mean scores on the QRAD and its subscales. One-way ANOVAs were run to explore any differences between experiences and mean scores on the QRAD and its subscales with appropriate post-hoc analyses. Finally, to determine a more robust model of potential relationships, multivariate linear regression analyses were conducted to determine whether any of the variables predicted QRAD scores, both total and subscales, with the demographics, DAS and AAQ as the independent variables. The regressions used the Enter method. Due to the novelty of the examination, the chosen significant level was $p<.05$.

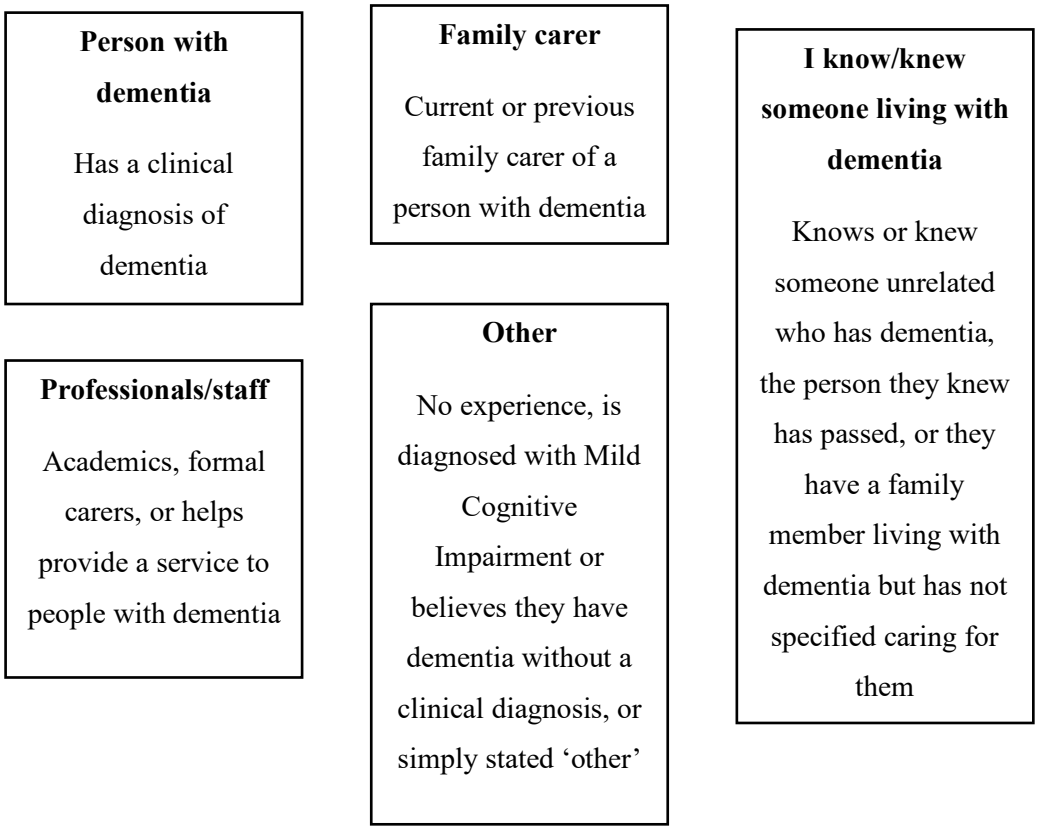
How the 'experience' variable was reorganised

The 'experience' demographic variable was re-sorted due to the low number of participants in some categories. While completing the survey, participants could choose from a drop-down list of eight options to demonstrate their experience with dementia. These options were: 1) person living with dementia, 2) family carer of a person with dementia, 3) formal carer of a person with dementia, 4) I know someone who has dementia, 5) dementia service provider, 6) dementia service worker, 7) dementia service volunteer, and 8) other (see appendix 3). Selecting 'other' enabled participants to provide a free-text answer describing their experience. However, to improve data analyses, the information provided by those who chose 'other' experience was revisited, then participants were recategorised into the rest of the categories where possible based on their most

recent experience. In this process, we decided to incorporate those who knew someone with dementia into the category 'I know someone with dementia'. Some participants could not be recategorised into other experiences, so they stayed as 'other'. Figure 3.1 shows the final categories and their included groups.

Figure 3.1

The reorganised experience variable and what each group encompasses



Data cleaning

After the reorganisation of the experience variable, the full dataset was examined for missing data. On inspection of the raw dataset, SPSS stated that there were 2497 valid cases, when the official sample size was 3144. However, when examining the different variables, it was found that at most, 30 participants' data were missing from any variable. As a result, any missing data were replaced through series mean imputation, meaning all cases could be preserved for analysis, as SPSS automatically deletes missing data from analysis. Series mean

imputation was the most appropriate imputation method due to the missing data occurring completely at random. It enabled the inclusion of large sample sizes within the analyses. For example, using the variable with the most missing data (DAS item 'we can do a lot now to improve the lives of people with dementia', 3114 valid cases), the mean before imputation was 5.80 with a standard deviation (*SD*) of 1.10. After series mean imputation, the mean remained the same with a slightly reduced *SD* (1.09).

After mean imputation, assumptions for each analysis were checked by BH. For the correlations, the assumptions of linearity and continuous data were met. For the independent-samples t-tests, meeting the assumptions varied by analysis. For all analyses, the assumptions that the independent variable and dependent variable would be categorical and continuous respectively, was met, as well as the assumption regarding independence of observations. The homogeneity of variance, tested by Levene's test for Equality of Variances, was violated on a couple of analyses (see results), and therefore the 'equal variances not assumed' row on SPSS was reported. For one-way ANOVAs, as with the independent samples t-test, assumptions regarding the independent variable, dependent variable, and independence of observations were met. Any outliers were also removed to enhance the accuracy of the analyses. However, the assumption of homogeneity of variance was violated for all ANOVAs, so the Welch's F result has been reported, as well as Games-Howell post-hoc tests. Finally, regression assumptions were checked. Linearity, homoscedasticity, and collinearity assumptions were all met. Residuals were also checked using P-P plots of the standardised residuals and were found to be graphically met. We also used Cook's distance to identify potentially influential data points. Using the recommended test value of -1/+1, we identified no data points over the threshold. However, there were standardised residuals outside of the range of -3/+3, suggesting extreme scores were present. Further explanation of how we dealt with these residuals is below.

For all analyses, normality was graphically checked using P-P plots and histograms and statistically checked using skewness and kurtosis statistics and the Shapiro-Wilk test. The Shapiro-Wilk test was chosen over Kolmogorov-Smirnov due to its power for larger sample sizes (Razali & Wah, 2011). While normality was met graphically, there were statistical violations for all groups of analysis apart from the ANOVAs. Referring to the Central Limit Theorem, which states that with a sufficiently large sample, the means will approximate a normal distribution (Kwak & Kim, 2017; Schwabe et al., 2015), no outliers were removed in the analyses reported below. Regarding the regression analyses, we ran the regressions twice: with all valid cases (n=3144) then with outliers/extreme scores (standardised residuals outside the range of -3/+3) removed, leading to different sample sizes in each analysis. However, upon inspection of assumptions, it was noticed that removal of outliers meant the independence of observations assumption, checked with Durbin-Watson statistics, was then violated, despite being met with all valid cases involved. We also identified that the results of the regressions did not majorly change when extreme scores were removed (see appendix 5 for examples of the regression sensitivity analyses).

3.3 Results

A total of 3144 participants responded to the survey, and all were included in the analyses. The mean age of the participants was 64.24 (*SD*=12.0). Three participants data were missing from this variable. Participants' ages ranged between 19-97, with 2676 (85.1%) aged between 52 and 81. The majority were female (n=2204, 70.1%). People with dementia (n=125) made up 4.0% of the total participants and family carers (n=824) made up 26.2%. Those who either know or knew someone with dementia accounted for nearly half (n=1520, 48.4%).

For people who were classified as having 'other' experience (n=242, 7.7%), the experiences included those who had no experience of dementia, those who believed they had dementia but were not formally diagnosed, those

diagnosed with mild cognitive impairment, members of the community that did not provide a service, or people who had simply stated 'other'. Nearly all of the sample were of White ethnicity (n=3058, 97.3%; see table 3.1). When examining the demographics, we decided to remove 'prefer not to say' and 'other' from the analyses due to the small numbers in these groups and forgo any analyses involving the 'ethnicity' variable due to limited representation from non-White participants.

Table 3.1

Demographic details of participants

Demographic	N	%
Gender		
Female	2204	70.1
Male	926	29.5
Prefer not to say/Other	14	0.5
Experience		
Person with dementia	125	4.0
Family carer of a person with dementia	824	26.2
I know/knew someone with dementia	1520	48.4
Professionals/staff in dementia care	433	13.8
Other	242	7.7
Ethnicity		
Asian or Asian British	26	0.8
Black, Black British, Caribbean or African	15	0.5
White	3058	97.3
Mixed/multiple ethnic groups	31	1.0
Other ethnic group	14	0.5

3.3.1 Overall attitudes towards human rights in dementia

The mean score regarding attitudes towards human rights in dementia was 41.03 (*SD*=8.22) out of 85. Scores ranged between 17-73. Table 3.2 demonstrates the spread of answers for each statement on the QRAD scale from the 3144 participants. The statements have been ordered according to the most positive attitude.

Overall, the attitudes across all items and subscales were widely distributed. The least strongly endorsed statement was 'people with dementia should always live in group homes where staff can take care of them', with 3.5% agreeing with the statement, suggesting that many participants believed that people with dementia can and should live at home within their wider community and should maintain independence and be empowered to do so. Additionally, under 6% endorsed the statement 'you cannot inspire hope once a person is experiencing symptoms of dementia' (5.8%), echoing the theme of empowerment and optimism. Most participants agreed with the statements that 'people using dementia services should be empowered to make their own decisions' (70.4%) and 'people with dementia have the right to make their own decisions, even if I do not agree with them' (65.1%), suggesting participants agree that people with dementia should have the right to legal capacity. However, many participants agreed that when a person with dementia experiences a crisis, decisions should be made for them by healthcare professionals or family members (40%) and just over a quarter agreed with the statement that people with dementia should not be given important responsibilities (25.8%).

Regarding coercive practices, over 70% of participants disagreed with the use of isolation within locked rooms (77.6%) and pressuring people with dementia and other people using dementia services to undertake treatment and support they do not want (73.5%). Furthermore, 63.8% disagreed that 'controlling people…is necessary to maintain order'. Despite this, 31.3% felt that involuntary admission does more harm than good for people with dementia, and 19.2% of

participants agreed that 'the use of seclusion and restraint is needed if people using dementia services become threatening'. This spread of attitudes indicates that attitudes towards involuntary and coercive measures is mixed.

It is important to note the high percentage of participants who provided 'neutral' or 'don't know' answers. Over 50% of participants stated neutral attitudes towards the statement that involuntary admission does more harm than good, and over 40% were ambivalent regarding whether medication was the most important factor to help reduce the impact of symptoms of dementia. Several other items had over 30% of participants stating neutral attitudes. For example, 37.1% of participants did not know whether the service environment had little to do with the wellbeing and mental health of people with dementia, and 36.8% reported neutral or don't know attitudes towards people with dementia being given important responsibilities. A further 34.1% answered neutrally with the statement 'people with dementia and related psychosocial disabilities should not be hired in work requiring direct contact with the public'.

3.3.2 Demographic factors of attitudes towards human rights in dementia

Older age was associated with more negative attitudes towards human rights in dementia, r=.19, p<.001. Additionally, females were found to have more positive attitudes towards human rights in dementia than males, with lower scores on the QRAD and its subscales compared to males (table 3.3).

Levene's test demonstrated that the only one-way ANOVA that did not violate the homogeneity of variance was that between experience groups and the subscale QRDecisionsD. Consequently, the results below, apart from the QRDecisionsD subscale, are Welch's F. Significant differences between experience groups in their attitudes towards human rights in dementia were found, F(4,580.95)=37.07, p<.001. Games-Howell post-hoc tests determined that professionals/staff reported significantly more positive attitudes towards people with dementia as human rights holders than people with the condition (p=.02). They also reported significantly more positive attitudes than family carers

(p<.001), those who know or knew someone with dementia (p<.001), and those with 'other' experience (p<.001). Family carers reported significantly more positive attitudes than people who know or knew someone with dementia (p<.001) and those with 'other' experiences (p<.001). The means, SDs, and ANOVA results of the subscales can be found in table 3.4.

3.3.3 Age, gender, and types of experience as predictors of attitudes towards human rights in dementia

The three predictors (age, gender, and experience) explained 5.4% of the variance (R^2=.054, F(3,3137)=59.32, p<.001). Age significantly predicted attitudes towards dementia and human rights (β=.11, p<.001), as did gender (β=2.35, p<.001), while experience did not (β=.22, p=.159).

3.3.4 Relationships between attitudes towards dementia, attitudes towards ageing, and attitudes towards human rights in dementia

More positive attitudes towards dementia were found to be associated with more positive attitudes towards human rights in dementia, r=-.52, p<.001, while a similar, yet weaker, relationship was identified between attitudes to ageing and attitudes towards people with dementia as rights holders, r=-.21, p<.001.

Table 3.2

Spread of answers across the QRAD in percentages

QRAD statement	Strongly agree / agree	Neutral or don't know	Strongly disagree / disagree
3. People with dementia should always live in group homes where staff can take care of them[a]	3.5%	12.21%	84.13%
16. People at risk of harming themselves or others should be isolated in a locked room[c]	4.23%	17.88%	77.55%
8. Following the advice of people who have lived experience of dementia (people with dementia and their family members and supporters) is too risky[c]	5.57%	25.51%	71.82%
6. You cannot inspire hope once a person is experiencing symptoms of dementia[a]	5.76%	14.44%	79.10%
10. It is acceptable to pressure people using dementia services to take treatment they do not want[c]	7.57%	18.70%	73.54%
14. Controlling people using dementia services is necessary to maintain order[c]	7.95%	27.70%	63.84%
7. People using dementia services should be empowered to make their own decisions about their treatment*[c]	70.42%	20.93%	8.30%
13. People with dementia have the right to make their own decisions, even if I do not agree with them*[c]	65.11%	25.41%	9.38%
4. People with dementia and related psychosocial disabilities should not be hired in work requiring direct contact with the public[c]	9.73%	34.13%	55.92%

9. The opinions of health practitioners about care and treatment should carry more weight than those of a person with dementia[b]	14.89%	32.09%	52.75%
2. The service environment has little to do with people with dementia's mental health and wellbeing[a]	15.59%	37.12%	46.56%
5. Taking medication is the most important factor to help reduce the impact of the symptoms of dementia[a]	16.44%	42.11%	41.38%
17. Involuntary admission does more harm than good*[c]	31.29%	51.34%	17.27%
15. The use of seclusion and restraint is needed if people using dementia services become threatening[c]	19.15%	32.00%	48.45%
11. People with dementia should not be given important responsibilities[c]	25.80%	36.83%	37.06%
12. When people with dementia experience a crisis, health practitioners and families should make decisions based on what is best for the person[b]	39.99%	31.52%	28.05%
1. Nothing can be improved within dementia services without additional resources[a]	45.26%	23.63%	30.95%

*reverse scored, [a]QRServicesD, [b]QRCoercionD, [c]QRDecisionsD

Table 3.3

Means, standard deviations, and t-statistics to showcase the differences between females and males on the QRAD

		QRAD	QRServicesD	QRCoercionD	QRDecisionsD
Female (n=2204)	Mean (*SD*)	40.06 (*8.04*)	12.18 (*2.90*)	16.34 (*4.03*)	11.53 (*2.90*)
Male (n=926)	Mean (*SD*)	43.44 (*8.09*)	12.66 (*2.83*)	18.44 (*4.26*)	12.34 (*3.01*)
t-statistic		-10.73	-4.19	-13.09	-.7.07
Significance	*p*-value	<.001	<.001	<.001	<.001

Table 3.4

Means and standard deviations of experience groups across the QRAD

Experience		QRAD	QRServicesD	QRCoercionD	QRDecisionsD
Professionals/staff (n=433)	Mean (*SD*)	37.56 (*8.72*)*	11.27 (*3.13*)*	15.62 (*4.33*)*	10.67 (*3.05*)*
Family carers (n=824)	Mean (*SD*)	39.89 (*7.99*)	12.07 (*2.90*)	16.24 (*4.20*)	11.58 (*2.96*)
Person with dementia (n=125)	Mean (*SD*)	40.46 (*9.43*)	12.59 (*3.13*)	16.86 (*5.32*)	11.01 (*3.24*)
I know/knew someone with dementia (n=1520)	Mean (*SD*)	42.31 (*7.72*)	12.59 (*2.74*)	17.57 (*3.93*)	12.15 (*2.86*)
Other (n=242)	Mean (*SD*)	43.44 (*7.95*)	13.16 (*2.57*)	17.96 (*4.15*)	12.32 (*2.76*)
Significance of overall ANOVA	*p*-value	<.001	<.001	<.001	<.001

*professionals/staff had significantly more positive attitudes than all other groups

3.3.5 Predictors of attitudes towards human rights in dementia

Attitudes towards dementia and attitudes towards ageing as predictors

Attitudes towards dementia and attitudes towards ageing were both found to predict attitudes towards human rights in dementia, with both explaining 27.6% of the variance (R^2=.276, F(1,3141)=598.55, p<.001). The multiple regression coefficients, and 95% Confidence Intervals (CIs) can be found in table 3.5. To identify whether there were any substantial differences between the DAS and AAQ regarding the variance explained, simple linear regressions with each of them as predictors were completed. Attitudes towards dementia explained 27.2% of the variance (R^2=.272, F(1,3142)=1172.58, p<.001) and significantly predicted attitudes towards human rights in dementia (β=-.29, p<.001). Attitudes to ageing explained 4.6% of the variance (R^2=.046, F(1, 3142)=151.13, p<.001) and significantly predicted attitudes towards human rights in dementia (β=-.14, p<.001).

Multiple regressions were then conducted regarding the DAS and AAQ subscales respectively. The DAS subscales 'dementia knowledge' and 'social comfort' significantly predicted attitudes towards human rights in dementia, explaining 28.2% of the variance (R^2=.282, F(2,1341)=615.80, p<.001). Regarding the AAQ subscales, the three predictors explained 5.6% of the variance (R^2=.056, F(3, 3140)=62.23, p<.001). Psychosocial loss (β=-.27, p<.001) and psychological growth (β=-.21, p<.001) significantly predicted attitudes towards human rights in dementia, but physical change did not. Due to the small effect size and variance explained by the whole AAQ, we decided not to report the regressions involving the AAQ subscales and the QRAD subscales (although these can be found in appendix 6).

Attitudes to dementia and attitudes to ageing as predictors of the QRAD subscales

Attitudes towards dementia and attitudes towards ageing significantly predicted attitudes towards the mental health/dementia services approach, explaining 13.0% of the variance (R^2=.130, F(2,3141)=234.72, p<.001).

Additionally, ‘dementia knowledge’ and ‘social comfort’ significantly predicted attitudes towards the mental health/dementia services approach, explaining 13.0% of the variance (R^2=.130, F(2,1341)=235.56, *p*<.001).

Attitudes towards dementia and attitudes towards ageing explained 19.9% of the variance (R^2=.199, F(2,3141)=388.97, *p*<.001), and both significantly predicted attitudes towards involuntary and coercive practices. ‘Dementia knowledge’ and ‘social comfort’ also explained 19.9% of the variance, significantly predicting attitudes towards involuntary and coercive practices in dementia, (R^2=.199, F(2,1341)=389.89, *p*<.001).

Attitudes to dementia and attitudes to ageing significantly predicted attitudes towards people with dementia as decision makers and full members of society, explaining 22.4% of the variance (R^2=.224, F(2,3141)=452.97, *p*<.001). Both ‘dementia knowledge’ and ‘social comfort’ significantly predicted attitudes towards people with dementia as decision makers and full members of society, with both predictors explaining 23.8% of the variance (R^2=.238, F(2,1341)=491.62, *p*<.001).

Table 3.5

DAS and AAQ regression coefficients relating to attitudes towards human rights in dementia

	QRAD	QRServicesD	QRCoerciveD	QRDecisionsD
DAS	β=-.28**	β=-.06**	β=-.12**	β=-.09**
	[-.30, -.26]	[-.07, -.06]	[-.13, -.11]	[-.10, -.09]
Dementia	β=-.41**	β=-.102**	β=-.16**	β=-.15**
knowledge	[-.46, -.37]	[-.12, -.09]	[-.18, -.14]	[-.17, -.14]
Social	β=-.22**	β=-.05**	β=-.11**	β=-.06**
comfort	[-.25, -.20]	[-.06, -.04]	[-.12, -.09]	[-.07, -.05]
AAQ	β=-.04**	β=-.02**	β=-.02**	β=-.01*
	[-.06, -.02]	[-.03, -.01]	[-.03, -.01]	[-.02, -.00]

*p<.05,**p<.001, **total scale in bold**

3.4 Discussion

This was the first survey of attitudes towards people with dementia as holders of human rights. Overall attitudes varied considerably, with many participants providing 'neutral' or 'don't know' answers to several questions. Over 50% of the participants responded 'don't know' regarding whether involuntary admission does more harm than good. This suggests a lack of knowledge regarding human rights in dementia. One statement that received particularly positive responses was 'people with dementia should always live in group homes where staff can take care of them', as over 80% disagreed. Moreover, over three-quarters of participants disagreed with the proposed practice of isolating people with dementia at risk of harming themselves or others in locked rooms. However, most participants agreed that people with dementia have the right to make their own decisions and should be empowered to do so but also agreed that decisions should be made for them when the person is experiencing a crisis. This suggests participants believed that the right to legal capacity should not be exercised by people with dementia under specific circumstances, infringing the principles of the CRPD.

Older age was associated with more negative attitudes towards human rights in dementia, and females in the current sample had significantly more positive attitudes than males. Moreover, professionals/staff held more positive attitudes towards rights in dementia than people with dementia, family carers of people with dementia, people who know or knew someone with dementia, and those with other experiences. In addition, age and gender significantly predicted attitudes, but different types of experience, such as being a person diagnosed with dementia or being a professional or staff member working in dementia care, did not. More positive attitudes towards dementia were related to more positive attitudes towards people with dementia as rights holders, as were attitudes towards ageing, albeit with a weaker relationship, suggesting differences between thoughts around ageing and dementia.

3.4.1 Methodological challenges

Within the analyses, almost all results were found to be significant at $p<.001$. The probability of finding a significant result is influenced by sample size, data variability, effect size, and the type of statistical test (Van Walraven & Austin, 2012). While aware of the potential for outliers to skew the results, hence removing them as part of the sensitivity analyses, the sample size within each analysis was still very large. Thus, 95% CIs were included within the reporting of some of the results to provide more information about the estimates. To account for this, the Bonferroni correction could have been used to reduce the probability of a Type 1 error, that is, rejecting the null hypothesis incorrectly (Emerson, 2020). The Bonferroni correction involves dividing the significance level by the number of tests (Emerson, 2020). However, there are concerns over the Bonferroni correction. Researchers have argued that by reducing the risk of a Type 1 error, the likelihood of a Type 2 error (incorrectly accepting the null hypothesis; Armstrong, 2014) is increased. This is because, depending on the number of tests performed, the significance level can become incredibly small, and it is therefore harder to achieve a statistically significant result (Andrade, 2019).

However, the likelihood of a Type 1 error is also dependent on the assumptions that must be met for each statistical test to produce valid and reliable results. The assumption checks completed before the analyses were conducted demonstrated statistical deviations from normality, regardless of the removal of outliers. Using the Central Limit Theorem principles, that the larger the sample size, the closer the sample means are to a normal distribution (Kwak & Kim, 2017), the full sample (n=3144) was analysed, with sensitivity analyses completed to examine any differences in results when the outliers were removed. In the regression analyses, the assumption of normal distribution was statistically not met, but all other assumptions were. But, once any extreme scores, determined by standardised residuals, were removed, statistical normality was still violated, specifically the kurtosis, and the assumption of the independence of observations was then also violated.

Additionally, BH, SMi, and MO received emails from a small number of participants on JDR to state issues with the questionnaires, both in a technological sense and a conceptual sense. Regarding the technical issue, a few participants wrote that they could not see all options for answering the questions, regardless of how much they scrolled across the screen or zoomed out in the browser, meaning it is possible the results would have differed if all options were available to these participants. Conceptually, some described they could not provide accurate answers due to the 'one-size-fits-all' approach to the questions, stating that dementia and its impact varies day to day, even minute to minute, and therefore their answers would have been 'it depends on ...'. A quote that summarises this point well is: "certainly the question of whether people with dementia should be treated against their will is an extremely complex and ethically difficult one, and merits more than a forced choice from agree/disagree boxes. When people lose their capacity to make rational decisions and, for example, start attacking others or putting themselves at risk of serious injury, then there is little else that can be done except curtail their freedom. That is not the same as saying 'people with dementia should be isolated'. But in practical terms, for severe and advanced cases, it may sometimes come to that, especially at night". Another participant argued that the different diagnostic types of dementia would also influence the answers given. This suggests that the results might be different if the questionnaire took account of the different stages and types of dementia. But it also highlights possible stereotypes associated with the severity of a specific subtype of dementia.

3.4.2 Findings in the context of previous research

Previous research has provided mixed findings regarding age and attitudes towards dementia (Brookman et al., 2025; Kim et al., 2023; Newton et al., 2021). Systematic reviews have also produced inconsistent results; Herrmann et al. (2018) identified that younger people held more negative attitudes than older people towards dementia, while Nguyen and Li (2020) found the opposite, and the results of the present study were in line with their findings. It is possible that younger people have higher levels of access to updated

information regarding dementia and therefore are more aware of the misconceptions of dementia (Zhang et al., 2023). Moreover, Brookman et al. (2025) found that younger people were more likely to make personhood-related statements in dementia, which has implications for attitudes towards and practices relating to human rights in dementia.

The results of the current study were also in line with those of Farina et al. (2020) and Kim et al. (2023), who reported that females hold more positive attitudes towards dementia than males. It is widely reported that females are more likely to be involved in the support of people with dementia than males, and that there are gender differences in the ways that care and support are provided. For example, males tend to focus on the functional aspects of supporting people with dementia, trying to restrict emotional attachment and see care-providing as a task-based exercise, while females spend more time on care-related tasks and provide a so-called more comprehensive approach to supporting their loved one (Gurayah, 2015; Poisson et al., 2023). Additionally, females have been regarded as having superior caring qualities compared to males, and thus become positioned as family carers before any support is required (Fletcher, 2021). As a result, it could be argued that females would be more likely to have more positive attitudes towards the human rights of people with dementia.

This study found that professionals and staff members associated with dementia care and research held more positive attitudes towards people with dementia as holders of human rights, followed by family carers, then people with dementia. This is inconsistent with previous literature. For example, a recent ADI report regarding stigma in dementia stated that the number of healthcare professionals reporting negative attitudes towards dementia had increased over the last five years (ADI, 2024). However, this ADI report focuses on the global picture, but studies conducted specifically in the UK have indicated a different story. For example, Cheston et al. (2019) reported that people working with people with dementia held more positive attitudes than those with no work or personal experience of dementia in regard to both hope and optimism for people with dementia and the recognition of

personhood. Moreover, the findings of this study, alongside Cheston et al., suggest that attitudes in UK health and social care professionals, as well as academics in the field of dementia, are not representative of the global context. However, professionals and staff in dementia services or research are more likely to receive training and be instructed to follow policies and standards (Brear et al., 2024), including those that incorporate human rights standards, so it could be expected, and indeed hoped, that professionals and staff hold more positive attitudes.

Finally, the current study found that more positive attitudes towards dementia and attitudes towards ageing were associated with more positive attitudes towards human rights in dementia. This fits with the findings of Tuntland et al. (2025), who reported that negative attitudes and misconceptions around dementia restrict reablement practices that would promote and enable people living with dementia to gain or regain control over their lives, living a life meaningful to them, and encourage them to participate socially and in activities. This is an example of recovery-oriented practice based on the CRPD principle 'habilitation and rehabilitation' (UN, 2006). Additionally, our study suggested that dementia and ageing are thought of in different ways, seen by the weaker relationships and predictive values identified in the analyses. This is despite the fact that the recent ADI 'global changes in attitudes to dementia' report identified that the misconception that dementia is a natural part of ageing is still widely held (ADI, 2024). While this was a global report, the current study was UK-based, suggesting differences between the UK and other regions. If this misconception was strongly believed in the UK, it would have been expected that the current study would have found relationships of a similar strength between attitudes to dementia, attitudes towards ageing, and attitudes towards human rights in dementia.

3.4.3 Limitations

A strength of this study was that the adaptations made to the different measures, particularly the QRAD, were verified by PPI contributors. By including people with lived experience in its development, the research method and findings would be more relevant and useful to those directly

affected by the topic, as well as resulting in better care and services (Staley et al., 2021). Additionally, the lack of exclusion criteria for recruitment meant that there could be a wide representation of age, genders, and experiences brought by participants to the study. However, the use of JDR may limit the generalisability of the results. People who sign up for JDR are those with a vested interest in dementia research and are more likely to be living with dementia, support someone who is, know someone living with the condition, or have an interest in the topic. So, their attitudes towards the human rights of people with dementia may be different to those in other sample populations. Moreover, there is a lack of ethnic diversity in this study, so the results cannot be generalised to other ethnic groups. This is challenging, because the evidence suggests cultural differences regarding beliefs about dementia, which could then influence attitudes towards the human rights of people with dementia (Farina et al., 2021; Metzelthin et al., 2024; Mussie et al., 2022).

Furthermore, online recruitment methods, such as JDR, may reduce levels of recruitment from those categorised within older age, ethnic minority, or poorer socio-economic groups. This could be due to a lack of internet access, limited internet literacy, or discomfort using technology. The most recent OFCOM report identified that in 2024, 6% of the adult (16+) UK population did not have internet access at home, and when split by age, over 20% of this group were aged 65+ (OFCOM, 2025). They also reported that in those aged 75+, an additional 8% had access to the internet but chose not to use it. To mitigate this, other forms of recruitment, for example postal surveys or advertisements in newspapers or shop windows, could be used.

The cross-sectional nature of this study also reduces our ability to understand attitudes and potential changes of attitudes over time. Attitudes have been reported to change over time, particularly if participants have undergone training to reduce stigma (Agudelo-Hernández et al., 2025; Poynton-Smith et al., 2023). Furthermore, using self-report measures within research brings risks. Participants may provide answers they believe will enact the changes needed in society, in this case, by answering attitudinal items more negatively. In contrast, it could be that participants provide socially

desirable answers by suggesting they have positive attitudes, when in fact, their answers are not truthful. Moreover, due to the analytical techniques used, it could be that there are confounding variables that influence attitudes towards human rights in dementia. For example, we did not control for people who may be familiar with human rights standards such as the CRPD. We also cannot infer causation between variables, particularly for correlation and regression analyses.

3.4.4 Future directions and implications

There is a need for in depth examinations of attitudes towards human rights in dementia in different cultural groups. There are many different cultural beliefs about dementia as a condition and the lack of diversity in this present study means we cannot be sure of any ethnic or cultural differences in attitudes specifically towards human rights in dementia. Furthermore, the survey could be administered at different time points to ascertain any changes in attitudes over time. Additional variables, such as further demographic variables, for example, educational background, or positive psychology concepts, including wisdom, could also be investigated regarding potential relationships with attitudes towards people with dementia as holders of human rights. More analyses could also be conducted in the form of mediation and moderation analyses to determine the strength of the relationships identified with or without other factors. Future research could also utilise qualitative methods to enable participants to express their attitudes and reasons behind them in more depth.

There are also implications for people living with dementia, their supporters, policymakers, and other stakeholders in dementia care. The findings suggested that people with dementia are not necessarily seen as rights holders by the current sample, which has an influence on the support and care received. Not being able to fully enjoy their human rights can have significant consequences on their quality of life (Gronholm et al., 2024). Therefore, this study highlights the need for awareness campaigns to not only reduce stigma around dementia but also educate the population on human rights issues within dementia. Although attitudes were not against human rights in

dementia, the number of participants who gave neutral or 'don't know' answers to several statements suggests a lack of knowledge of human rights for people with dementia, including the CRPD principles. The QualityRights initiative could be one such educational campaign, although it is not specific to dementia. Additionally, this study demonstrates the need for guidance regarding how services can protect, respect, and promote the human rights of people with dementia, particularly when looking at the number of participants who agree with the statement 'nothing can be improved in dementia services without additional resources'.

3.5 Conclusion

This is a novel study exploring attitudes towards people with dementia as holders of human rights. The results suggest that many people's attitudes are not supportive of human rights, in accordance with the CRPD, in dementia care. But these attitudes may be moderated by different demographic and conceptual factors. Moreover, there were significant numbers of participants who provided neutral answers, suggestive of a lack of knowledge of human rights and issues in dementia care. The study shows that there is a need for awareness campaigns in human rights, educational initiatives, and policy reforms to ensure that people with dementia are seen as rights holders, enabling and empowering them to live a life meaningful to them and have the full enjoyment of their human rights.

4. Preliminary psychometric examinations of the QualityRights Attitudes to Dementia scale (QRAD)

4.1 Introduction

In an effort to reduce human rights denials for people with mental health conditions and psychosocial disabilities, including dementia, the WHO developed and launched the QualityRights initiative (WHO, 2022a). This initiative was based on the Convention on the Rights of Persons with Disabilities (CRPD) principles and involves providing training to improve understanding and reduce stigma regarding people with mental health conditions and psychosocial disabilities (WHO, 2022a). As part of this objective, the WHO developed a scale to measure attitudes towards people with mental health conditions and psychosocial disabilities as rights holders. As part of the doctoral study into attitudes towards human rights in dementia, this scale was adapted to focus specifically on dementia. To our knowledge, there are no standardised or validated measures that specifically examine attitudes towards people with dementia as rights holders. Therefore, it is important to test the reliability and validity of the adapted measure.

Psychometric tests evaluate the psychometric properties of a scale, such as reliability and validity. The tests conducted can determine how accurate, useful, and relevant a scale is (Ohiri et al., 2024). Reliability refers to how consistent a measure is over time and in similar conditions, and there are several types of reliability that can be examined in a scale (Ohiri et al., 2024). Test-retest reliability concerns the consistency of a test administered over time, examining whether the results are the same when repeated (Roberts et al., 2006). Inter-rater reliability is the investigation of whether results of a test are consistent when different researchers perform the same assessment (Ahmed & Ishtiaq, 2021). Finally, internal consistency refers to the consistency of the measure itself, meaning that items on a scale should be capable of measuring the same construct (Bajpai & Bajpai, 2014).

Validity is defined as the extent to which a measure accurately measures the construct it is supposed to (Ahmed & Ishtiaq, 2021). Reliability is vital for a measure to be considered valid, but validity is not required for reliability, because a consistent test might not measure the desired construct (Ahmed & Ishtiaq, 2021; Ohiri et al., 2024). There are several types of validity. Content validity works to ensure the scale includes a representative set of items that relates to all aspects of the concept (Bajpai & Bajpai, 2014). Construct validity is defined as how well the scale measures the theoretical basis of the concept (Ahmed & Ishtiaq, 2021). Criterion validity is the measure of how the scale relates to other valid measures investigating the same or similar underlying concepts (Ohiri et al., 2024).

The WHO's QualityRights Attitudes questionnaire (QRA) was produced through an expert consensus approach (Poynton-Smith et al., 2023). Literature reviews were conducted to identify any existing measures relating to attitudes towards people with mental health conditions and psychosocial disabilities before the first iteration of the QRA was created, basing the human rights concepts on the CRPD principles (Moro et al., 2024). This draft was then sent to a group of stakeholders with a wide range of expertise, including human rights advocates, academics, organisations of people with mental health conditions and psychosocial disabilities, and members of the government. The feedback led to rounds of revisions and the second draft was reviewed by a second group of stakeholders before the final version was produced (Moro et al., 2024). The final scale had 17-items and included three subscales. While this scale includes questions relating to dementia, we needed to adapt the scale for use in the study previously discussed (chapter 3). In consultation with the WHO Policy, Law and Human Rights team, all items were reworded to pertain specifically to dementia (QRAD).

4.1.1 Aim

This study aimed to examine psychometric properties of the QRAD scale, looking at internal consistency, criterion validity, and construct validity, including a factor structure.

4.2 Methods

The majority of the methods, such as the design, participants, and measures used have been described in chapter 3.

4.2.1 QRAD and the adaptations made

To adapt the questionnaire to meet the aims of the previous study, we took each item and changed words and phrases to ensure the items pertained specifically to dementia. For example, 'people with psychosocial disabilities/mental health conditions should not be given important responsibilities' was changed to 'people with *dementia* should not be given important responsibilities'. To ensure our changes were clear, we asked a group of people with lived experience of dementia to look over our documents. A total of five patient and public involvement (PPI) contributors were consulted, including two couples consisting of a person with dementia and their family supporter, and one previous family supporter. The adaptations were accepted by these contributors, and they were paid for their time in accordance with the National Institute for Health and Care Research (NIHR) PPI guidance. The items for the QRAD can be found in appendix 3. The original scale (QRA) was found to have good internal consistency in a Ghanaian population (α=.86, Moro et al., 2024). Given the QRA was based on the CRPD principles, adapting the scale to ask dementia-specific questions would be valid, as a recent Delphi consultation endorsed the CRPD as a valid and reliable measure of quality practice in human rights in dementia (Panagiotidou et al., 2024).

4.2.2 Dementia Attitudes scale (DAS; O'Connor & McFadden, 2010)

The DAS was included as a scale with some similar aspects to the QRAD and was used to assess the criterion validity of the QRAD. Its properties are discussed in chapter 3 and the individual items are in appendix 3.

4.2.3 Analyses

Missing data were replaced by series mean imputation. This means we replaced all missing data in each variable with the overall mean of that

variable. Sensitivity analyses were completed before psychometric testing began. The full dataset of 3144 participants was found to statistically deviate from normality, although graphic representations appeared to show the data were normal. Using the Central Limit Theorem, which states that the larger the sample, the distribution of the sample means will be closer to normal (Schwabe et al., 2015), all analyses were conducted on the full sample. Sensitivity analyses were also conducted to determine the effect of removing outliers and the results are in appendix 7.

Reliability analysis: Internal consistency

We investigated the internal consistency of the QRAD and its subscales using Cronbach's alpha (Cronbach, 1951). Internal consistency refers to the consistency of participant responses across the items of the scale and it is argued that a Cronbach's alpha value of 0.7 and above indicates good reliability (Kilic, 2016). Reliability analyses were completed to determine how internally consistent the adapted scale was in the sample we recruited.

Criterion validity: Convergent and divergent validity

Criterion validity can be determined based on the strength of the relationships between different items on different scales, with moderate correlations stated to be those over 0.4 (Dancey & Reidy, 2007). The DAS and QRAD both measure attitudes towards dementia, but the QRAD scale specifically explores aspects of human rights. Nevertheless, some items on the DAS could be seen as asking questions related to the CRPD principles. Thus, it was important to examine any potential relationships between these individual items on the DAS and other items of a similar underlying construct on the QRAD, examining convergent validity (Mohajan, 2017). DAS items 'I am uncomfortable being around people with dementia' (Q6) and 'I would avoid an agitated person with dementia' (Q9) were predicted to moderately associate with QRAD 'controlling people using dementia services is necessary to maintain order' (Q14), 'the use of seclusion and restraint is needed if people using dementia services become threatening' (Q15), and 'people at risk of harming themselves or others should be isolated in a locked room' (Q16),

because they appeared to ask about coercive methods to deal with behaviours that challenge. Additionally, DAS items 'people with dementia can enjoy life' (Q14), 'I admire the coping skills of people with dementia' (Q18), and 'we can do a lot now to improve the lives of people with dementia' (Q19) were predicted to moderately correlate with QRAD item 'you cannot inspire hope once a person is experiencing symptoms of dementia' (Q6). These items appear to ask questions related to recovery-oriented and person-centred care practices.

Divergent validity, also known as discriminant validity, assesses the degree to which measures examining different constructs are distinct and thus have little to no association with each other (Mohajan, 2017). It was predicted that DAS items 'every person with dementia has different needs' (Q7) and 'I admire the coping skills of people with dementia' (Q18) would not correlate with QRAD item 'taking medication is the most important factor to help reduce the impact of symptoms of dementia' (Q5). This is because the DAS items suggest an underlying concept of hope and recovery-oriented and person-centred attitudes, but the QRAD item suggests there is no hope and medication is the only option. Additionally, DAS items 'every person with dementia has different needs' (Q7) and 'it is important to know the past history of people with dementia' (Q11) and QRAD item 'when people with dementia experience a crisis, health practitioners or families should make decisions based on their ideas about what is best for the person' (Q12) were predicted to not be strongly related. The DAS items appear to state that knowing the person is important in general and advocates for person-centred care, while the QRAD item relates to best-interest principles in decision-making, which is an infringement on a person's right to legal capacity (UN Committee on the Rights of Persons with Disabilities, 2016).

Construct validity: Confirmatory factor analysis (CFA)

Construct validity was examined using CFA on SPSS/AMOS v29. We wished to evaluate the three proposed latent factors: 1) attitudes towards the mental health/dementia services approach, 2) attitudes towards involuntary and coercive practices, and 3) attitudes towards people with dementia as decision-

makers and full members of society. The CFA was performed using weighted least squares, known as asymptotically distribution-free estimates in SPSS/AMOS v29. This approach was chosen due to the kurtosis scores of several items suggesting deviation from normality, but also to ensure the results were more accurate due to the large sample size (Browne, 1984). The estimation of the following goodness-of-fit indices were used to examine the model fit: Chi-Square (X^2) significance value (p<.05), Chi-Square/degrees of freedom ratio (CMIN/DF; ≤5), Comparative Fit Index (CFI; >.95), Tucker-Lewis Index (TLI; >.95), Root Mean Square Error of Approximation (RMSEA; <.06; (Hu & Bentler, 1999). Multiple goodness-of-fit indices are recommended to provide more accurate results. Furthermore, factor loadings were considered acceptable if they were >0.3 (Hair et al., 2010).

4.3 Results

4.3.1 Demographics of the participants

Overall, 3144 participants completed the wider study, including the QRAD. The full demographic details of the participants can be found in chapter 3 (page 58).

4.3.2 Reliability analysis: Internal consistency

Reliability testing was conducted on the total scale and its subscales for the full dataset (n=3144). The Cronbach's alpha score for the total QRAD (17-items) was α=.825, indicating good internal reliability. Upon examination of the item-total statistics, the removal of two items (Q1 and Q2) would slightly improve the reliability score. Removing the items one by one, starting with Q1, the internal consistency score moved to .833, before the removal of Q2 also led to the reliability score being .837. Finally, the item-total statistics indicated that removing Q17 would improve the reliability again; once removed, the 14-item scale had good internal consistency of .839. A correlation matrix of all 17-items can be found in table 4.1.

Subscale 1: 'attitudes towards the mental health/dementia services approach'

The subscale measuring attitudes towards the mental health/dementia services approach was found to have poor internal consistency within the current sample (α=.544) for all five items. The item-total statistics suggested that removing any items from the subscale would not improve the reliability score, although removing item one ('nothing can be improved within dementia services without additional resources') would not worsen the internal consistency of the subscale.

Subscale 2: 'attitudes towards involuntary and coercive practices'

This subscale had acceptable reliability (α=.752) with all seven items. The item-total statistics identified that the removal of item 17 ('involuntary admission does more harm than good') would slightly improve the Cronbach's alpha (α=.760), but the subscale would still demonstrate acceptable reliability.

Subscale 3: 'attitudes towards people with dementia as decision-makers and full members of society'

This subscale was found to have questionable reliability with all five items (α=.670). Investigation of the item-total statistics showed that the removal of item eight ('following the advice of other people who have lived experience of dementia… is too risky') would slightly improve the internal consistency score to α=.681. However, this meant the scale would still have questionable reliability.

Table 4.1

Correlation coefficients between the QRAD items (n=3144; a key word of each item is included)

	Q1[a]	Q2[a]	Q3[a]	Q4[c]	Q5[a]	Q6[a]	Q7[c]	Q8[c]	Q9[b]	Q10[b]	Q11[c]	Q12[b]	Q13[c]	Q14[b]	Q15[b]	Q16[b]	Q17[b]
Q1. Resources	1	.19*	.16*	.10*	.19*	.14*	.06*	.11*	.08*	.05*	.09*	.11*	.08*	.03*	.04*	.07*	.01
Q2. Environment		1	.18*	.13*	.20*	.19*	.13*	.17*	.11*	.11*	.14*	.07*	.13*	.16*	.12*	.15*	.01
Q3. Group homes			1	.34*	.26*	.31*	.22*	.23*	.31*	.27*	.27*	.17*	.20*	.30*	.22*	.29*	.15*
Q4. Not be hired				1	.20*	.34*	.26*	.19*	.32*	.24*	.47*	.18*	.24*	.31*	.25*	.23*	.12*
Q5. Medication					1	.21*	.17*	.20*	.28*	.22*	.20*	.22*	.15*	.25*	.21*	.23*	.07*
Q6. No hope						1	.26*	.22*	.26*	.27*	.32*	.18*	.21*	.32*	.19*	.23*	.09*
Q7. Empowered							1	.23*	.36*	.33*	.34*	.18*	.45*	.32*	.21*	.23*	.15*
Q8. Risky advice								1	.26*	.20*	.18*	.14*	.17*	.24*	.14*	.18*	.06*
Q9. Opinions									1	.43*	.37*	.26*	.33*	.35*	.29*	.27*	.19*
Q10. Pressure										1	.35*	.28*	.35*	.45*	.33*	.30*	.20*
Q11. Responsible											1	.30*	.33*	.39*	.29*	.24*	.13*

Q12. Crises	1	.20*	.31*	.27*	.21*	.16*
Q13. Decisions		1	.34*	.22*	.23*	.19*
Q14. Control			1	.45*	.40*	.1*
Q15. Restraints				1	.51*	.22*
Q16. Isolation					1	.13*
Q17. Involuntary						1

*p<.001

4.3.3 Relationships between attitudes towards dementia and attitudes towards human rights in dementia

As examined in chapter 3, attitudes towards dementia correlated moderately with attitudes towards human rights in dementia, r=-.52, p<.001. To explore this further, the subscales of the DAS, 'dementia knowledge' and 'social comfort', were correlated against the QRAD and its subscales: 1) attitudes towards the mental health/dementia services approach, 2) attitudes towards involuntary and coercive practices, and 3) attitudes towards people with dementia as decision-makers and full members of society (table 4.2). All relationships were significant but varied between weakly and moderately correlated.

Table 4.2

Correlation coefficients between the DAS and the QRAD (and subscales; n=3144)

	QRAD	QRServicesD	QRCoercionD	QRDecisionsD
DAS	-.52*	-.35*	-.44*	-.47*
Dementia knowledge	-.47*	-.32*	-.38*	-.45*
Social comfort	-.43*	-.29*	-.38*	-.38*

*p<.001, **full scale in bold**

4.3.4 Criterion validity: convergent and divergent validity

All items from the DAS were correlated against the individual items from the QRAD using all valid cases (n=3144; table 4.3). No correlations were above 0.4, suggesting no moderate relationships between items on the DAS and items on the QRAD. The highest association was found between 'people with dementia can enjoy life' (DAS) and 'you cannot inspire hope once a person is experiencing symptoms of dementia' (QRAD), r=-.38, p=.000, one of the predictions for a moderate relationship, suggesting the more someone thinks people with dementia can enjoy life after symptoms and diagnosis, the more they think hope can be provided to people experiencing symptoms.

In addition, analyses identified that the less someone feels uncomfortable around people with dementia, the less likely they are to believe that controlling people using dementia services to maintain order is needed (r=-.22, p<.001), seclusion and restraint is necessary if people in dementia services become threatening (r=-.21, p<.001), and people with dementia should be isolated in a locked room if they are at risk of harming themselves or others (r=-.18, p<.001). Additionally, participants who were less likely to avoid an agitated person with dementia were also less likely to think that controlling people in dementia services is necessary (r=-.21, p<.001), the use of seclusion and restraint is needed if people in dementia services become threatening (r=-.27, p<.001), and people with dementia should be isolated in locked rooms if there is a risk of harm (r=-.21, p<.001). Moreover, respondents who admire the coping skills of people with dementia are more likely to think hope can be inspired to people experiencing symptoms of dementia (r=-.23, p<.001), as are participants who believe that a lot can be done now to improve the lives of people with dementia (r=-.27, p<.001).

In addition, in terms of divergent validity, there were little-to-no correlations between some of the items. In relation to the predicted items that would not correlate, there were very weak relationships between the DAS item ‘every person with dementia has different needs’ and QRAD items ‘taking medication is the most important factor to help reduce the impact of symptoms of dementia’ (r=-.11) and ‘when people with dementia experience a crisis, health practitioners or families should make decisions based on their ideas about what is best for the person’ (r=-.09). Furthermore, there was a very weak association between DAS item ‘it is important to know the past history of people with dementia’ and the QRAD item relating to crises and decisions (r=-.05) as well as a weak correlation between DAS item ‘I admire the coping skills of people with dementia’ and the QRAD item regarding medication as the most important factor (r=-.07).

The weakest associations of all correlations were those involving Q1 (‘nothing can be improved within dementia services without additional resources’), Q2 (‘the service environment has little to do with people with dementia’s mental health and wellbeing’), and Q17 (‘involuntary admission does more harm than

good') of the QRAD, with no correlations over 0.2. Specifically, all correlations between items on the DAS and item one of the QRAD were all below 0.1, suggesting very weak relationships.

4.3.5 Construct validity: CFA

All valid cases (n=3144) were entered into the CFA and the model used weighted least squares. The cut-off values for goodness-of-fit indices described above were followed (Hu & Bentler, 1999). The Chi-Square value for the default model was significant, $X^2(116)=939.76$, $p=.000$, with a CMIN/DF ratio of 8.10, suggesting that the model does not fit the data well. The CFI and TLI were .67 and .61 respectively, also indicating a poor model fit. However, the RMSEA was .048, 95% Confidence Intervals (CIs) [.045, .050], suggesting the model fits well regarding error approximation. Upon inspection of the model, one item did not meet the threshold for factor loadings (Q1=.25), while Q2 (.35) and Q17 (.30) also had low but acceptable factor loadings. See figure 4.1 for the factor figure.

Table 4.3

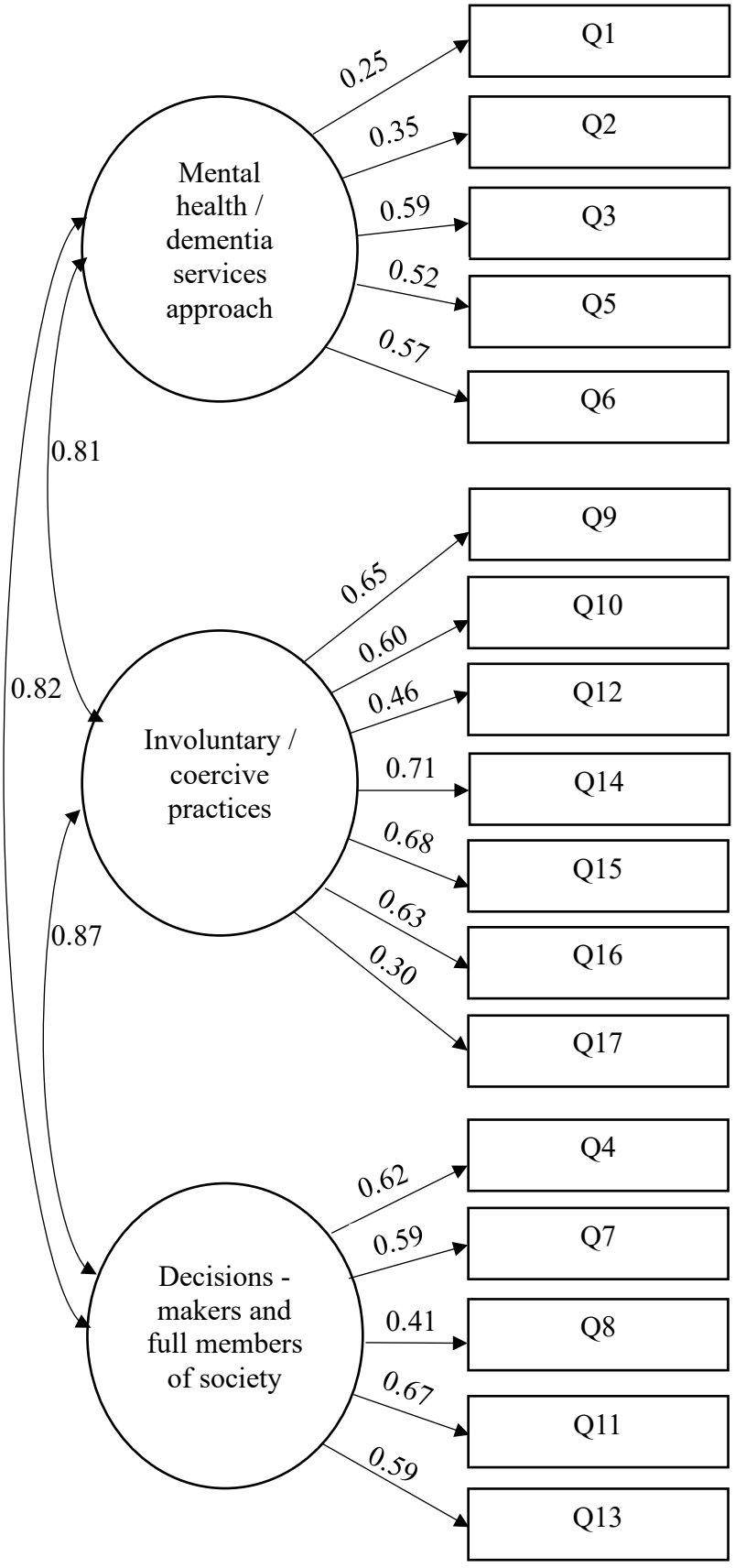
Correlation coefficients between the DAS and QRAD items to assess criterion validity (n=3144; a key word of each DAS item is included)

DAS	QRAD																
	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q15	Q16	Q17
1. Rewarding	-.04	-.11	-.16	-.26	-.09	-.28	-.24	-.15	-.20	-.23	-.27	-.12	-.21	-.22	-.21	-.16	-.10
2. Afraid	-.02	-.08	-.17	-.19	-.08	-.22	-.12	-.12	-.15	-.16	-.16	-.07	-.12	-.20	-.19	-.18	-.05
3. Creative	-.07	-.14	-.21	-.31	-.15	-.31	-.26	-.18	-.26	-.23	-.33	-.16	-.23	-.24	-.19	-.19	-.09
4. Confident	-.04	-.09	-.18	-.25	-.08	-.25	-.18	-.17	-.19	-.16	-.24	-.10	-.17	-.21	-.22	-.19	-.10
5. Comfortable	-.02	-.10	-.19	-.23	-.10	-.21	-.17	-.16	-.16	-.14	-.21	-.08	-.13	-.19	-.18	-.17	-.06
6. Uncomfortable	-.06	-.09	-.18	-.20	-.07	-.22	-.13	-.14	-.17	-.20	-.19	-.12	-.12	-.22	-.21	-.18	-.09
7. Different needs	.01	-.10	-.15	-.15	-.11	-.18	-.18	-.13	-.16	-.14	-.17	-.09	-.10	-.20	-.16	-.21	-.07
8. Not familiar	-.01	-.09	-.17	-.13	-.12	-.13	-.10	-.17	-.17	-.16	-.12	-.06	-.08	-.17	-.19	-.23	-.06
9. Agitated	-.05	-.08	-.16	-.22	-.08	-.21	-.14	-.13	-.20	-.18	-.22	-.13	-.14	-.21	-.27	-.21	-.09
10. Things nearby	.03	-.08	-.09	-.08	-.08	-.15	-.14	-.13	-.13	-.12	-.08	-.05	-.11	-.15	-.14	-.12	-.07
11. Past history	.05	-.10	-.06	-.04	-.07	-.11	-.15	-.13	-.12	-.11	-.09	-.05	-.05	-.12	-.14	-.12	-.06

12. Interacting	-.06	-.15	-.22	-.26	-.17	-.33	-.25	-.19	-.26	-.24	-.28	-.12	-.21	-.27	-.22	-.22	-.10
13. Relaxed	-.04	-.08	-.17	-.25	-.08	-.25	-.18	-.13	-.22	-.18	-.25	-.12	-.18	-.23	-.25	-.20	-.13
14. Enjoy life	-.09	-.16	-.24	-.29	-.13	-.38	-.27	-.18	-.24	-.22	-.27	-.14	-.25	-.26	-.19	-.18	-.09
15. Kind	-.07	-.18	-.22	-.21	-.16	-.29	-.26	-.24	-.26	-.20	-.21	-.12	-.22	-.28	-.21	-.22	-.09
16. Frustrated	-.06	-.13	-.15	-.14	-.08	-.18	-.11	-.13	-.17	-.15	-.17	-.11	-.12	-.19	-.17	-.18	-.09
17. Taking care	-.08	-.12	-.25	-.17	-.13	-.18	-.15	-.20	-.20	-.17	-.14	-.06	-.15	-.21	-.20	-.21	-.10
18. Coping skills	.03	-.08	-.12	-.20	-.07	-.23	-.21	-.12	-.14	-.15	-.21	-.08	-.16	-.16	-.12	-.10	-.09
19. Improve	-.05	-.13	-.14	-.19	-.07	-.27	-.21	-.16	-.14	-.17	-.20	-.11	-.17	-.16	-.14	-.13	-.09
20. Behaviours	-.03	-.16	-.15	-.20	-.13	-.21	-.26	-.17	-.22	-.18	-.22	-.13	-.17	-.21	-.21	-.20	-.08

Figure 4.1

Confirmatory factor analysis path diagram



4.4 Discussion

Overall, the QRAD showed good internal consistency, an acceptable factor structure, and good validity, within the limits of the data obtained. This suggests the QRAD has adequate psychometric properties regarding attitudes towards human rights in dementia. Internal consistency of the QRAD was examined on the whole sample (n=3144) and the scale had good reliability, while the different subscales ranged between poor to acceptable reliability. This indicates that the items within the whole measure the same underlying construct.

Although the removal of some items would improve the reliability score, this improvement would have been very minimal. The analyses indicated that removing items Q1 ('nothing can be improved within dementia services without additional resources'), Q2 ('the service environment has little to do with people with dementia's mental health and wellbeing'), and Q17 ('involuntary admission to services does more harm than good') would slightly improve the internal consistency of the QRAD. Additionally, removing items 1 and 17 would have slightly improved the Cronbach's alpha score of their respective subscales.

To ensure the scale was valid, correlations were conducted between items on the DAS and the QRAD, before completing a CFA to determine whether the hypothesised latent factors described above were valid. The correlations between the DAS items and the QRAD did not demonstrate moderate relationships, often characterised as >0.4 (Dancey & Reidy, 2007). Instead, all correlations were weak, suggesting that even if similar concepts appear to be measured in both scales, there are significant differences in the underlying concepts of the items. This is unsurprising, because the DAS was created to specifically examined dementia knowledge and social comfort around people with dementia while the QRA, and thus the QRAD, were developed based on the CRPD principles and therefore examine attitudes towards human rights in dementia.

The highest correlation was found to be between two items theorised to be moderately related to each other ('people with dementia can enjoy life' and 'you cannot inspire hope once a person starts experiencing symptoms of dementia'; -.38). These items appear to relate to the hope and empowerment of people with dementia, a human rights aspect demonstrated by CRPD Article 26 'habilitation and rehabilitation', as well as the personal recovery CHIME framework (Leamy et al., 2011).

The factor analysis conducted also demonstrated that the latent factors hypothesised were valid subscales. However, Q1 did not meet the set factor loading threshold of 0.3 and therefore, questions remain over the importance of this item on the scale. Additionally, Q2 and Q17 had low but acceptable factor loadings. This could be due to the large sample size analysed potentially influencing the results (Knoke, 2005). Upon examination of the inter-item correlations (table 4.2) of all QRAD items, Q1, Q2, and Q17 had the lowest correlations with the other items, corroborating the factor analysis results. Items 1 and 2 arguably do not constitute human rights elements as protected by the CRPD, instead investigating attitudes towards policy, practice, and therapeutic nihilism. However, the same cannot be said for Q17, which clearly examines attitudes towards involuntary admission to services, a human right protected by the CRPD under Articles 14, 15, and 16.

4.4.1 Methodological challenges

The goodness-of-fit indices used to validate the factor model were inconsistent, with only one (RMSEA) of the five indices used suggesting good model fit. Lai and Green (2016) state that this is not uncommon for analyses using structural equation modelling, but it is important to understand why it occurs in a study. It is known that sample sizes, particularly, larger sample sizes, can influence the goodness-of-fit indices, particularly the Chi-Square statistic (Knoke, 2005). Additionally, our data were nonnormal, and CFA assumes the normality of data, but it is unknown how to define RMSEA and CFI indices when data are nonnormal (Lai & Green, 2016). Due to the inconsistencies of model fit, our factor model must be considered with caution.

The assumption of normality was violated in all analyses conducted. Regardless of the removal of outliers, the statistical normality was still violated. In addition, the results of the sensitivity analyses indicated little difference in the results between analyses with or without outliers. Consequently, we followed the principles of the Central Limit Theorem due to the large sample size (Schwabe et al., 2015). Violation of normality, however, could influence the results and increase chances of a Type 1 error, meaning the null hypothesis may have been wrongly rejected as we conclude there is a significant result when in reality there is not (Kim, 2015).

4.4.2 Findings in the context of previous research

The findings support those of Moro et al. (2024) who reported that the original QRA scale has good validity and reliability. Their research identified that the QRA questionnaire, measuring attitudes towards people with mental health conditions and psychosocial disabilities, had a good internal consistency (α=.86), while the adapted scale had a Cronbach's alpha of .83. However, Moro et al. (2024) reported that the internal reliability of the subscales was either moderate or good, with the 'services' subscale scoring .61, the 'coercion' subscale scoring .77, and the 'decisions' subscale Cronbach's alpha .75, while the current study found Cronbach's alpha scores of .54, .75, and .67 respectively. These scores suggest poor, acceptable, and moderate internal consistency of the QRAD subscale (Kilic, 2016). The present study also found that the removal of some items would slightly improve the internal consistency of the total QRAD and its subscales, whereas Moro et al. (2024) did not report this. It is possible that these differences are due to the different populations who responded to the questionnaire, but also because the questions were adapted to relate specifically to dementia. The progressive nature of the condition could mean that the questions related differently than to those of mental health conditions and psychosocial disabilities that have a higher chance of clinical recovery.

The QRA scale was based on and developed in line with the CRPD, as people with lived experience of mental health conditions and psychosocial disabilities, as well as human rights advocates, were involved in the process

(Moro et al., 2024). Moro et al. examined face validity by asking seven stakeholders, including people with lived experience, and reported the scale appears to measure attitudes relating to human rights and is easy to understand. The adapted scale was also found to be clear to understand by the PPI contributors who helped us adapt the scale. It can be inferred, therefore, that the QRAD appears to measure attitudes towards human rights in dementia based on the CRPD as the items on the original scale were not dramatically adapted. This is important, because Panagiotidou et al. (2024) reported that a Delphi e-consultation fully endorsed the CRPD principles as quality standards for human rights in dementia, providing face validity for the QRAD. They did, however, also find that clarification around the CRPD principles explicitly for dementia was desirable due to the complexities of the CRPD being implemented in practice in care aspects such as capacity assessments and protection from abuse, neglect, and discrimination.

Moreover, the psychometric results of this current study identified adequate convergent and divergent validity in comparison to the DAS. These analyses indicate that the QRAD does in fact measure what it is meant to. Stronger correlations were identified between items that appeared to measure attitudes towards hope and optimism in dementia, as well as items measuring attitudes towards negative opinions and coercive practices. But items that did not appear to have similar underlying constructs were found to have very weak associations, providing the QRAD with divergent validity. Moro et al. (2024) reported that the QRA had convergent and divergent validity when compared to subscales of the Community Attitudes towards the Mentally Ill scale (Taylor & Dear, 1981). This scale included items related to social restrictiveness, benevolence, and authoritarianism, which, in relation to the CRPD, examined attitudes towards community inclusion, equal recognition before the law, and recovery-oriented and person-centred approaches.

The present research also confirmed the three latent factors hypothesised by Moro et al. (2024). This provides strength in the argument that the QRA scale is a robust measure that can be adapted to different populations. However, Moro et al. (2024) reported that all items met the 0.3

factor loading threshold, while one of the items in the current study did not. This study also identified that two other items were close to the threshold of 0.3. These low loadings were identified on items 'nothing can be improved in dementia services without additional resources (Q1), 'the service environment has little to do with people with dementia's mental health and wellbeing' (Q2), and 'involuntary admission does more harm than good' (Q17). These items also had the lowest factor loadings for Moro et al. (2024). This is interesting because Moro et al. (2024) designed their study to examine all psychometric properties of the QRA scale, conducting power analyses to determine recruitment and determined that all items on the scale met the factor loading threshold of 0.3. In contrast, the current study used data gathered for a different purpose and we obtained a very large sample size for this purpose; this could have skewed the results, and one item of the QRAD was found to be below the desired threshold. Questions 1 and 2 of the QRA scale could be seen to ask questions related to the quality of services rather than be specifically human rights focused. However, item 17 asks about involuntary admission, which is a coercive practice and therefore it would be assumed that this factor loading onto the 'coercive' subscale would be stronger.

Upon reflection of the results, it was noticed that the items that had the lowest correlations with other items on the QRAD, as well as the DAS, were items 1, 2, and 17, all of which had the lowest factor loadings in the factor analysis. Additionally, item 12 ('when people with dementia experience a crisis, healthcare practitioners or families should make decisions based on their ideas about what is best for the person') also had weaker correlations with all items on the QRAD. Inspection of the factor analysis diagram indicated that this item was on the lower side of the factor loadings (.46). It also correlated weakly with all items on the DAS, with the highest correlation .16, with DAS item 'people with dementia can be creative'. However, in the sensitivity analyses conducted, with the 2288 participants, the factor loading of item 12 was .38 (appendix 7). The factor loadings of items 1, 2, and 17 were .23, .45, and .32 respectively within the sensitivity analyses. This suggests that the removal of outliers in attempts to meet assumptions has not changed the outcome of the factor analysis, as the only item that did not meet

the threshold of 0.3 was item 1, as found above.

4.4.3 Limitations

Full psychometric analyses, including face validity and test-retest reliability, were not completed, although face validity was established through previous literature. In addition, the criterion validity tests were performed with the DAS which does not specifically address human rights of people with dementia. Secondly, the sample of participants were recruited through Join Dementia Research (JDR), which could mean that people who participated in the study are invested in dementia research, somewhat limiting the generalisability of the findings. We also lacked diversity within the demographics of our sample. This study was conducted on a UK-based sample only; therefore, it cannot be concluded that the results are representative of global populations.

Linked to this, and the consequence of self-report measures, the participants could have provided socially desirable answers or have given answers to skew the results to show more negative results in order to demonstrate the need for change. Thirdly, Cronbach's alpha was used to examine internal consistency. According to Moro et al. (2024), Cronbach's alpha assumes that all items on an instrument have equivalent factor loadings. As a result, the internal consistency in this study may not be as accurate, as the factor loadings identified are not equal. Paola (2020) argues that more than one measurement of validity and reliability should be presented to strengthen evidence that a scale is valid and reliable, making results more trustworthy.

4.4.4 Future directions and implications

Future studies should aim to recruit more diverse, representative samples to determine the generalisability of this research and the QRAD overall. Not only should different ethnic groups be recruited, but people who may lack access to, or have difficulty using, technology should be offered the opportunity to participate on paper or supported to complete the survey online. Additionally, future research could complete full psychometric testing within a similar population, examining measures that look at human rights aspects in their design to determine concurrent validity. Further reliability tests could also be

conducted, such as test-retest validity.

To examine the criterion validity of the QRAD in more depth, the scale could be compared against another scale based on the CRPD principles, such as the 'Wellbeing at Work and Respect for Human Rights' (Atzeni et al., 2024). Moreover, the examination and subsequent removal of item 1 from the overall QRAD, which we feel examines aspects of policy guidance, highlights the need for guidance relating the human rights-based approaches of care in dementia, demonstrating how dementia services and policies can respect, protect, and promote the human rights of people with dementia in the context of different legal frameworks.

4.5 Conclusion

This study found that the QRAD had adequate psychometric properties to measure attitudes towards people with dementia as holders of human rights in a UK population. The research thus supports the use of the QRAD in the general UK population to obtain clearer understandings of attitudes relating to human rights in the context of people with dementia. Further psychometric testing could show the questionnaire is appropriate for wider use and in different settings and populations.

5. A content review of national dementia plans: are human rights considered?

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5.1 Introduction

People with dementia can experience infringements of their human rights in accordance with the Convention on the Rights of Persons with Disabilities (CRPD; UN, 2006). For example, they can be denied legal capacity due to the use of substitute decision-making processes and coercive practices in care services (Donnelly, 2019; Mariani et al., 2017). Coercive practices, such as involuntary treatment, seclusion, and restraints can cause exclusion from the wider community, and substantially worsen wellbeing and quality of life (Øye & Jacobsen, 2020; Ralph & Espinet, 2019; Steele et al., 2020). Also, persons with dementia might only be provided with limited and segregated activities and have little to no access to community spaces (Steele et al., 2020; Steele et al., 2019). Moreover, they have rarely been included in opportunities to participate in the design or delivery of services or policies that affect them (Breuer et al., 2022; Gerritzen et al., 2023; Giebel et al., 2020).

These infringements are those primarily identified by the WHO in their mission to improve the quality of life for people with dementia and their families, but other denials of human rights can occur too. For example, people with dementia and their families can be denied access to the information and environments that others have access to, including community facilities, services, and technologies. This is a right protected by Article 9 (accessibility). They can also experience limited access to devices and assistive technologies that enable personal mobility (Article 20), a lack of respect for their privacy (Article 22), and infringements on their right to work and employment, both the opportunity to maintain a living by working, but also having reasonable

adjustments made to ensure the work environment is inclusive, open, and accessible (Article 27; UN, 2006).

In 2017, the WHO adopted their 'Global action plan on the public health response to dementia 2017-2025' to achieve "a world in which… people with dementia and their families live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality" (WHO, 2017, p.4). All 194 WHO Member States adopted the global action plan at the World Health Assembly in 2017, signifying a commitment to make dementia a priority. The first action area of the plan calls for governments to develop and implement national dementia policies, strategies, or plans, with the goal that 75% of the WHO Member States will have done so by 2025 (WHO, 2017).

Plans should emphasise a human rights-based approach, aligning with the CRPD and other rights standards (Cahill, 2018; UN, 2006; WHO, 2018). A human rights-based approach in dementia is essential because it ensures that people with dementia, as well as their family members, are treated with respect and dignity, empowered to enact control over their lives, and live with autonomy and independence. This approach should provide a legal framework to other approaches in care such as recovery-oriented and person-centred care, and uphold the fundamental human rights of people with dementia (Butchard & Kinderman, 2019; Kinderman et al., 2018). As of 2025, the CRPD has been ratified by 193 countries, with the governments having agreed to incorporate its principles into their policies and practices (UN, 2025). This is important, because there is growing concern over the human rights denials of people with dementia, with arguments that governments are not doing enough to protect those with dementia and their families and supporters (Benoist et al., 2024).

The priorities of plans have ranged from specific care and treatment frameworks to the inclusion of and equality for people with dementia (Sun et al., 2020). While past reviews of national dementia plans have not addressed human rights in depth, Alzheimer Europe, which regularly monitors the content of national dementia plans, identified in their 2023 report that the number of plans reporting legal mechanisms to protect legal capacity, such as

advance care planning, has increased (Alzheimer Europe, 2023). They also reported that the number of plans aligning with human rights standards has risen. Nonetheless, there is a need to do a global review of the human rights content of the national dementia plans.

5.2 Methods

5.2.1 Design

This qualitative study utilised a deductive content analysis to conduct a comprehensive assessment of human rights content in national dementia plans around the world (Elo & Kyngäs, 2008). This design was chosen due to its effectiveness in categorising large amounts of qualitative data, allowing for a broad, yet precise summarisation of a particular phenomenon in both data collection and analysis (Elo & Kyngäs, 2008). Additionally, deductive content analysis is a flexible approach that allows more key words relating to the studied phenomenon to be identified; in this present study's case, certain human rights terms in English may not be recognised in other languages, therefore the design enabled us to compensate for this. No ethics approval was sought for this study due to the use of publicly available data.

5.2.2 Procedure

Search strategy

Plans were identified using the Alzheimer Disease International (ADI) and Alzheimer Europe websites, as well as the MiNDbank database. MiNDbank is an online database developed by the WHO that provides easier access to international resources, including national policy documents (WHO, 2024). Scoping searches were also conducted on Google and Google Scholar using the search strategy '[country]' + 'dementia plan OR dementia strategy'. The results were limited to the first 10 pages, and the search was conducted in incognito mode. The WHO recommends conducting research like this in incognito mode so that the searches cannot be traced to the researcher(s), enhancing privacy. These searches were conducted between March and May 2023. All plans identified were downloaded into PDF.

Inclusion criteria

To be included in our review, the plans had to be:

- National dementia plans or strategies
- Developed after the adoption of the CRPD
- Developed by the national government and/or ministry of health
- Developed by UN Member States (UN, 2024)
- Publicly accessible
- Full-text or the exact version from ADI, Alzheimer Europe, or MiNDbank
- Written in English or amenable to translation
- The most recent version of the plan (regardless of whether the implementation period is over)

Translation

Due to the nature of this review, several plans were not immediately available in English. To help translation, the ADI recommended DocTranslator, a free website that translates PDFs into the chosen language (DocTranslator, 2023). For most plans, the website worked well. For plans that could not be translated due to their underlying format, paragraphs were copied directly into Google Translate, which powered the DocTranslator.

Materials

BH created a categorisation matrix in the form of a template to enable a systematic content search relating to human rights in national dementia plans (see appendix 8). The matrix contained specific CRPD Articles to ensure the five human rights aspects we were particularly interested in were incorporated (see pre-determined human rights themes). These Articles included Articles 5, 8, 9, 12, 14, 15, 16, 19, 25, 27, 28, and 29, taking inspiration from the ADI and Dementia Alliance International (DAI) report in 2016 (ADI & DAI, 2016). Other terms and words synonymous with human rights, such as ‘autonomy’, ‘empowerment’, and ‘legal capacity’ were also included. The synonyms allowed us to obtain a more complete picture of the human rights content and

provided a method to collect data that might otherwise be missed in different languages. Specific mentions of the CRPD, WHO global action plan, and the terms ‘human right(s)’ or ‘right(s)’ were also searched for. The matrix included space for the name of the plan, the year it was launched, the name of the assessor (BH, YM, JW, or SH), and a summary of the plan to be written. Additionally, BH created a glossary of the CRPD Articles and rights synonyms (appendix 9). The template and glossary were created on Microsoft Word, before the template was transferred to JISC Online Surveys and the materials were shared with the assessors.

Piloting

To ensure the validity and reliability of the template, the assessors piloted the methods using three plans from different WHO regions. This piloting exercise helped ensure the assessors understood the aims and methods of the review after being trained by BH. The team individually searched for any human rights content using the search function (Control+F) on the plans and inputted key words and phrases from the template. All assessors then fully read through the plans to contextualise the content identified and ensure no information was missed. All rights content was extracted word-for-word complete with page number(s) and was submitted onto the online survey for BH to download and add to a shared OneDrive folder. BH then collated the submitted data and produced a feedback sheet before discussing this with principal investigator MO. A team meeting was then held with the other three assessors to talk through any discrepancies. By piloting, the reliability of our methods was strengthened. The review also had high validity by using the CRPD principles and related synonyms to analyse the rights content.

Final procedure

Once piloting was complete, the remaining plans were randomly and equally distributed among YM, JW, and SH before being randomly assigned a second assessor. Additionally, BH analysed every plan included for analysis. This ensured the plans were independently assessed at least twice in significant depth. After examination, the assessors met with each other to complete

consensus work and discuss any discrepancies. If no agreement at these consensus meetings could be reached, BH and MO met to review and agree on any remaining issues. Afterwards, the data were transferred onto Microsoft Excel spreadsheets, allowing the researchers to clearly see any gaps in the content (see appendix 10). BH and YM then collated and combined the data to remove any duplications of content.

5.2.3 Analysis

Pre-determined human rights themes

The themes were assembled to match the rights groupings in the WHO's QualityRights initiative, a global initiative guided by the CRPD principles that aims to improve the lives of people with mental health conditions and psychosocial disabilities, including dementia (WHO, 2022a). The WHO states that the right to health for people with mental health conditions and psychosocial disabilities is reliant on several fundamental human rights principles, and it specifies the following: a) respect for legal capacity, b) non-coercive practices, c) participation, d) community inclusion, and e) recovery-oriented and person-centred care. As a result, these were the chosen themes.

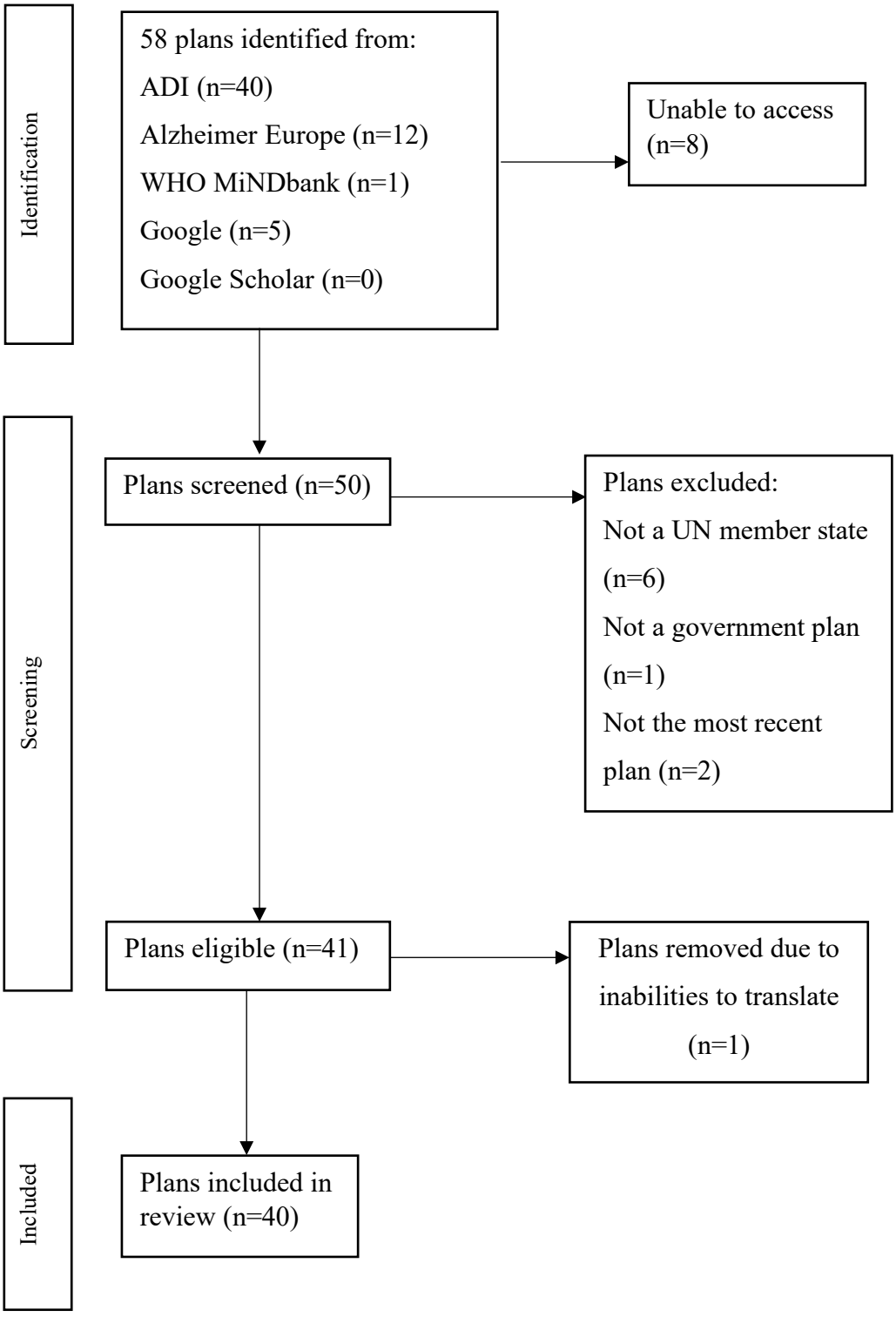
5.3 Results

Searches identified 58 plans worldwide. After screening (figure 5.1), 40 plans were included in the final analysis (see appendix 11).

The eight inaccessible plans were those for Armenia, China, the Republic of Korea (version four), Russia, Singapore, Thailand, Uruguay (2023 version), and Vietnam. Additionally, we could not translate the plan from Costa Rica due to its underlying format (the translation website would not recognise the PDF, nor could its contents be copied and pasted into Google Translate). Plans of Bonaire, Curacao, Gibraltar, Macao SAR, Puerto Rico, and Taiwan were excluded because they do not pertain to UN Member States (UN, 2024). Although we were able to access plans from Uruguay (from 2016) and the Republic of Korea (version three), they were excluded from analysis because they were not the most recent plan at the time of searching (ADI, 2023b).

Figure 5.1

Flow diagram of the search and screening process of the review



5.3.1 Overview of the analysed plans

The plans analysed were launched between 2010 and 2023, with Belgium (Wallonia) the oldest plan and Scotland's fourth version the most recent at time of searching (Scottish Government, 2023; Wallonia Government, 2010). Plans where the implementation period had expired but no further plan had been launched, for example, Australia (Department of Health and Aged Care, 2015) were also included. Twenty-seven plans were from the European WHO region (Austria, Belgium Flanders, Belgium Wallonia, Cyprus, Czechia, Denmark, England, Finland, France, Germany, Greece, Iceland, Republic of Ireland, Israel, Italy, Luxembourg, Malta, Netherlands, Northern Ireland, Norway, Portugal, Scotland, Slovenia, Spain, Sweden, Switzerland, and Wales), six from the Americas WHO region (Canada, Chile, Cuba, the Dominican Republic, Mexico, and the United States), three from the Eastern Mediterranean (Iran, Kuwait, and Qatar), three from the Western Pacific (Australia, Japan, and New Zealand), and one from Southeast Asia (Indonesia). The full name, year, and leader(s) responsible for each national dementia plan can be found in appendix 11.

There were no plans from Africa, which matched the report from the ADI (Benoist et al., 2024). Despite the Belgium Flanders and Belgium Wallonia plans coming from one UN Member State, we chose to include both due to their different governments and ministries of health (Flemish Ministry of Welfare, Public Health and Family, 2021; Wallonia Government, 2010). Similarly, the plans from all four countries in the United Kingdom were included. Thirty-five plans were from high-income countries, four from upper- to middle-income countries, and one from a low- to middle-income country.

Thirty-eight plans were dementia-specific, and two countries (Finland and Qatar) integrated dementia into other health strategies, such as Qatar's National Health Strategy 2022 (Ministry of Public Health, 2018). All plans provided a global and national context for their rationale, and all dementia-specific plans provided a summary of dementia as a condition, its aetiology, and risk factors. Some plans also contextualised each of their action areas.

5.3.2 References to human rights, the CRPD, and the WHO global action plan

Of the plans analysed, 36 (90%) specifically mention the terms ‘rights’ or ‘human rights’ within their plans. Eleven (27.5%) mentioned the CRPD, whether in the main body of the plan or the references. In addition, 10 out of the 21 plans (25%) launched after 2017 mentioned the WHO’s global action plan. Table 5.1 shows the number of plans that mentioned anything in relation to the human rights themes, with examples of the explicit CRPD Articles that relate to each theme.

CRPD Articles work together to ensure that the human right of persons with disabilities are respected, protected, and promoted, and hence each theme can be covered by several Articles or principles. For example, respect for legal capacity – that is, the right to make decisions and have those decisions respected – could refer to decisions about things that affect a person’s day-to-day life as well as decisions about things that affect the person’s overall care, overlapping with the right to participation in the design and delivery of services and support options.

Table 5.1

Human rights aspect with the according CRPD principle, lay definition, and the number of plans that mention each aspect

Rights grouping	Explicit CRPD principle(s)	Lay definition(s)	# of plans (%)
Community inclusion	Article 19: Living independently and community inclusion	The right to remain free and independent and to receive the same opportunities and services as others in the place of their choosing, enabling people to live independently and participate in their communities.*	39 (97.5%)
Recovery-oriented and person-centred care	Article 26: Habilitation and rehabilitation Article 3: General principles such as respect for inherent dignity, individual autonomy (including the freedom to make one's own choices), and the independence of persons; respect for difference; and acceptance of persons with disabilities	Enabling people to identify what recovery means to them; helping them gain or regain control over their life, have hope for the future, and live a life meaningful to them.† Tailoring care to people's interests, abilities, and needs while taking account of their histories and personalities.‡	31 (77.5%)

Respect for legal capacity	Article 12: Equal recognition before the law	The right to make decisions for oneself and have those decisions respected by others.* The right to be recognised as a person before the law and have one's decisions legally respected.§	28 (70%)
Non-coercive practices	Article 16: Freedom from exploitation, violence, and abuse	The right to practices that do not involve the use of involuntary admission, involuntary treatment, seclusion, or physical, chemical, or mechanical restraint.*	24 (60%)
Participation	Article 29: Participation in political and public life	The right to participate in decisions about society as a whole, such as the design and delivery of care services and the development of policies and procedures, regardless of their expertise and experience.*	24 (60%)

*WHO (2021a); †Leamy et al. (2011); ‡Terada et al. (2013); §UN Committee on the Rights of Persons with Disabilities (2016)

5.3.3 Community inclusion

People with dementia have the right to live and the right to make the same choices in life as others. They are entitled to choose where and with whom they live and to have the same access to community services as the general public (WHO, 2021a). Article 19 (living independently and being included in the community) of the CRPD, among others, encompasses this right (UN, 2006). The related term "dementia-friendly communities/societies" was used in the content searching. Thirty-nine (97.5%) of the plans mentioned community inclusion, primarily through the provision of dementia-friendly communities. Several of the references to community inclusion were recognitions that people with dementia should be included in the community and should be supported in this endeavour. To achieve this, many plans stated that dementia-friendly communities would be created in the wider community.

> "People in dementia should be able to participate in social and community life." - Austria (Federal Ministry Labour, Social Affairs, Health and Consumer Protection, 2015, p. 7)

> "Develop dementia friendly communities, where all aspects of the community's built environment and approaches are dementia friendly, inclusive, promote respect and acceptance and enable participation." - Australia (Department of Health and Aged Care, 2015, p. 9)

5.3.4 Recovery-oriented and person-centred care

Recovery-oriented care means enabling people with dementia to gain or regain control over their lives, have hope for the future, and live a life meaningful to them (Leamy et al., 2011; WHO, 2021a). It relates to the conceptual framework of personal recovery, which encompasses five themes: connectedness, hope, identity, meaningfulness, and empowerment (Leamy et al., 2011). Person-centred care refers to using a collaborative approach with the person concerned and incorporating the person's opinions, voices, and personal histories into their care (Terada et al., 2013). While both concepts clearly overlap, there are differences. Although no specific Article of the CRPD covers recovery-oriented and person-centred care, Article 26

(habilitation and rehabilitation) arguably comes closest regarding recovery-oriented approaches (UN, 2006). Additionally, Article 3 (general principles) aligns with person-centred principles ("respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons… respect for difference and acceptance of persons with disabilities"; UN, 2006). Within this theme, we also searched for the following synonyms: "agency", "dignity", and "empowerment". This theme was mentioned by 31 plans (77.5%). Several countries provided explicit actions relating to recovery-oriented and person-centred approaches to dementia care.

> "Support should be tailored to the individual person with dementia and their carers, not to managers of different services or health services" - Slovenia (Ministry of Health, 2016, p. 13)

> "Develop an efficient and coordinated system of care for people with dementia… under a network approach (including long-term care), to provide person-centred and integrated care" - Dominican Republic (Ministry of Public Health, 2020, p. 25)

5.3.5 Respect for legal capacity

Respect for legal capacity is defined as the right to make decisions for oneself and to have one's decisions respected by others; it is primarily represented by Article 12 of the CRPD (equal recognition before the law; UN, 2006). It is the backbone of other human rights and includes the right to be recognised as a person before the law and have one's decisions legally respected (UN Committee on the Rights of Persons with Disabilities, 2016). It also refers to the right to make legally-binding decisions (Arstein-Kerslake & Flynn, 2017). We searched for keywords such as "legal capacity", "autonomy", "supported decision-making", and "advance care planning". Overall, 28 plans (78%) mentioned legal capacity. Several included the word "autonomy" in the overarching aims of their plans, demonstrating that governments and ministries acknowledge that people with dementia should be in control of and have freedom of choice in their lives.

> "The vision of this plan …[is that] people with dementia and their caregivers receive the quality care and support they need with dignity, respect, autonomy, and equity" - Dominican Republic (Ministry of Public Health, 2020, p. 19)

Some countries also demonstrated their awareness that supporting people with dementia and their family members in maintaining autonomy and legal capacity is protected by their own laws and international regulations.

> "As a signatory to the Glasgow Declaration, the Welsh Government has previously committed to promote the rights, dignity and autonomy of people living with dementia" - Wales (Welsh Government, 2018, p. 3)

Regarding specific actions to promote and protect the right to legal capacity, countries referred to ensuring that measures for advance care planning and supported decision-making would be provided.

> "Objective delivery … i. Work towards the development of advance care directives" - Malta (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015, p. 61)

5.3.6 Non-coercive practices

Coercive care practices are those that go against the wishes of the person receiving care, such as forced admission to services, forced treatment, seclusion, and mechanical, physical, and chemical restraints (WHO, 2021a). They are also practices that are undertaken without the person's consent. The CRPD protects the rights to freedom from coercion with the following Articles: liberty and security of person (Article 14), freedom from torture and cruel, inhuman, or degrading treatment or punishment (Article 15), and freedom from exploitation, violence, and abuse (Article 16; UN, 2006). Twenty-four plans (60%) mentioned coercive and non-coercive practices; however, few plans provided specific actions to ensure that coercive methods are not used within dementia care. Instead, there was mostly a recognition that

people with dementia have been and continue to be subjected to harmful practices.

> "Dementia will eventually impair the ability to make informed decisions and provide consent. There may therefore be… uncertainty as to whether a decision is voluntary or if the person displays opposition towards a measure. If the person displays opposition, the measure is considered coercive" - Norway (Norwegian Ministry of Health and Care Services, 2020, p. 79)

> "8.5 Legal, social and financial assistance to prevent abuse, violence or neglect in the care of the person with dementia" - Mexico (National Institution of Geriatrics & Secretary of Health, 2014, p. 62)

5.3.7 Participation

Participation refers to people with dementia, and their family supporters, being involved in societal decisions, such as the design and delivery of services and policies regardless of expertise (WHO, 2021a). It also involves the concept of citizenship: having rights, responsibilities, and meaningful opportunities within the wider community (O'Connor et al., 2022). The right to participation also encompasses the right to vote, the right to participate in public affairs, such as non-governmental organisations, the right to participate in cultural life, and the right to participate in recreational, leisure, and sporting activities (UN, 2006). We included "citizenship" as our synonym for this theme. It is guaranteed by Article 29 (participation in political and public life) and Article 30 (participation in cultural life, recreation, leisure, and sports) of the CRPD (UN, 2006). Twenty-four plans (60%) referred to or specifically mentioned participation.

> "According to Article 29 of the [CRPD], people with dementia should be able to play an active role in shaping public affairs… [and] given the opportunity to review the relevance and appropriateness of local planning processes from their perspective… This will allow people with dementia to be involved… in the planning of social spaces" -

> Germany (Federal Ministry for Family Affairs, Senior Citizens, Women and Youth & Federal Ministry of Health, 2020, p. 28)

> "Stakeholder participation in policy development and legislative changes concerning persons with dementia is ensured through a consultation portal… What will the situation be in 2030? Active participation of persons with dementia in discussions and decisions concerning their patient group" - Iceland (Ministry of Health, 2020, p. 8)

Nineteen countries (47.5%) declared that people with lived experience (both persons with dementia or their family members) had been involved in the design of the national dementia plan, and some specifically stated how they will continue to involve this population in the implementation of plans.

> "The national action plan for dementia was developed… [with] relevant actors in the field, citizens with dementia, their relatives, and experts and health professionals" - Denmark (Danish Ministry of Health, 2017, p. 7).

Table 5.2 shows further examples of governments incorporating human rights and the CRPD into their national dementia plans.

Table 5.2

Examples of narratives reflecting each of the key themes organised by the most mentioned rights aspect

Theme	Country	Quotation
Community inclusion		
Acknowledgements	Canada	"The strategy will encourage dementia-inclusive communities that support people living with dementia and caregivers in staying involved in their communities and at work for as long as possible" (p. 1)
	England	"people with dementia should be supported to live independently in their own homes for as long as they are comfortable" (p. 39)
	Slovenia	"The standard of care and support for patients should not only include staying in the home environment … also enable the person with dementia to play a visible and active role in the local community" (p. 8)
Actions	Australia	"Develop communities and workplaces that are dementia friendly" (p. 12) "Support people with dementia in residential aged care facilities to continue to be socially engaged both within and outside the facility (in the broader community)" (p. 21)
	Chile	"Implement daytime support centers for older people living with dementia and their immediate environment, to encourage their social participation" (p. 45)

	Dominican Republic	"Aim: Improve acceptance and understanding of dementias and make the community environment friendly, allowing people with dementia to participate in the community … Goal: The country has at least one dementia-friendly initiative" (p. 22)
	Kuwait	"Target 3: Creation of social and recreational activities for the elderly … Combating community isolation and integrating older people into society" (p. 8)
	The Netherlands	"What are we going to do? We want to create opportunities for persons with dementia … by providing opportunities for doing work, including volunteer activities, for example in Dementalent projects" (p. 14)
Recovery-oriented and person-centred care		
Acknowledgements	Australia	"Timely and accurate diagnosis also … gives people the power to control their life and plan for their future" (p. 10) and "Community participation for all people with dementia may be facilitated through the use of an enablement approach … Appropriate service structures may provide assistance to people with dementia to identify and pursue personally important, relevant and meaningful goals in their daily lives" (p. 17)
	Malta	"Empowering individuals with dementia will not only help in challenging stigma but will also encourage social inclusion and integration" (p. 47)

	New Zealand	“Placing the person with dementia, and their needs and wishes, at the centre of care and supporting them to make decisions will maximise their wellbeing and independence” (p. 3)
	Norway	“good dementia care involves seeing the individual and his or her needs and implementing individually adapted services based on the insight into the individual’s life story and disease history” (p. 9)
	Scotland	“Our ethos is to empower people living with early and midstage dementia to be the best they can be and to support them to live well with dementia” (p. 12); “Empowerment (International PANEL) - People should understand their rights, and be fully supported to participate in the development of policy and practices” (p. 15); and “person-centred care includes people with dementia being involved in design and delivery of services” (p. 30)
	Sweden	“The support needs to be based on the person's own wishes and remaining abilities” (p. 11)
Actions	Malta	“Develop a series of recommendations that would enhance good quality patient-centred dementia management and care (including dementia-friendly design) in long-term nursing and residential care settings” (p. 89)

	Norway	"Priority area 3: Improved quality of health care services: •prepare guidelines for good patient care pathways … • prepare a 'toolbox' for person-centered care and milieu therapy" (p. 13)
	United States of America	"Action 3.E.7: Expand resources to support person-centered care" (p. 92)
	Wales	"The team will flex to meet individual needs … people have the right to individualised and person-centred care. We will continue working with key stakeholders, including people living with dementia and their carers, to ensure that this happens [including]: • Developing individual care plans" (p. 19)
Respect for legal capacity		
Acknowledgements	Austria	"The strategy aims to create a system in which people affected by dementia and their families and friends: … • live in a community that promotes … autonomy to the greatest possible extent" (p. 16)
	Belgium (Wallonia)	"Foster the maintenance of autonomy … at each stage [of] illness" (p. 4)
	Canada	"Respects choice: The rights of individuals living with dementia to make their own decisions are broadly understood and facilitated" (p. 7)

	Finland	"It is important that everyone can participate in joint decision-making" (p. 23)
Actions	Australia	"Maximise opportunities for people with dementia and their representatives to plan for the future by raising their awareness of options" (p. 15)
	Norway	"To ensure … greater freedom of choice and codetermination in planning future treatment, the Government will strengthen its efforts to prepare, disseminate and implement advance care planning conversations" (p. 49)
	United States of America	"Action 3.D.8: Develop a Supported Decision-Making Model as an alternative to guardianship" (p. 89)
Non-coercive practices		
Acknowledgements	Canada	"Human rights: Includes the right to life and liberty, freedom from slavery and torture, freedom of opinion and expression" (p. 83)
	Chile	"The risk of neglect and abuse is also increased with an overwhelmed caregiver" (p. 18)
	Cuba	"abuse can manifest itself in different ways … little attention, abandonment, inadequate nutrition, lack of care, economic abuse and restriction of autonomy, or some more serious, such as physical abuse or sexual abuse" (p. 7)
Actions	Denmark	"Initiative 9: General screening of regulations concerning use of force. DKK 0.5 million [in funding] is allocated to carry out a screening" (p. 9)

	Luxembourg	"Measure: Definition of a formal framework organizing and limiting the use of means of restraint in long-stay institutions for the elderly" (p. 46)
	Malta	"Develop a working partnership, in collaboration with non-governmental organisations and other stakeholders operating in the field, to assess and address abuse in individuals with dementia, their caregivers and family members" (p. 116)
	Spain	"Develop information actions, training and action protocols, aimed at minimizing involuntary restraints, physical or pharmacological" (p. 56)
Participation		
Acknowledgements	Belgium (Flanders)	"Involving the voice of people with dementia at policy level should also be translated into practice by local authorities as an ambition, including in the context of building a dementia-friendly environment" (p. 16)
	Greece	"participation of people with dementia and their caregivers in the planning of services" (p. 17)
	Mexico	"People with dementia and their carers often have a unique perspective on their condition and on life … they must be involved in the formulation of policies, plans, laws and services" (p. 12)
	Norway	"A key goal is for individuals with dementia and their family members to be involved in decisions that affect them, and to have a say in the design of their own services" (p. 21)

	Scotland	"The best way to deliver better experiences for people is to include them in policy design and delivery" (p. IV)
Actions	Germany	"local authority associations will encourage municipalities to ensure that people with dementia and their relatives participate in planning processes and that their interests are taken into account … By the end of 2022, the local authority associations will campaign for such participation at municipal level" (p. 29)
	Wales	"We will: • Ensure people with dementia, their carers and families are involved in the development and delivery of dementia education and training" (p. 28)

5.4 Discussion

This was the first in-depth review of how human rights have been addressed in national dementia plans. Many plans address some aspects of basic human rights for people with dementia; in particular, community inclusion was covered in all except one of the plans, and most mentioned developing dementia-friendly communities to achieve this. Perhaps the most mentioned human rights aspects are easier for governments to promote for people with dementia. Concerningly, many plans did not adequately include non-coercive practices or participation, and the CRPD itself went unmentioned in almost 75% of plans, despite most of these countries having either signed or ratified the Convention. While this lack of specific mention of the CRPD does not on its own indicate that the plans overlooked certain human rights for people with dementia, our review of the content relating to human rights principles in the CRPD suggests that many plans did not align well with human rights standards. This is vitally important given growing concerns over the human rights of people with dementia. It also suggests a strong need for multisectoral action to protect and promote the human rights of persons with dementia in both policy and practice.

Although the findings suggest that the CRPD may not have been considered when governments developed their plans, supporting previous arguments (Swaffer, 2017), this current review is also consistent with the work of Vinay and Biller-Andorno, who found that social and cultural rights, such as community inclusion and recovery-oriented and person-centred care, were the foundations of national dementia plans (Vinay & Biller-Andorno, 2023). While advance care planning, increased dementia awareness, and holistic and individualised care were principles strongly considered in the eight plans they reviewed, the provision of alternative care to acute hospitalisation was mentioned only sporadically (Vinay & Biller-Andorno, 2023). The current review, alongside that of Vinay and Biller-Andorno, contrasts with the work of Cahill, who found that political and civil rights, such as freedom from coercion, were more likely than social and cultural rights to be included in plans (Cahill, 2018). Both reviews, as well as the current review, found that

governments have placed emphasis on respect and dignity, although our analysis showed that these terms tended to be used in descriptions around what people with dementia are entitled to rather than specific actions to ensure that these needs are met.

It is important to note that the present analysis was more extensive than the other two reviews; we took a comprehensive approach by using the CRPD as a whole rather than using selected items. Additionally, both previous reviews were of a much smaller scale in comparison to the present one; Vinay and Biller-Andorno (2023) reviewed eight plans and Cahill (2018) examined 10. Perhaps these reviews were smaller than ours due to the time of their completion. This current review was conducted close to the end of the WHO's global action plan target deadlines. Nonetheless, the current assessment has revealed similar findings to those of the previous studies, especially when considering that each country tailored its plan to meet its context-specific needs, and therefore it would be expected that visions for the plans and subsequent actions would differ somewhat.

Furthermore, acknowledgements and actions relating to increasing awareness and reducing stigma to achieve community inclusion for people living with dementia were consistently included in national dementia plans, a finding also noted by previous reviews (Chow et al., 2018; Sun et al., 2020). This is important because stigma and beliefs around dementia are some of the main contributors to human rights denials for people living with dementia (Benbow & Jolley, 2012). Additionally, the results showed that although participation was mentioned in 60% of the analysed plans, actions to ensure that this became part of standard practice were few and far between. This supports the claim that the participation of persons with dementia in planning activities and policies is needed, but in practice is lacking (Schmachtenberg et al., 2022). The present findings also support the recommendations of Boeree et al. (2021), who argue that policymakers must collaborate with people with dementia and their family supporters in the development, execution, and evaluation of national dementia plans because it would enhance their effectiveness and overall usefulness. Additionally, they argue that without the

involvement of people with lived experience, any of the benefits that materialise from a plan's implementation would not be felt by the people who should benefit most (Boeree et al., 2021). This echoes the claim that there are considerable gaps between the goals and visions of government policies and the lived experiences of those with dementia (Cahill, 2018). From a human rights-based point of view, the participation of people with dementia, and their family supporters, in the design and delivery of national dementia plans is a fundamental right in accordance with the CRPD (UN, 2006).

5.4.1 Limitations

To reduce the risk of reviewer bias, each plan was assessed by at least two independent researchers. Additionally, publicly available data were used in this review. That said, not all plans that have been launched were publicly accessible, meaning we were unable to access eight plans. Moreover, we could not translate a further two. The plans missing from the current analysis were mainly from the Eastern Mediterranean and Western Pacific WHO regions. Furthermore, in order to include as many plans as possible in this review, we relied on a translation website powered by Google Translate rather than translating and then back-translating ourselves; as a result, the translations may have inaccuracies or misinterpretations or may have missed content. Finally, some of the plans included in this review had already, or have since, expired, meaning their implementation period was over. However, at the time of searching, the included plans were still the most recent plan for those countries, and being publicly available, we chose to include them in the review.

5.4.2 Future directions and implications

Since the completion of the review, several countries – for example, Australia, Brazil, Malta, and Uruguay – have produced new national dementia plans (Benoist et al., 2024). Further research should be conducted to investigate whether these new plans have a human rights focus, as well as whether future plans of the countries included in this review showcase any changes in their human rights content. Additionally, future research could examine the

implementation of national dementia plans to assess the extent to which the actions outlined in the plans have been achieved in practice. Ancidoni et al. (2025) recently reviewed the implementation of the Italian national dementia plan in relation to the WHO's global action plan targets, and any future research could utilise the research framework in that study to conduct similar reviews. This research could refer to Article 4 of the CRPD, which relates to the general obligations of countries that have ratified the Convention. Finally, future work should consider developing a global report on good practice of rights-based care in dementia.

There are substantial implications for policy and practice following our review. First, the results can be used by the WHO, ADI, and Alzheimer Europe, among national governing bodies, to advocate for a stronger human rights focus within plans to ensure the protection and promotion of the rights of people with dementia. This review supports WHO efforts to monitor progress on the global action plan targets, as well as ADI efforts to regularly report on the global picture of national dementia plans. ADI recently called for an extension of the WHO's global action plan targets to 2035 in its 2024 From Plan to Impact report (Benoist et al., 2024). The target is for 146 countries to have a national dementia plan by 2025 – and yet, as of the aforementioned ADI report, only 38 plans were currently in place, while others have expired and yet others did not have funding for their implementation (Benoist et al., 2024; WHO, 2017). Because none of the global targets were on track to be accomplished by 2025, WHO Member States discussed a potential extension of the global action plan at the 156th session of the Executive Board, and at the 78th World Health Assembly in May 2025, the decision was made to extend the global action plan by six years to 2031 (WHO, 2025a).

The present review highlights where governments are falling short in complying with the CRPD and indicates how future plans can become more human rights focused. Policy commitments should not remain mere paper promises – they should be actively implemented with clear accountability measures. Countries are required to report to the UN Committee on the Rights of Persons with Disabilities every four years on the measures taken to respect,

protect, and promote the rights of persons with disabilities, and it is important that this process also includes reporting on the actions taken to safeguard the rights of persons with dementia. At a national level, mechanisms such as national human rights groups, health services (including mental health services), and care quality commissions could integrate the monitoring of dementia-related human rights into their existing functions. Moreover, national and international non-governmental organisations, such as ADI, and organisations of persons with disabilities, such as DAI, can play a pivotal role in monitoring and ensuring accountability.

5.5 Conclusion

This review systematically assessed the human rights content of national dementia plans. We found that nearly all plans covered basic human rights, especially regarding the inclusion of people with dementia within the community. However, many plans did not sufficiently align with human rights standards, including the CRPD. There was a lack of specific actions regarding non-coercive practices and ensuring the participation of people with dementia in the design and delivery of services and policies that affect them. Significant improvements are needed to guarantee the human rights of people with dementia; therefore, governments can use our findings to better understand the rights of their citizens with dementia and identify actions and frameworks to improve protections for them. Additionally, people with dementia can be encouraged to participate in the implementation of current plans, as well as the design and delivery of future ones. We join calls for a multisectoral effort to be implemented to ensure the human rights of persons with dementia.

6. The search for community dementia services for consideration in the good practice guidance

Associated publication: Harden, B., Funk, M., Drew, N., McDermott, O., Seeher, K., Dua, T., & Orrell, M. (2024). Developing good practice guidance for community dementia services: Person-centred and rights-based care approaches. *WAPR E-Bulletin, 53*, 92-101.

6.1 Introduction

People with dementia, as well as their family members and supporters, have a variety of complex needs which span the health and social sector, among others, and require coordinated efforts between all of them, including legal, transportation, and employment sectors, to meet these needs (WHO, 2018). The WHO published the 'Global action plan on the public health response to dementia 2017-2025', aiming to improve access to better quality dementia services and policies, as well as to reduce stigma and discrimination (WHO, 2017). However, there is a lack of community dementia services worldwide, and long-term care pathways in dementia are often fragmented or even entirely absent (Gauthier et al., 2022; Giebel et al., 2021; WHO, 2017). Services currently in place can be of poor quality and difficult to navigate, resulting in needs that remain unaddressed, leading to excess disability (Giebel et al., 2023; Morrisby et al., 2021; WHO, 2017). Consequently, the human rights of people with dementia and their families and supporters can be infringed.

The WHO strongly advocates for community-based services around the world to develop and implement recovery-oriented, person-centred, and rights-based care that upholds and reinforces the principles of the Convention on the Rights of Persons with Disabilities (CRPD; UN, 2006). Key elements of practices that comply with the CRPD include respect for legal capacity, the right to non-coercive practices, the right to participate, particularly in the design and delivery of services, research, and policies that affect them, and the right to be included in the community (WHO, 2021a). In addition, services

must demonstrate person-centred and recovery-oriented care approaches. Rights-based approaches in care have strengthened person-centred approaches by providing a legal framework that requires both services and governments to respect, protect, and promote human rights (Kinderman et al., 2018). The CRPD commits governments and healthcare providers to deinstitutionalise existing facilities, integrate dementia care into community-based services, and provide sustainable care and support throughout the course of the condition. This rights-based approach empowers people with dementia to live in the community and receive care that aligns with their needs, values, wishes, and preferences (WHO, 2017). Support services should be person-centred, accessible, affordable, culturally appropriate, and community-based to ensure the fundamental freedoms and basic human rights of people with dementia are respected, protected, and fulfilled.

In 2021, the WHO launched their 'Guidance on community mental health services: promoting person-centred and rights-based approaches' (WHO, 2021a). The guidance described different community mental health services around the world that promote and protect the human rights of people with mental health conditions and psychosocial disabilities, emphasising the rights to legal capacity, non-coercive practices, participation, community inclusion, and recovery-oriented and person-centred care. The document described how each service or network of services was run and emphasised the CRPD principles upheld by them. During the production of this guidance, the WHO were encouraged by several stakeholders to develop a similar document for community dementia services.

There are significant challenges to achieving recovery-oriented, person-centred, and rights-based care in community dementia services. Stigma and resultant discrimination towards people with dementia can be hard to change, but there are also limitations in resources as well as political and legislative frameworks. However, the guidance document will aim to show that countries can develop and scale up the desired care approaches in dementia services. It will present good practice services examples that have successfully implemented these approaches within a wide range of contexts

and legal frameworks, without compromising people living with dementia's right to legal capacity, non-coercive practices, participation, community inclusion, and personal recovery, while ensuring they remain at the heart of their care. The examples in the document will illustrate how recovery-oriented, person-centred, and rights-based care can be achieved, inspiring policymakers, healthcare providers, and the general population worldwide. There will be a strengthened focus on the diversity of services, by both geographical location and income status, especially with the knowledge that nearly two thirds of people with dementia live in low- to middle-income countries (Wimo et al., 2023; Wolters & Ikram, 2018). The guidance will not aim to label 'best' practices, since the services are meant to be examples of good practice and the services may not be the 'best' in their field.

6.1.1 Aim

The overarching aim was to develop robust methodology to enable the production of good practice guidance for community dementia services. The aim of this chapter was to find services for potential inclusion in the dementia guidance.

6.2 Method

6.2.1 Design

The study comprised of seven phases divided into two work packages. The research design and methodology were based on and further developed from the original WHO guidance for community mental health services (WHO, 2021a). The phases in Work Package 1 consist of mixed methods, including literature and internet searches and online surveys. This was to conduct a global search and selection process for good quality dementia services.

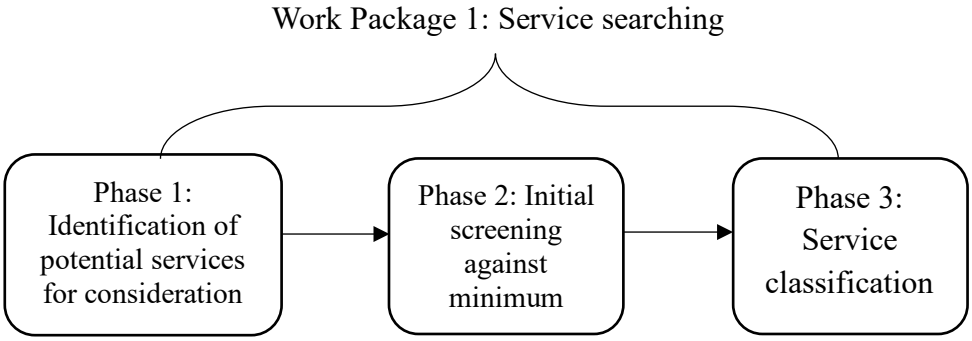
Layout of work packages

Phases 1, 2, and 3 formed Work Package 1 ('service searching'), while Work Package 2 included Phases 4, 5, and 6 ('human rights assessments and service validation'). Although designed to be independent from one another, the

Phases, particularly Phases 3, 4, and 5, often ran concurrently. All work completed was saved into a shared OneDrive folder, labelled 'WHO Services Project', accessible by all team members across both work packages to enable easier transitions and training of the work package contributors. Figure 6.1 demonstrates the flow of the Phases described in this chapter, also known as Work Package 1.

Figure 6.1

Work Package 1 of the methodology for the WHO good practice guidance in human rights for community dementia services



6.2.2 Ethics

Although we were primarily obtaining public data, we were also asking for the contact details of service providers and survey respondents, and as such, we gained ethical approval from the University of Nottingham Unit of Mental Health and Clinical Neuroscience Research Ethics Sub-Committee on the 18th July 2023 (reference: DPAP-2023-3112-4).

6.2.3 The Dementia International Advisory Network for Human Rights (DIAN)

Before Work Package 1 got underway, and to help comprehensively identify dementia services around the world and develop robust guidance, a substantial international network of contacts was developed. Using contacts at the WHO and from previous collaborations, a steering group was formed of stakeholders in the field of dementia. The DIAN network involved all WHO contacts and

networks, the WHO Collaborating Centre for Mental Health, Disability, and Human Rights (WHO-CC) at the University of Nottingham, the Global Dementia Observatory, Alzheimer's Disease International (ADI), Alzheimer Europe, Dementia Alliance International (DAI), international fellows from the Global Brain Health Institute, 250 participants from the 2022 Nairobi 'Brain Ageing and Dementia in LMICs' conference, the African Dementia Consortium which represents seven countries, INTERDEM, members of non-governmental organisations (NGOs), such as Human Rights Watch, and most importantly, people with lived experience of dementia from the European Working Group of People with Dementia. Other partners of the DIAN included: Office of the UN High Commissioner for Human Rights, the UN Department of Economic and Social Affairs, the International Disability Alliance, the NGO Committee on Ageing, HelpAge International, the International Federation on Ageing, the World Dementia Council, Humanity and Inclusion, the World Federation of Occupational Therapy, the World Psychiatric Association, the International Psychogeriatric Association, and the International Association of Gerontology and Geriatrics.

As a result, the network included a variety of professions and backgrounds relating to the health and social care needs of people with dementia, family members and supporters, as well as a range of academics, service providers, and policymakers. From the DIAN, a steering committee was developed to meet with the WHO-CC every four or five months to provide feedback and advice on the work completed. The steering group members includes representatives from Human Rights Watch, WHO, DAI, and ADI.

6.2.4 Contributors to Work Package 1

The following people affiliated with the WHO-CC were involved in phases 1-3: Briony Harden (BH), Martin Orrell (MO), Orii McDermott (OM), Justin Weiss (JW), Selina Hsuan (SH), Tanmay Nainwal (TN), Ira Makhijani (IMa), Rachel Orrell (RO), Abhisri Chadalavada (AC), and Sherryn Man (SMa). A more detailed description of the contributions made by each researcher can be found in appendix 12.

6.2.5 Phase 1: identification of potential services for consideration

To ensure as many services as possible were initially identified, various methods were used, including internet searches, literature searches, and an online survey sent to the DIAN to obtain recommendations. This phase was completed by BH, JW, and SH. With 195 countries to search, BH provided JW and SH with a list of the countries separated into the WHO regions (African, The Americas, Eastern Mediterranean, European, South-East Asia, and Western Pacific) as well as a list of countries not included in a WHO region (see appendix 13), complete with information such as the income status of each country as of the time of the searches. Income status refers to the Gross National Income of the nation's residents and businesses within a given period, which indicates the economic performance of a country (European Commission, 2025). Four categories of income status were reported and subsequently used in the organisation of the services: high-income, upper- to middle-income, low- to middle-income, and low-income (International Financial Reporting Standards, 2023). Having the income status of each country enabled us to investigate the diversity of services across the globe. This list also provided a checklist for team members to check off their progress. The work was shared between all team members. The team were also provided with a table of the service classifications (Phase 3) so that initial categorisation could occur.

Internet search

The internet searches were conducted on the Google search engine in English while in incognito mode. Using incognito mode is WHO policy as it enables searches to be somewhat protected from website tracking. The search strategy was '[country name] + community dementia services' and the date range was limited to '2000-2022', because the services with an internet presence were more likely to still be providing support. The first 10 pages of results were scanned for information.

Literature search

The literature searches were conducted on Google Scholar in English to identify any services mentioned in academic or grey literature who would not otherwise have an internet presence. The literature searches were conducted using the same search strategy, date limitations, and results restrictions as the internet searches. However, to be more robust, we developed a more advanced search strategy as allowed by Google Scholar. We added five key terms in human rights to identify any rights-specific information: 'legal capacity', 'non-coercive practices', 'participation', 'community inclusion', and 'recovery-oriented and person-centred care'.

Online survey and DIAN

An online survey (appendix 14) was created in JISC Online Surveys version 2 and was sent to the DIAN in a standardised email (appendix 15), who were encouraged to cascade it to their contacts, and for their contacts to also circulate it, utilising a snowball approach. The survey contained an informed consent page, which detailed the aims of the project and gave contact details of the WHO-CC team (BH, MO, and MF), a page regarding details of the person completing the survey, including contact details, country of location, and affiliations to the service being recommended, before a page about the service itself. This service page asked for the service name, contact details for the service or a key contact person, the category or categories of service it falls into, the type of dementia it provides support for (if applicable), and then free text boxes for respondents to provide initial evidence regarding the efficacy of the service, evidence for the protection of people's human rights, and any additional information deemed necessary in relation to the guidance.

A glossary was linked to the survey which provided definitions and examples of rights-based approaches (appendix 16). In addition, a space for links and images to be deposited was provided. Once completed, the survey respondents were met with a debrief page which reiterated the aims of the project and the WHO-CC team email addresses. On the debrief page, a link to a separate survey for respondents to add their contact information was

incorporated, so that the WHO-CC team could maintain connection with them for potential follow-up emails or calls (appendix 17).

The survey was only available in English, and as a result, the DIAN were encouraged to translate the questionnaire into their local language before distribution. They were also encouraged to back-translate into English for the researchers. Using translation then back translation before the survey responses were sent back to the WHO-CC would ensure greater accuracy in the answers provided than if the WHO-CC, who only spoke English, attempted translation through translation websites.

Collation of the service information gathered

The results of the searches and online survey responses were added to a shared spreadsheet, a new sheet per WHO region, with all columns labelled using the survey questions. Additional columns were added towards the start of each sheet labelled 'income country status' and 'where found' to help keep track of the method efficacy and diversity of services. Upon investigation of the spreadsheet, gaps within the information were clearly identifiable, both with regard to the service details and the human rights aspects. As a result, BH and new team members TN, IMa, and RO were tasked with sorting which services required more information before they could be screened in the next phase. To help, BH shared the service screening criteria with the team, and gave them instructions to colour-code the services by highlighting the rows on the spreadsheet. They were to highlight a service 'red' if the service required a lot of additional information, 'yellow' if the service needed some additional information, and 'green' if the service was good to move forward in the process. The services highlighted 'red' and 'yellow' were then shared between the team, who then used both Google and Google Scholar to obtain more information, using the same limitations and rules as before. Any further information found was added directly to the spreadsheet.

6.2.6 Phase 2: initial screening against minimum service criteria

Three screening processes were completed throughout the full production of the guidance. This phase was to evaluate the service information gathered in

Phase 1 against minimum service criteria. Services were removed if they met any of the following criteria:

1. dementia initiatives that are not delivered within services: for example, associations and organisations (Alzheimer's Society) and Dementia Friends initiatives
2. training and advocacy programmes: for example, initiatives that only enable people living with dementia to access services, or programmes that only deliver training
3. prevention programmes: programmes that only focus on reducing risk factors for dementia
4. specific treatments/interventions (e.g. pharmacological, psychological, psychosocial interventions, and advanced care planning): services that only offer specific interventions such as Cognitive Stimulation Therapy
5. e-interventions, telephone services (such as hotlines): including Dementia UK's helpline, organisations which offer advice only over the phone, or interventions provided over apps or computers

Key considerations were made regarding how the service supports individuals with complex and/or additional needs if this were applicable. At this stage, flexibility included services that appeared to meet the criteria above, but the information was not detailed enough to be conclusive. This was especially the case for services from low- to middle-income and low-income countries or if the service appeared to demonstrate a novel and human rights-based approach to care.

To screen, the researchers were provided with the criteria above and then given instructions relating to the screening process. They were also provided with the service classifications so that the WHO-CC team could identify particular service activities, both to help screen and categorise the services in Phase 3. Each researcher was to screen independently. Colour-coding by highlighting the spreadsheet row continued to be the method of use, with additional colours added to provide some flexibility:

- Red – service to be removed
- Yellow – more information/clarification required before final decision could be made
- Green – service passed through to next phase
- Blue – unsure
- Grey – duplicate service (to be removed)

Piloting of the initial screening process

BH chose a random selection of 15 services to pilot the criteria and screening process with the other team members. A meeting was held before the pilot began and BH explained the criteria and process in more detail. All team members were given a week to screen the 15 services. The piloting suggested that the instructions and criteria were clear, with only two services given different colours among researchers. These discrepancies were discussed at another team meeting, and we arrived at a consensus. BH reported these findings to MO, who agreed the remaining services could be distributed among the research team, but BH was to screen them all. This also ensured the services were screened at least twice.

Completion of the initial screening process

The workload was divided by WHO region, with TN, IMa, and RO being given almost equal numbers. More services were coded as 'unsure' than desired, and BH and MO felt that the screening process should be repeated with a clearer set of instructions. Moreover, a major query that was presented to BH, and later to MO, was whether a dementia association, such as The Alzheimer's Society, was considered a service, a network of services, or something different. This was despite the criterion 'dementia initiatives that are not delivered within services: for example, associations and organisations (Alzheimer's Society) and Dementia Friends initiatives'. The WHO-CC team argued that while these associations should be removed in accordance with the criterion, they did provide support that could be considered a standalone community dementia service. This led to significant discussions between MO and BH, and later the WHO team, but only after the team members had to end

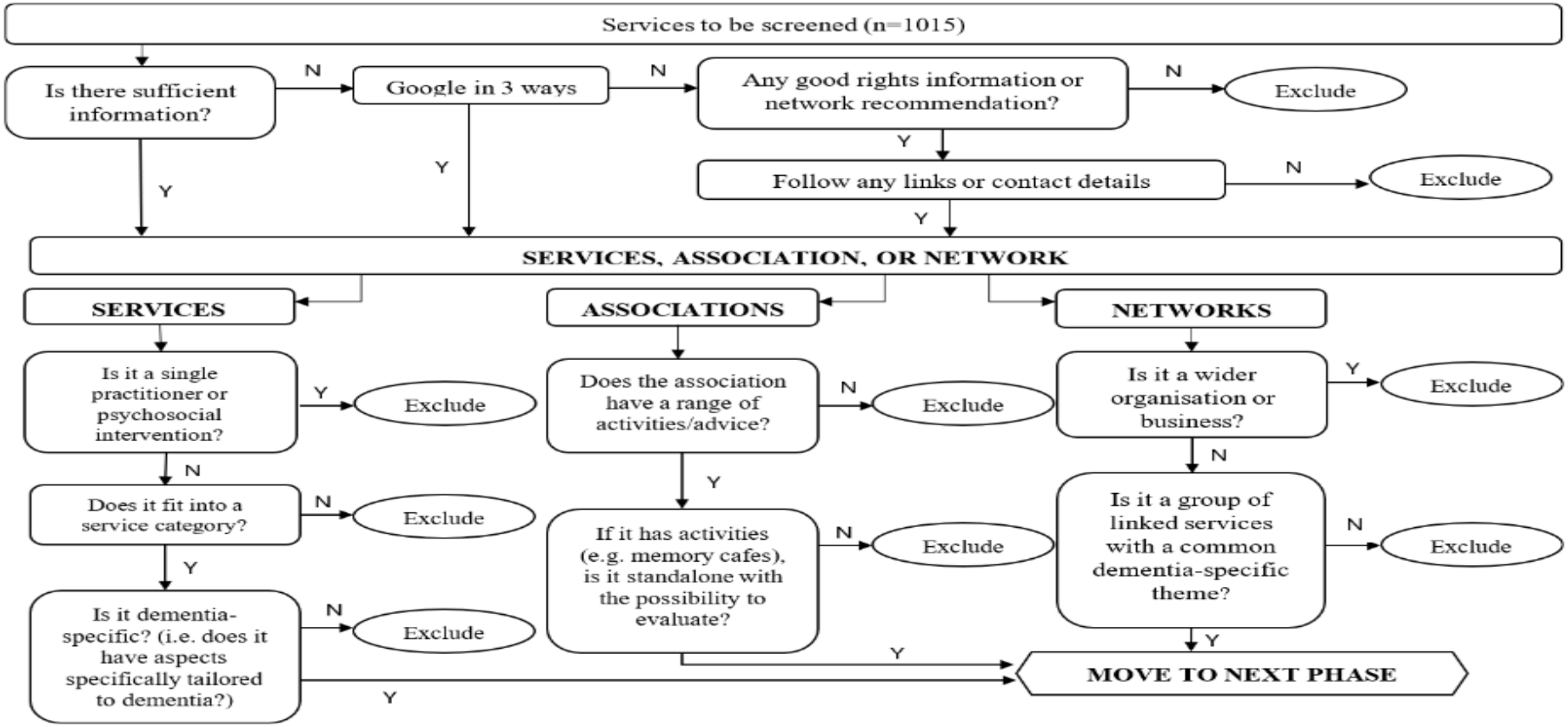
their involvement with the project due to work commitments. It was decided that associations would not automatically be excluded if they appeared to provide standalone services and supports that could be evaluated. To provide clarity, BH, MO, and OM developed an algorithm (figure 6.2) for the WHO and WHO-CC team members.

Secondary screening with the use of an algorithm and consensus work

The algorithm created by BH, MO, and OM contained questions for team members to think about when screening the services. It started by asking the researchers to consider whether there was sufficient information to screen in the first place, before providing methods to consider before moving forward if the answer was no, such as googling the service in three different ways. From here, three pathways developed: 1) services, 2) dementia associations, and 3) network of services. Definitions for these pathways were developed and provided to the research team partaking in this phase (BH, SMa, and AC; appendix 18). Each pathway had its own questions to consider before the service or network could be moved to the next phase. As well as using the algorithm exclusion criteria, we continued to use the initial service exclusion criteria, adding codes to each criterion to help determine the reason for exclusion, with the first criterion designated ‘code A’ and the last criterion denoted ‘code E’. The use of the algorithm was piloted on a random selection of 30 services, with all researchers examining the services for a week. The piloting suggested the algorithm was valid and reliable. The remaining services were then distributed equally among the researchers, again with BH screening all services, meaning at least two researchers independently screened each service. The same colour-coding instructions were given. The team were given a month to complete this task to ensure progress on the project continued. Any services that were coded ‘unsure’ were again taken to a consensus meeting with all team members and MO.

Figure 6.2

Algorithm to ensure a more robust screening process (Y=yes, N=no)



6.2.7 Phase 3: classification of services

This phase has run throughout the development process. During the initial searching for services, BH and the team members used an updated service classification table, originally developed by Panagiotidou et al. (2021; table 6.1). This process started in the second phase to help keep track of the spread of services, but also to enable an easier classification phase later on for BH and MO. There was a significant chance of overlap between service activities and, thus, classifications, as noted by Panagiotidou et al. (2021). As a result, services were given a 'primary' classification, denoting the main activities of the service, while also being assigned 'secondary/other' classification(s) to capture the service as a whole.

6.3 Results

This section discusses the results of Phases 1-3. Figure 6.3 demonstrates the search and screening process of these phases. Overall, 1015 services were identified through the scoping exercise and after a rigorous screening process, 379 services remained for potential inclusion in the guidance. The following sections describe the results in more detail.

6.3.1 Phase 1: identification of potential services for consideration

Using all search methods, 1015 services were identified. Most services were found through the internet searches (n=813), followed by the literature search (n=178). As shown in table 6.2, a geographically diverse spread of services was identified. A small number of services were identified in the non-WHO Member states, which included countries like Gibraltar and Taiwan, while only 37 services were found in the South-East Asia WHO region, which encompassed countries such as Bangladesh, India, and Thailand. Most services were identified in the Americas (n=378) and European (n=319) regions. Over 750 services were from countries with a high-income status, and both upper- to middle-income and low- to middle-income countries had 106 and 107 services respectively. The only low-income countries (n=37) were identified in the African and Eastern Mediterranean regions. Of the 24 services recommended by the DIAN and the online survey, 10 of these were from the European region.

Table 6.1

Community dementia service classifications identified by Panagiotidou et al. (2021)

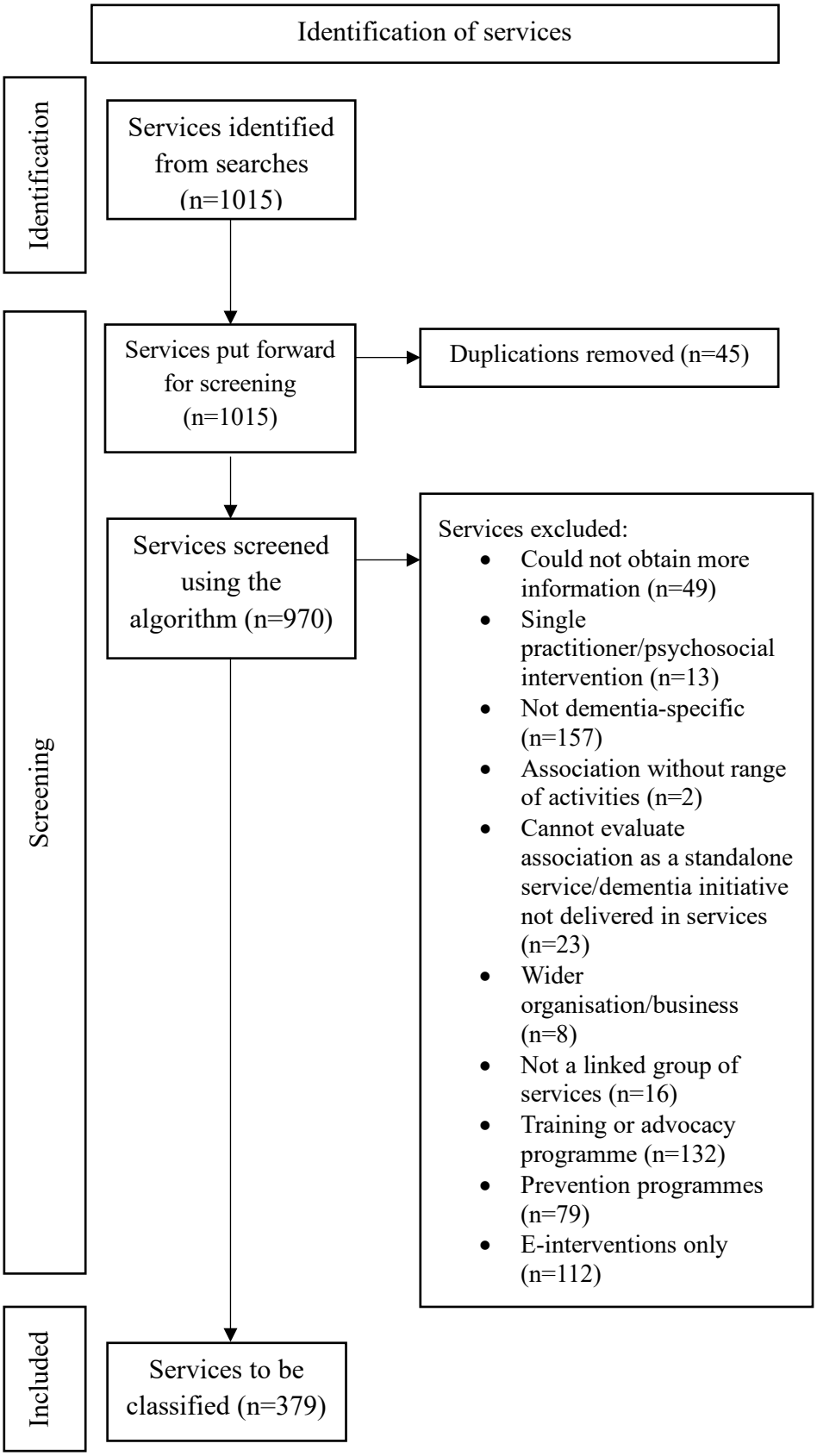
Category of service	Examples of functions of service
Peer support services	• Support groups, helplines, therapy sessions, counselling • Carer information and education: online resources, newsletters, drop-in centres, training sessions, wellbeing advice
Social cultural, recreational (SCR) services	• community choirs, music and arts • social groups • sports and exercise programmes • trips and outings • nature-based activities • community centres including activities and social support
Hospital based services	• Mental health liaison services for dementia diagnosis and care • Medical care (physical health checks and monitoring for co-morbid conditions; mental health care) • Specialist support (e.g. young onset dementia)
Support and respite services	Home support: • Support with daily activities - bathing, dressing, toileting and exercising etc

	• Home support with laundry, shopping, errands, and preparing meals • Help with medications for comorbid conditions for physical health problems • Home and garden maintenance • Home safety assessments • Assistive technology including alarms, falls detection, mobility support, & communication • Companionship, and respite at home • Health care services to help with medication and other medical services • Transport Financial support and planning, legal advice, social security, insurance, wills etc Respite: • Overnight respite stays in safe environment
Crisis Services	• Emergency preparedness plans • Crisis helplines (eg abuse/neglect) • Police safe places scheme • Ambulance services and emergency care • Multidisciplinary crisis and home treatment teams • Services for protection from abuse/neglect

Community health services	• Memory services for assessment, diagnosis and interventions (eg medication, cognitive stimulation groups, medication review) • Coordination and management role including referral to other specialists (e.g. occupational therapy, nutrition, speech and language therapy) • Counselling, information and education sessions
Supported living accommodation	Residential, nursing homes and supported housing • Support with daily activities - bathing, dressing, toileting and exercising etc • access to health care, help with medication and other medical interventions • meal provision • social, cultural, recreational activities
Palliative/End-of-Life Care Services	• Care and medication • Counselling and information • Future, financial and legal advice (eg advanced care planning)

Figure 6.3

Flow diagram of the search and screening process of Work Package 1



6.3.2 Phase 2: initial screening against minimum service criteria

Initial screening results

BH, TN, IMa, and RO originally removed 299 services. Of this number, 254 services were removed because they did not meet the inclusion criteria or they met some of the exclusion criteria, while 45 were removed because they were a duplicate (table 6.3). Over 430 services did not meet the exclusion criteria, while 160 services needed further information before a conclusion could be drawn. However, 125 services were coded 'unsure' for various reasons. The screening team stated that they were unsure about these services due to not quite having the right information, or the services were an association, such as Alzheimer's Society in the UK. Once MO and BH discussed the 'unsure' services, a total of 453 services were put forward for further consideration. Due to the number of 'unsure' services to be debated by BH and MO, the screening process was completed in a more rigorous manner using the algorithm detailed above.

Table 6.2

Number of community dementia services identified during Work Package 1 organised by WHO region (n=1015)

WHO region	Total number	Found	Income status
African	103	Google = 43	HIC* = 1
		Scholar = 59	UMIC* = 20
		Survey = 1	LMIC* = 49
			LIC* = 33
Americas	378	Google = 348	HIC = 320
		Scholar = 23	UMIC = 53
		Survey = 7	LMIC = 2
			Unknown = 3
Eastern Mediterranean	40	Google = 20	HIC = 12
		Scholar = 20	UMIC = 5
			LMIC = 5
			LIC = 4
European	319	Google = 261	HIC = 303
		Scholar = 48	UMIC = 16

		Survey = 10	
South-East Asia	37	Google = 30	UMIC = 6
		Scholar = 6	LMIC = 31
		Survey = 1	
Western Pacific	117	Google = 97	HIC = 103
		Scholar = 15	UMIC = 6
		Survey = 5	LMIC = 6
			Unknown = 2
Non-Member states	21	Google = 14	HIC = 19
		Scholar = 7	UMIC = 1
			Unknown = 1
Total	1015	Google = 813	HIC = 758
		Scholar = 178	UMIC = 106
		Survey = 24	LMIC = 107
			LIC = 37
			Unknown = 4

*HIC=high-income countries, UMIC=upper- to middle-income countries, LMIC=low- to middle-income countries, LIC=low-income countries

Screening results after the use of the algorithm

A total of 86 services had no consensus between AC, BH, or SMa, while 26 were coded as 'unsure'. The 86 services with no consensus were moved forward in the process, while the 26 services coded as 'unsure'were taken directly to MO, who removed 12 services due to meeting the exclusion criteria. The remaining 14 services were put forward for service classification and further information finding regarding their rights-based practices. Overall, 379 services were put forward for further consideration in future phases. Table 6.4 shows the number of services per WHO region before and after using the algorithm.

Table 6.3

Results of the initial screening organised by WHO region

Region (total services found)	Removed	More info needed	Unsure	Selected	Replication
African (103)	54	26	4	16	3
American (378)	60	78	52	178	10
Eastern Mediterranean (40)	12	7	10	10	1
European (319)	74	34	26	160	25
South-East Asia (37)	4	5	9	17	2
Western Pacific (117)	45	8	23	39	2
Non-members (21)	5	2	1	11	2
Total (1015)	254	160	125	431	45

6.3.3 Phase 3: classification of services

After screening, BH, AC, and SMa categorised the majority of services as 'supported living accommodation' (n=172). The next highest number of

services was ‘support and respite’ (n=73). Despite having 379 services, only two were classified as ‘crisis’ services and five were categorised as ‘palliative/end-of-life services’. Over 300 services were identified through internet searches (n=317) and 315 were from high-income countries. Table 6.5 shows the services organised by WHO region. Further classification work took place throughout phase 4 (chapter 7).

Table 6.4

Number of community dementia services through to Phase 3 before and after the algorithm was used

WHO region	Before	After
African	25	15
The Americas	181	149
Eastern Mediterranean	6	6
European	156	136
South-East Asia	21	21
Western Pacific	59	47
Non-member states	5	5
Total	453	379

Table 6.5

Number of community services after the completion of Phase 2 organised by WHO region (n=379)

WHO region	Total numbers	Found where?	Income status	Primary service category
African	15	Google = 14	UMIC* = 8	Peer support = 2
		Scholar = 1	LMIC* = 7	Support and respite = 5
				Supported living accommodation = 7
				Palliative/End-of-life = 1
Americas	149	Google = 139	HIC* = 135	Hospital-based = 5
		Scholar = 6	UMIC = 11	Support and respite = 36
		Survey = 3	LMIC = 1	Community health = 7
		Other = 1	Unknown = 2	Supported living accommodation = 101
Eastern Mediterranean	6	Google = 5	HIC = 3	Peer support = 2
		Scholar = 1	LMIC = 3	Support and respite = 3
				Community health = 1
European	136	Google = 99	HIC = 130	Peer support = 15
		Scholar = 28	UMIC = 5	Hospital-based = 8
		Survey = 9	Unknown = 1	Support and respite = 7

				Crisis=2 Community health = 50 Supported living accommodation = 40 Palliative/End-of-life = 4 Network = 2 Unsure = 8
South-East Asia	21	Google = 19 Scholar = 2	UMIC = 3 LMIC = 18	Peer support = 2 Hospital-based = 1 Support and respite = 5 Community health = 4 Supported living accommodation = 8 Network = 1
Western Pacific	47	Google = 38 Scholar = 5 Survey = 4	HIGH = 42 UMIC = 2 LMIC = 32	Peer support = 7 Hospital-based = 1 Support and respite = 15 Community health = 7 Supported living accommodation = 15 Network = 1

				Unsure = 1
Non-Member states	5	Google = 3 Scholar = 2	HIC = 5	Peer support = 1 Hospital-based = 1 Support and respite = 2 Supported living accommodation = 1
Total	379	Google = 317 Scholar = 45 Survey = 16 Other = 1	HIC = 315 UMIC = 29 LMIC = 32 Unknown = 3	Peer support = 29 Hospital-based = 16 Support and respite = 73 Crisis = 2 Community health = 68 Supported living accommodation = 172 Palliative/End-of-life = 5 Network = 4 Unsure = 9

*HIC=high-income countries, UMIC=upper- to middle-income countries, LMIC=low- to middle-income countries

6.4 Discussion

Through vigorous scoping searches, over 1000 services around the world were identified for potential inclusion in the good practice guidance for community dementia services. Most of the services were from high-income countries. Following strict inclusion and exclusion criteria, the number of services were reduced to 379. Over 310 of these services were still from high-income countries, suggesting a lack of diversity in geographical and financial spread. Moreover, 172 services were classified as 'supported living accommodation', such as residential or nursing homes, or supported housing. The work completed for Phases 1-3 has shown that there are a multitude of services around the globe for people with dementia and their families, despite the majority identified being from high-income countries. However, the lack of geographical diversity means that service providers and policymakers should make more effort to ensure the needs of every person affected by dementia around the world are met.

6.4.1 Methodological challenges

This study went through significant changes from the original concept note that was developed in 2022, not only due to other commitments on the part of the main researchers, but also due to the changes of WHO-CC team members. The WHO-CC hosted several interns throughout the development of the document; medical students looking for research experience from the University of Nottingham, and summer interns from the Mailman School of Public Health at Columbia University in New York. Another intern, from Wellesley College in Massachusetts, gained a scholarship to come and work on the project in person. This meant that several training and progression meetings occurred to ensure all researchers were on the same page. BH met with the summer interns on a weekly basis to provide quick answers to any queries. However, the turnover of the research team created difficulty in that each member learned and trained differently and there were lots of clarifying questions that arose throughout, with interruptions to progress.

Originally, the Phases were written to run separately, but in practice, they, and the Work Packages, often ran concurrently. Additionally, one of the original methods of searching for services was to utilise previous collaborations with services from members of the WHO, WHO-CC and the DIAN. However, due to sending the survey to the DIAN and related members, it was deemed unnecessary to complete this method separately. Additionally, we sought to screen the services against minimum human rights criteria as well as the service criteria in Phase 2. But services identified lacked the information to be able to do this, possibly due to limited understanding of the human rights aspects we asked about, and therefore, this was moved to Work Package 2. We also struggled with obtaining responses to our calls for more information, either about the service or their practices in relation to human rights. Alongside this, services, or the respondents to our survey and additional contacts had difficulty providing the information relating specifically to their practices, and the internet searches mostly identified basic, overall information rather than specific dementia-related practice information.

In addition, the service classification list and definitions went through major changes. In April 2023, a meeting between the WHO and WHO-CC took place, and it was agreed that another category should be included (‘networks of services’), and that the classification ‘social, cultural, and recreational services’ should be incorporated into the networks category. ‘Networks of services’ was a category within the WHO’s previous guidance for community mental health services. In this guidance, the WHO defined ‘networks of services’ as different types of services that are coordinated together across regions, whole countries, or internationally’. The WHO stated an example of a dementia network is the French memory services network ‘MAIA’, which was designed to coordinate services from different sectors, including the medical and social sectors, by improving information sharing and providing unified responses to people with dementia and their families (Pimouguet et al., 2013). Despite this recommendation, the initiative MAIA no longer seems to be in effect, with very limited information and publications identified in the last decade.

To simplify the definition of a network of services for the team members, the WHO-CC stated a network was ‘several services or projects linked by a shared theme which could be across different regions, cross-country, or international’. However, when MO and BH discussed their classifications with MF, ND, TD, and KS during the screening process, it was discovered that the WHO-CC team had been using a different interpretation of the ‘networks of services’ definition provided by the WHO. The WHO then stated that due to this, the services classified by BH and MO were not to be considered networks under the WHO’s definition.

6.4.2 Findings in the context of previous research

The searches for community dementia services identified many worldwide, with 1015 found. Of these, 758 were from countries designated as high-income, compared to 37 from low-income countries. Considering that nearly two-thirds of people with dementia live in low- to middle-income countries (Wimo et al., 2023), this suggests a significant disparity in resources between different income statuses. Our search results match the scoping searches of multiple reviews conducted for the World Alzheimer Report 2016 by ADI, which examined elements of healthcare, including quality, to provide recommendations for improvements (Prince et al., 2016). These reviews used several academic databases to conduct their searches, while we used both Google and Google Scholar, and all used similar search strategies.

It could be that people living in low- to middle-income countries or low-income countries lack dementia literacy. Dementia literacy does not just refer to knowledge of dementia, but transforming this knowledge into beliefs and actions (Smith et al., 2022). Dementia literacy can help people with dementia, family members and supporters, service providers, and policymakers to understand and utilise information, develop and maintain resources, and implement strong, coordinated action plans to improve access and quality of care people with dementia and their families receive (Soriano, 2023). In some low- to middle-income countries, there is no word for dementia (De Jager et al., 2015; personal communication, 8th August 2025), whereas other countries have not considered dementia as a distinct condition

(Johnston et al., 2020). Levels of dementia literacy have a profound impact on the care provided to people with dementia and their families, and therefore, a lack of literacy suggests the need for awareness campaigns and training.

Moreover, of the 103 services identified from the African WHO region, only one was from a high-income country. Only one country in the African WHO region was designated high-income (International Financial Reporting Standards, 2023). Despite the size of the region, this indicates that several barriers to accessing or developing services exist, or that the services are transient. Firstly, attitudes towards dementia in sub-Saharan Africa can be seen as a normal consequence of ageing, previous sins, or witchcraft (Brooke & Ojo, 2020; De Jager et al., 2015; Mussie et al., 2022), and therefore, nothing can be done to help people with the condition, possibly preventing the development of community services for dementia in the first place. Additionally, people with dementia and their families might not seek the help of services for fear of being shunned or stigmatised and discriminated against (Brooke & Ojo, 2020; Bruinsma et al., 2022). On a more practical level, it could be that services do exist, but they might lack access to internet-based communication so they would be unable to receive the survey cascaded throughout networks. It could also be that, at the time of searching, they did not have an internet presence.

In addition, due to the financial situations of low- to middle-income and low-income countries, even if the desire to develop services exists, the process of developing services might not be affordable. The WHO is pressing for the availability of universal health coverage, one of the Sustainable Development Goals (WHO, 2025d). Universal health coverage means that everyone can access the full range of health services when and where they need them, regardless of their financial circumstances (WHO, 2025d), a human right also protected by Article 25 of the CRPD (UN, 2006). To achieve this, the WHO recommends that at least 5% of the gross domestic product of each country is spent on public healthcare, but most countries, particularly low- to middle-income countries and low-income countries, have been unable to spend this (WHO, 2025c). It could be that governments in poorer countries

are unable to meet this threshold due to insufficient public funding, meaning that the public must pay for services themselves, despite being on low incomes (Human Rights Watch, 2025), limiting access to health care. All of this suggests that there could be significant systemic and financial barriers in low- to middle-income countries to developing and providing community-based dementia services.

6.4.3 Limitations

A strength of this study was the development of valid and reliable techniques to ensure a robust methodological process and training of the team members. By piloting the algorithm developed specifically for the screening process, which had not been part of the original plan, we were able to verify the method and provide a resource for the screening process. Additionally, the WHO and the DIAN were presented with the algorithm during the piloting process and agreed that this would be a good screening technique to follow. Despite this, over 370 services required further information regarding the specific support provided and their human rights-based practice.

Another strength of the development process is that we searched comprehensively for, and subsequently identified, community dementia services around the globe, illustrating different types of services in different legal and policy frameworks. However, despite the use of multiple search methods, services without an internet presence in any sense, as well as the network not being aware of services, may have been missed. This was an issue also encountered by the WHO team while developing their community mental health services guidance (WHO, 2021a). This is particularly the case for services from low- to middle-income countries, or low-income countries. Additionally, most of the services recommended through the survey were from the Americas, European, and Western Pacific regions, where many countries are of high-income status (International Financial Reporting Standards, 2023). We also identified services that described being ‘dementia-friendly’ or cared for people with dementia alongside other conditions, without specifically stating what they did for dementia. Furthermore, lots of generic health services stated that they provided dementia care as part of their remit, but

again, did not specify the details. Therefore, it could be considered that these services would not constitute a dementia-specific community service.

Additionally, the searches were conducted in English, which could have reduced the number of services identified or recommended due to differences in translation. In the case of some regions of the world, such as sub-Saharan Africa, there is no word for 'dementia' (De Jager et al., 2015), which would mean that for people experiencing symptoms of dementia, there are potentially services that provide support without stating the name of the condition. The use of the online survey with the DIAN network also means there is the potential for researcher bias. All of the DIAN members have a vested interest in the field of dementia and therefore may work closely with some community dementia services which may not actually provide the most appropriate or rights-based care. However, they could have recommended these services out of their own preference and obligation.

Finally, there were problems with how the services were categorised due to the significant overlap of service activities. Multiple services provided more than one type of support; for example, a dementia care village provided peer support with groups, respite for family supporters, and palliative/end-of-life services. Therefore, this service could have been categorised within these three classifications. However, on advice from the WHO, we had to investigate the service further to determine which activities are the main type of support provided to determine the primary classification. Secondary classifications were also determined to present the whole picture of the service. Furthermore, we had different service categories to the WHO 'Global status report on the public health response to dementia' (WHO, 2021c), meaning there are discrepancies in the way services have been identified and organised by two different WHO publications. However, the global status report was produced before the scoping search was conducted by Panagiotidou et al. (2021), on which we based our categories. Nevertheless, this issue does bring into question how best to categorise services with multiple activities.

6.4.4 Future directions and implications

Other publications that have reviewed services have grouped them together based on geographical location, including the WHO regions, or the country income status, or by a different type of service classification (Prince et al., 2016; WHO, 2021c). One review in the World Alzheimer Report 2016 organised their services by phases of care – detection and diagnosis, early post-diagnostic support, and continuation of support (Prince et al., 2016). As a result of the different classification systems used in reviews, a conceptual model could be developed to determine how community dementia services should be organised, for example, cost, type of service, or geography. This could enable easier and more systematic evaluation processes of the global picture of dementia services.

Work Package 1 has significant implications for the global dementia care and human rights picture. While we noted there are many services available around the world, the majority are from high-income countries where the resources are most accessible and strongest. But the fact services from low- to middle-income countries were also identified suggests that it is possible to provide good quality care in circumstances where there are more financial constraints and resources are limited. The 379 services put forward for service classification also demonstrate a mix of the same services within different cultures and frameworks, suggesting that these types of services can provide good care across different legal and policy frameworks. People with dementia can use these results to find similar services within their locality, but also use the information gathered to understand what type of support is provided and to ascertain which types of support would best meet their needs. This is also the same for family supporters. Service providers and policymakers should use these findings to plan further services around the world to enable easier access to support for people with dementia and their families.

6.5 Conclusion

This intensive and comprehensive scoping exercise and literature search resulted in a global picture of available services for dementia care to be used in the next stage of evaluating human rights-based practices. A variety of services were identified across the world, providing different types of support in a broad range of legal and political frameworks in diverse services and countries. However, the information gathered for each service varied in depth and specificity, meaning screening processes and service classifications were difficult to complete, despite the improvements in methodology. Implications for people with dementia and their families include being able to identify similar services near to them geographically but also decide which services would provide the most appropriate support.

7. Collation and assessments of rights-based practices of services for the good practice guidance

Associated publication: Harden, B., Funk, M., Drew, N., McDermott, O., Seeher, K., Dua, T., & Orrell, M. (2024). Developing good practice guidance for community dementia services: Person-centred and rights-based care approaches. *WAPR E-Bulletin, 53*, 92-101.

7.1 Aim

The aim for this chapter, hereafter referred to as Work Package 2, was to collate the service information on the remaining 379 services and assess their practices in relation to human rights. Although Phases 5 and 6 are included within the Work Package, this chapter will only discuss the results of Phase 4 ('full screening of services within each service category').

7.2 Methods

7.2.1 Design

Similarly to Work Package 1, the methods in Work Package 2 employed mixed methodology. Work Package 2 covered Phases 4-6 (figure 7.1). Work Package 2 involved the use of online surveys, rating documents, and interviews with some services for follow-up were conducted. This was to assess and validate the remaining services as good quality in rights-based practices.

7.2.2 Ethics

Ethical approval from the University of Nottingham Unit of Mental Health and Clinical Neuroscience Research Ethics Sub-Committee was obtained on the 18th July 2023 (reference: DPAP-2023-3112-4).

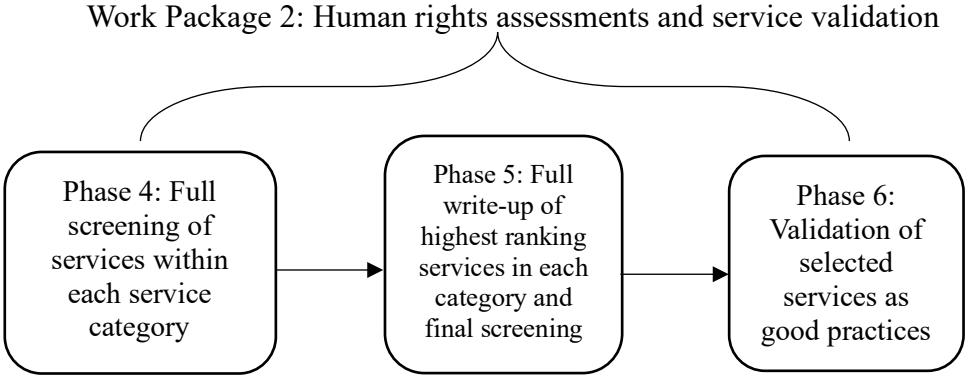
7.2.3 Contributors in Work Package 2

The following people were involved in phases 4-6: Briony Harden (BH), Martin Orrell (MO), Orii McDermott (OM), Abhisri Chadalavada (AC), Insha

Merchant (IMe), Jack Cahill (JC), and Ella Kaye (EK). A more detailed description of the contributions made by each researcher can be found in appendix 12. The Dementia International Advisory Network for Human Rights (DIAN) provided feedback throughout the process.

Figure 7.1

Work Package 2 of the methodology of the WHO good practice guidance for community dementia services



7.2.4 Phase 4: full screening of services within each service category

Services that have progressed through phases 1-3 had all information independently reviewed by the WHO Collaborating Centre (WHO-CC) team to determine any missing information and from where the missing information could be sought.

Retrieving information on the rights-based practices of services

For the services that passed through the initial screening against minimum service criteria, an additional spreadsheet with only these services was created and kept separately from the initial services. More information was required regarding their practices in relation to how they respect, protect, and promote the human rights of people with dementia and their families and supporters. To do this, BH created another online survey on JISC version 3 (appendix 19) which focused specifically on the five human rights aspects associated with the guidance, encouraging the respondents to write freely regarding how their practices uphold the Convention on the Rights of Persons with Disabilities (CRPD) principles. Definitions, examples, and prompts were provided on the

survey to make the questions clearer and gain more accurate data. ZS and IMe, who joined the project in May 2024, were tasked with sending emails (appendix 20) to all remaining services using the contact details we had for them asking for more information through the survey. BH was copied into every email, and her contact details were provided in case of queries. The services were provided with a deadline of two weeks from the date of the email sent to them. Reminder emails were sent closer to the deadline. The final date for the survey to be answered was 30th June 2024.

Any responses received were added to the new spreadsheet which included the information previously gathered. They were also added to a word document in the format to be potentially used in the final guidance. Service folders were also created to help collate all evidence links and information, such as service reviews or academic papers, specific to that service. AC returned to the team and helped BH go through all service documents to identify any gaps, including in service categories and search for evaluations of the services until December 2024.

Lack of diversity in services after the survey responses

There were limited numbers of peer support services, crisis services, and palliative/end-of-life care services, as well as geographical gaps. As a result, the initial 379 services were reviewed to try and identify potentially promising cases that could alleviate these gaps. The identified services were seen to be the most promising in each category due to their descriptions and practices. The survey was re-sent to these services and gave an additional deadline of 16th June 2025.

The rating and scoring system

The WHO-CC team then used the descriptions provided by the services to rate each one according to human rights criteria based on the CRPD principles:

- The right to legal capacity: promoting autonomy, independent decision-making, and fostering independence

- Non-coercive practices: explicit reference to implementing services without coercion, force, restraint, etc.
- Participation: people with lived experience of dementia involved in the development or implementation of the service
- Community inclusion: direct links to the community provided, additional services offered, culturally-appropriate practices
- Recovery-oriented and person-centred care: supporting people to regain control promoting meaningful relationships in life, providing rehabilitative support, helping empower the person, maintaining hope for the future, supporting people to retain their identity, and placing the person at the forefront of their care.

Using a rating booklet created by BH (appendix 21), the team examined the number of criteria each service met, before rating the extent to which the criteria were met on a scale of 1-5 (1- not met/unsatisfactory [with additional criteria on the front of the rating booklet], 2-no/limited information available/found, 3-partially met/satisfactory, 4-good, 5-very good). Services were also given a '1' if they promoted medication as a primary or principal course of action or if the principles of how the service was delivered or outcomes achieved contravened one or more international human rights standards, such as the CRPD. The contraventions could be that: involuntary admission/treatment was allowed, seclusion/restraint was allowed in the service, legal capacity is not recognised (decision-making lies with family member, staff, or others), or Electronic Convulsive Therapy (ECT) undertaken without informed consent. In the original scoring system, '2' was used to denote unsatisfactory, but this was recoded to '1' (hence, '1' represented unsatisfactory practices while '2' then meant no or limited information available/found). This meant that each area of rating would function like a scale, so the total score was meaningful with higher scores indicating better practices.

The lowest score a service could be given was five, while the highest was 25. Any services that were rated '1' by at least two team members in an area were put to the side to be reviewed by BH and MO. The raters also indicated which pieces of evidence had been identified to demonstrate

service's recovery-oriented, person-centred, and rights-based care practices. By evidence, we meant any quantitative and qualitative data available, quality reports, service evaluations, and reviews on social media among other pieces of potential evidence.

Training the team members and piloting the rating booklet

Throughout the rating process, a total of four meetings with the team were held to discuss progress and any discrepancies in ratings. The first three were held within the first month of the rating process for training purposes. Firstly, BH met in person with MO and OM to discuss the booklet and rating procedure. The next one was conducted online between BH, AC, IMe, and EK to train them with the booklet, explaining the criteria and how to provide BH with the ratings. The booklet had been circulated a few days prior to the meetings. The booklet was designed to be simple to understand, and the raters had no questions regarding its use.

To ensure the booklet was reliable and valid, a piloting process took place, with all six raters completing ratings on three services from different service classifications and WHO regions. Every rater was instructed to complete the QualityRights e-training launched by the WHO to obtain knowledge regarding human rights, if not already done so, and they were encouraged to complete further reading on the current issues that can be seen within dementia care. Every rater had two weeks to complete this process. The raters completed the ratings independently before the scores were sent to BH to collate. A consensus meeting was then held between all raters to discuss how the process went and what methods they used, with IMe online and EK not present due to illness. The meeting was minuted and notes sent to all team members accordingly. A separate meeting was held between BH and EK to clarify the minutes and reiterate the main findings.

After the consensus meeting

Following the meeting, BH separated four of the raters (OM, EK, AC, and IMe) into two teams and gave them a list of services to rate. BH and MO rated all services as project leaders. This meant all services were rated by at least

four people. The raters had 8 weeks to complete all ratings. BH then had a final meeting with AC, IMe, and EK to thank them for their work and obtain information regarding how they rated. Provided they met the minimum threshold, services from low- to middle-income countries and under-represented geographical regions were prioritised where possible and appropriate as well as services with more details and useful evaluation data. For any services still lacking information after the initial rating process, MO and BH conducted semi-structured interviews with the services using the rating booklet as a guide to ensure we gathered relevant information. The outcomes of this piloting process, consensus meeting, and final procedure can be found in the results section.

7.3 Results

This section will discuss the screening and rating of the remaining 379 services from Work Package 1 (chapter 6). Thirty-two services responded to the calls for more information regarding how they uphold the human rights of people with dementia and their families. Of these, 22 were rated, with 20 of these services moving forward to Phases 5 and 6. Figure 7.2 details the process.

7.3.1 Phase 4: Full screening of services within each service category

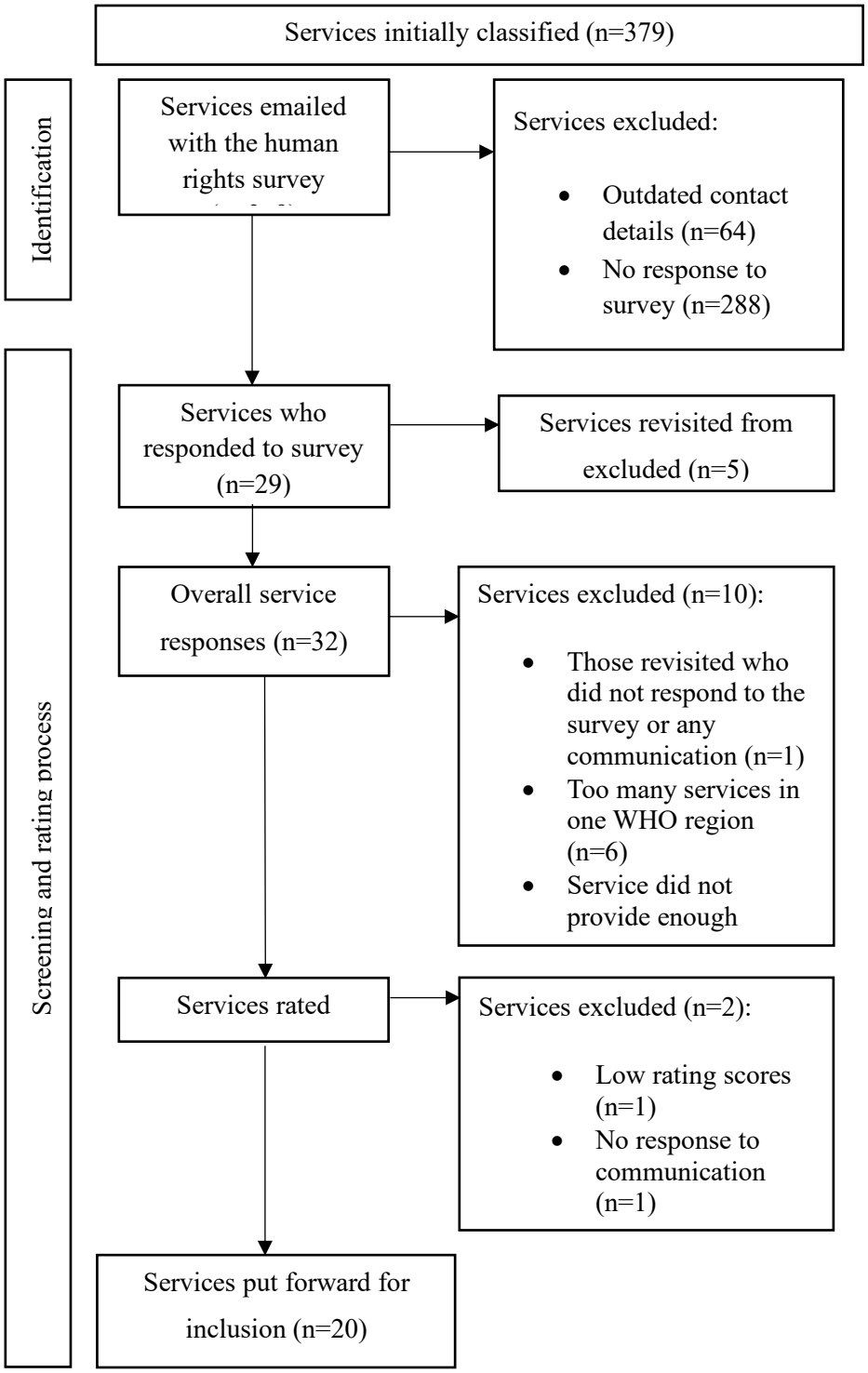
Retrieving information on the rights-based practices of services

Of the 379 services sent the human rights-specific survey, 64 were removed due to not having recent or updated contact details from within the last 10 years, determined through emails that bounced back to the researchers or phone numbers that did not work. We received 29 responses to our survey before the initial deadline of 30th June 2024. Of the five more promising services which could help the WHO-CC fill gaps within service categories and geographical regions, three responded to the re-sent survey. Overall, 32 services were put forward for rating (table 7.1). Twenty-six were from high-income countries, with 13 of these from the European WHO region. Nine were from the Americas and six were from the Western Pacific. Seven services were classified in the previous phase as ‘support and respite’, a

further seven classified as ‘networks’ and six were categorized as ‘supported living accommodation’.

Figure 7.2

Flow diagram of the search and screening process of Work Package 2



BH and MO then met in-person to review the services obtained and their human rights information, as well as the general service description. Using the service and human rights criteria, and the guidance by the WHO that we should aim for a maximum of three services per category, 10 services were removed, primarily from the Americas, European, and Western Pacific regions. Five services were removed from the Americas; three due to the number of services in the region, and two others because the respondents did not provide human rights-based answers. Three were removed from the European region because there were still 13 from the WHO region overall, and two were removed from the Western Pacific region as one did not provide enough human rights information and the other was a revisited service that could potentially fill a gap previously identified, but they did not respond to any of our communication.

Results of the piloting exercise

The three piloted services were from the 'support and respite', 'community health', and the 'network' categories. They represented three countries from two WHO regions (European and Western Pacific), and all services scored above 15, suggesting the services had adequate information to rate the human rights aspects. Two services had one rights aspect (community inclusion) rated '2' by one rater, suggesting a lack of information. No services were given a rating of '1'. Overall, the ratings were relatively consistent, ranging between 17-25, suggesting good human rights-based care practices. At the consensus meeting held following the piloting, the researcher who gave the score of '2' for limited information changed their mind after hearing the discussions and said they had not read the service information properly and misunderstood some elements.

Table 7.1

Number of community dementia services that responded to the human rights survey organised by WHO region (n=32)

WHO region	Total numbers	Found where?	Income country	Primary service category
African	2	Google = 1	LMIC* = 2	Support and respite = 1
		Scholar = 1		Palliative/End-of-life = 1
Americas	9	Google = 6	HIC* = 7	Peer support = 1
		Scholar = 1	UMIC* = 2	Hospital-based = 2
		Survey = 2		Support and respite = 4
				Community health = 1
				Supported living accommodation = 1
Eastern Mediterranean	1	Scholar = 1	LMIC = 1	Peer support = 1
European	13	Google = 6	HIC = 13	Hospital-based = 1
		Scholar = 2		Crisis = 1
		Survey = 3		Community health = 1
				Supported living accommodation = 3
				Network = 7
South-East Asia	1	Google = 1	LMIC = 1	Supported living accommodation = 1

Western Pacific	6	Google = 2 Survey = 4	HIC = 6	Peer support = 2 Hospital-based = 1 Support and respite = 1 Community health = 1 Supported living accommodation = 1
Total	32	Google = 16 Scholar = 5 Survey = 11	HIC = 26 UMIC = 2 LMIC = 4	Peer support = 3 Hospital-based = 3 Support and respite = 7 Crisis = 1 Community health = 1 Supported living accommodation = 6 Palliative/End-of-life = 1 Network = 7

*HIC=high-income countries, UMIC=upper- to middle-income countries, LMIC=low- to middle-income countries

We also identified that raters had been using slightly different methods to rate. For example, three of the raters used the whole service document to rate the human rights aspects, whereas the other three only used the information provided in the specific sections that related directly to that human right. Upon discussion, it was agreed by all raters, that to obtain the full picture provided by the information, all ratings going forward would be completed by looking at the service information as a whole, rather than looking at the specific sections. The piloting process helped gain validity and reliability for the booklet and also ensured all raters were conducting the ratings in similar ways, albeit independently.

Results of the overall rating process

The remaining 19 services were rated by MO, BH, OM, AC, EK, and IMe. Two of these services were technically the same type of service providing the same activities, but they ran in two different countries with different legal frameworks and contexts, and as such were treated as two different services. Overall, ratings for all services ranged between 8-25, with seven services having a human rights aspect scored a '1' or 'unsatisfactory' by one person; however, due to the rule that services scored a '1' by at least two raters in one area, these seven services did not meet the threshold to be put aside for discussion by BH and MO. Instead, a consensus meeting was held and the discrepancies and reasoning behind the scores investigated.

Reasons for the rating of 'unsatisfactory' included 'residents being locked in the grounds' and 'the use of diversion by staff members'. This suggests infringements on the human rights of people with dementia using these services with coercive measures, so these services were discussed with the WHO. The WHO team advised us that there should be some flexibility in cases like this, as services have a duty to protect the safety of the people they are caring for. They also suggested that we should think about how people would live their lives outside of these services; for example, thinking about whether people with dementia and their families lock the doors of their own homes to protect safety. Safeguarding could be preventing harm from others or protecting people from harming themselves. As a result, these services were

re-rated and given scores of ‘3’ or ‘satisfactory’. Table 7.2 shows the raw ratings of all six raters.

Of the rated services (n=22), 15 received a score of ‘2’ indicating no or limited information for the human rights aspect being rated. These services were researched and then discussed further at the consensus meeting. After review, the score was changed to either a ‘3’ or ‘4’ for eight of the services. The remaining seven that required more information were contacted with questions pertaining to the required aspect with a deadline to respond by mid-April 2025. Once the information was received, the services were rerated, with only three remaining with ‘no or limited information’. No services were given a score of ‘unsatisfactory’ following the additional information. Online semi-structured interviews were held with two of the three services and scores adapted accordingly, moving from 15 for one service and 20 for the other to 19 and 21 respectively. These interviews were structured based on the human rights survey and criteria.

Upon completion of the ratings, two services were removed from the upcoming phase: one was withdrawn due to low rating scores, and the other was removed as they did not respond to our communication for further information on their human rights-based practices. This meant that 20 services moved to Phase 5. All average ratings, once calculated, are in table 7.3. Examples of the information rated can be seen below alongside the average rating of that service for the rights aspect (table 7.4). Please note that any identifiable information has been redacted to retain confidentiality.

Table 7.2

Raw ratings given by all six raters (designated A-F)

		Legal capacity						Non-coercive practices						Participation						Community inclusion						Recovery-oriented and person-centred care					
# of service	Income	A	B	C	D	E	F	A	B	C	D	E	F	A	B	C	D	E	F	A	B	C	D	E	F	A	B	C	D	E	F
1*	HIC^	3	3	3	4	3	5	4	4	4	5	4	5	4	3	4	5	5	5	3	4	4	4	3	5	3	3	4	4	3	5
2*	HIC	5	4	4	4	4	5	4	4	4	4	5	4	4	3	4	3	5	4	3	4	4	4	4	2	4	5	5	4	4	5
3*	HIC	3	3	3	5	5	4	3	3	3	4	4	5	5	5	4	5	5	5	4	3	4	3	5	2	4	4	4	4	5	5
4	HIC	3	5	5	-	-	4	4	5	4	-	-	3	4	5	5	-	-	5	5	5	5	-	-	4	4	5	5	-	-	4
5	HIC	3	4	-	5	4	-	3	4	-	5	3	-	5	5	-	5	4	-	4	4	-	5	5	-	5	5	-	3	4	-
6	HIC	3	3	1	-	-	3	3	4	2	-	-	4	5	4	4	-	-	4	4	5	4	-	-	4	5	4	4	-	-	4
7	HIC	5	4	-	4	4	-	3	3	-	5	1	-	5	3	-	3	4	-	5	4	-	5	5	-	4	5	-	5	5	-
8	HIC	4	3	2	-	-	3	5	4	5	-	-	1	5	3	4	-	-	3	5	4	5	-	-	3	4	4	5	-	-	3
9	HIC	5	4	-	4	4	-	5	5	-	5	4	-	4	3	-	2	3	-	5	5	-	5	5	-	5	5	-	5	3	-
10	HIC	4	4	4	-	-	3	4	4	5	-	-	2	5	5	5	-	-	2	5	5	4	-	-	3	5	5	5	-	-	4
11	HIC	4	3	-	5	4	-	4	5	-	4	5	-	5	5	-	4	4	-	5	5	-	5	3	-	5	5	-	5	3	-
12	HIC	5	4	3	-	-	5	3	5	4	-	-	4	3	3	3	-	-	3	3	3	3	-	-	3	4	4	4	-	-	4

13	HIC	2	3	-	3	3	-	4	4	-	4	3	-	4	3	-	2	3	-	4	2	-	3	4	-	3	4	-	4	3	-
14	LMIC^	4	2	1	-	-	3	3	2	2	-	-	3	4	3	2	-	-	3	3	2	2	-	-	3	3	2	3	-	-	4
15	UMIC^	3	2	-	1	3	-	4	3	-	3	3	-	4	2	-	2	2	-	2	3	-	2	1	-	4	3	-	3	3	-
16	LMIC	3	3	2	-	-	3	3	4	4	-	-	3	4	4	3	-	-	3	5	4	4	-	-	3	4	5	4	-	-	3
17	HIC	4	3	-	2	2	-	3	3	-	3	1	-	5	4	-	2	3	-	5	4	-	3	3	-	4	4	-	3	3	-
18	HIC	4	3	1	-	-	3	4	2	2	-	-	2	4	2	1	-	-	2	4	4	3	-	-	3	4	3	1	-	-	3
19	LMIC	4	4	-	3	-	2	4	4	-	3	-	2	3	3	-	3	-	2	4	4	-	3	-	2	4	4	-	4	-	3
20	LMIC	-	3	-	2	3	3	-	2	-	3	2	3	-	4	-	4	4	3	-	3	-	4	4	3	-	3	-	4	3	4
21	HIC	-	4	-	5	4	5	-	4	-	4	5	4	-	3	-	2	3	3	-	4	-	4	3	3	-	4	-	4	4	5
22	HIC	3	3	-	2	3	-	3	3	-	3	2	-	3	5	-	2	4	-	5	5	-	4	5	-	4	5	-	3	4	-

*piloted services, ^HIC=high-income countries, UMIC=upper- to middle-income countries, LMIC=low- to middle-income countries

Table 7.3

Average ratings of the 22 rated services (to one decimal place)

# of service	Income	Legal capacity	Non-coercive practices	Participation	Community inclusion	Recovery-oriented and person-centred care	Total average rating (out of 25)
1*	HIC^	3.5	4.3	4.3	3.8	3.7	19.7
2*	HIC	4.3	4.2	3.8	3.5	4.5	20.3
3*	HIC	3.8	3.7	4.8	3.5	4.3	20.2
4	HIC	4.3	4	4.8	4.8	4.5	22.3
5	HIC	4	3.8	4.8	4.5	4.3	21.2
6	HIC	2.5	3.3	4.3	4.3	4.3	18.5
7	HIC	4.3	3	3.8	4.8	4.8	20.5
8	HIC	3	3.8	3.8	4.3	4	18.5
9	HIC	4.3	4.8	3	5	4.5	21.5
10	HIC	3.8	3.8	4.3	4.3	4.8	20.8
11	HIC	4	4.5	4.5	4.5	4.5	22
12	HIC	4.3	4	3	3	4	18.5
13	HIC	2.8	3.8	3	3.3	3.5	16.3

14[§]	LMIC^	2.5	2.5	3	2.5	3	13.5
15	UMIC^	2.3	3.3	2.5	2.3	3.3	12.8
16	LMIC	2.8	3.5	3.5	4	4	17.8
17	HIC	2.8	2.5	3.5	3.8	3.5	16
18[§]	HIC	2.8	2.5	2.3	3.5	2.8	13.8
19	LMIC	4	3.8	3	3.8	4	18.5
20	LMIC	2.8	2.5	3.8	3.5	3.5	16
21	HIC	4.5	4.3	2.8	3.5	4.3	19.3
22	HIC	2.8	2.8	3.5	4.8	4	18.3

*piloted services, [§]removed before Phase 5, ^HIC=high-income countries, UMIC=upper- to middle-income countries, LMIC=low- to middle-income countries

Table 7.4

Examples of the information rated and the average rating score

Service number	Human rights aspect	Average rating	Example
Service 2	Legal capacity	4.3	"We respect the non-verbal presentations and voices of people with dementia. We will have a comprehensive intake based on Prof Tom Kitwood Model regarding the Background, Personality, Health Condition, Neuro-impairment and Social Psychology. Our staff are trained by asking proper questions like MC [mental capacity] or Yes/No questions, to facilitate the decision-making of people with dementia. Visual hints and cues will be offered. We will provide suitable help according to different cognitive and functional performance assessments. It will be a strength-based approach, and we identify the value/capacity rather than the deficit of the person with dementia. We take the concept of disability and empowerment for both people with dementia and their care partners. We treat the person with dementia as the co-author or co-creator in research as well."
Service 13		2.8	"[redacted information]… For an admission to [redacted], all residents are required to have both a medical and financial power of attorney who authorizes their admission."

Service 5	Participation	4.8	the service works with [redacted] groups which bring together people with lived experience to inform the service, to provide feedback and to consult on specific issues. The service was developed from consultation with people affected by dementia and we continue to ensure user / carer voices shape the development of the service. This includes the running of monthly [redacted] groups where we bring together people living with dementia and their carers [redacted] where we are able to consult on any proposed changes, or just to hear what the developing needs and priorities are for people affected by dementia.
Service 15		2.5	“It is important to know about the person's history by receiving family/friend input as well as the person living with the disease. When presented, allow the person with dementia [to] guide how it will play out. Empowering them helps stimulate brain cells”

7.4 Discussion

This was the first study to rigorously develop methods for and assess good practice in recovery-oriented, person-centred, and rights-based care in community dementia services. Following the methods discussed, a selection of services that demonstrate good practice in human rights for people living with dementia were identified. The PhD study behind the development has been subject to significant feedback from the DIAN and people with lived experience of dementia at each stage. The work thus far has demonstrated that there is more work needed to ensure the human rights of people with dementia, and their family members, are upheld within care services.

7.4.1 Methodological challenges

Despite rating the services being an original method, there was no standardised booklet created by the WHO, so we had to develop the booklet during this phase to be used by all team members to improve understanding of the aspects of human rights and the overall reliability and validity of the study. However, to ensure the booklet was reliable and valid, we had to pilot it and adjust as required. This meant that the timeline for this phase was pushed back until the rating booklet was finalised.

Originally, the plan was for the guidance to be launched in December 2024. However, phase 4 did not get underway until May 2024, with the main process taking place in 2025. These timing changes occurred during phase 1 (‘searching for potential services’) due to the length of time it took to systematically search the internet and literature for services. The deadlines for each phase were constantly delayed due to the length of time each phase took and the changes to each phase and team members. Although aware of how ambitious the agreed timescales were due to the work needed, as well as BH completing other PhD studies alongside the development processes, we did not predict how many changes would have to be made to ensure a robust, rigorous production.

In addition, although we aimed to develop a transparent, robust rating system, we were still hindered by a lack of information regarding the rights-

based practices of services. Furthermore, despite several training workshops, the piloting, and consensus meetings, one or two raters consistently provided ratings that could be considered outliers. These two raters were not given the same services to rate, meaning at least three ratings were consistent with one another on each service. These two raters did not have significant experience relating to human rights and dementia; therefore, the differences in ratings could be due to preconceptions of differing experiences with dementia and human rights, differing levels of prior knowledge, time already spent on the project, and the subsequent knowledge and familiarity with the project.

7.4.2 Findings in the context of previous research

The findings during the methodological development of the guidance document have provided a clearer picture on the status of human rights in dementia worldwide. The results suggest that community dementia services often lack the quality of care necessary to meet the needs and preferences of people with dementia and their families and supporters, in line with the arguments of Gauthier et al. (2022) and Giebel et al. (2023). Moreover, our findings indicate that many services need to make improvements so that the human rights of people with dementia are respected, protected, and promoted (Read et al., 2020; Steele et al., 2020; Steele & Swaffer, 2024).

The majority of services that were given the lower ratings were those from low- to middle-income countries, as seen in table 7.3, where economic, cultural, and organisational resources can be scarce (Kupeli et al., 2018). As discussed by Uwakwe (2000), many low- to middle-income countries lack the resources to be able to take advantage of the pharmacological, psychological, and social developments that high-income countries can. It could also be that stigma or misunderstandings about dementia in low- to middle-income countries influenced the information provided by services, leading to lower ratings. We noted that the response for the services from low- to middle-income countries were often lacking detail describing practices in relation to human rights.

Of the 32 services that responded to our calls for more human rights-based information, many provided care that on the surface may seem like good practice in relation to human rights but was not compliant with human rights standards, particularly the CRPD. For example, service 21 stated that "Autonomy is upheld as far as possible, and advocacy for their best interests ensured (usually family, often also IMCA [Independent Mental Capacity Advocate])". This practice of best interests infringes the right to legal capacity in accordance with the CRPD (UN Committee on the Rights of Persons with Disabilities, 2016), but is actually a legal safeguard protected by the law within the country this service comes from. Legal capacity of people with dementia must be respected and those who wish to exercise their right should be supported to do so, with the support legally recognised (Flynn, 2018). This suggests that policies themselves are not in line with human rights principles, which is concerning considering the number of countries who have ratified the CRPD, meaning they must legally ensure actions are taken to uphold the human rights of people with disabilities, including those with dementia. This is in line with findings in chapter 5 of this thesis; many national dementia plans around the world do not align well with the CRPD, particularly concerning rights to freedom from coercion and the right to participation.

7.4.3 Limitations

The use of a valid and reliable rating system meant that the rating process had a more rigorous process, and the subsequent findings were robust. The piloting process ensured the rating booklet was a trustworthy method, and also strengthened the reliability of the WHO's initial human rights criteria used in the development of their previous 'community mental health services' guidance (WHO, 2021a). The subjectiveness therefore relied on in-depth knowledge of human rights; to ensure the raters obtained this knowledge, BH instructed them to complete the WHO's QualityRights e-training and to complete further reading. While this would reduce some of the subjectivity, all self-report measures, including the rating booklet, require some level of interpretation. This is why we also ensured that each service was rated by at

least four assessors, with BH and MO completing ratings on all of the services having been closely involved in all stages of the guidance thus far.

Additionally, many of the services did not provide the information required for full, in-depth ratings to be conducted. A lot of the information initially identified in Phase 1 was taken from websites, papers, and social media sites, such as Facebook, but this information was mostly based on promotional material. It did not describe the care provided in significant detail, mostly advertising the fact that they do offer dementia care and where people with dementia or their families can receive help. This could have also influenced the identification of services, potentially favouring private providers rather than public care providers. When contacted for more information, including prompts of the information required, some services still did not talk specifically about their practices or the supports provided, meaning the information was not dissimilar to that already found through the initial searches. However, it could also be that the services had limited time to be able to provide in-depth information due to service demands.

7.4.4 Future directions and implications

Key rights-based principles for community dementia services to respect, protect, and promote are the right to legal capacity, non-coercive practices, participation, community inclusion, and recovery-oriented and person-centred care approaches (WHO, 2021a). The results suggest that many services do not meet these requirements, and therefore, much work is needed to ensure the full enjoyment of human rights for people with dementia and their families and supporters. Also, we have highlighted the human rights issues within dementia care services and thus provide implications for stakeholders in the field of dementia care, including service providers and policymakers, to guarantee improvements. Our results also demonstrate the need for considerable training in human rights, such as the QualityRights training on Mental Health, Recovery, and Community Inclusion (WHO, 2022b)

By illustrating the highest-ranking services that demonstrate good recovery-oriented, person-centred, and rights-based care, people with

dementia can understand and advocate for their human rights and how they should be treated with equality and maintain access to good quality services. The document could also increase awareness of services within their locality or inspire them to look for similar services in their own communities and countries. In addition, by showcasing the information about these services potentially not otherwise available, such as the specific rights-based practices, the guidance could help people with dementia and their families to make informed choices about the services they use.

7.4.5 Developing the WHO good practice guidance

The PhD work has contributed to the development process for the WHO good practice guidance. The work beyond the PhD is currently in progress led by MO with continued contribution from BH. These stages involve the selection of the final list of services in collaboration with the WHO and the write up and subsequent editing of the guide. MO collated and edited the final 20 services into an initial document. MF and ND reviewed the document and a meeting with MO and BH was held, and it was agreed that two services (Meeting Centres UK and Meeting Centres Poland) could be combined into one case study on Poland with brief notes on the UK centres. An additional five services were removed because there were more services than required in some categories, for example, supported living accommodation, and a need for diversity between services. One of these services, the Memory Services Network Accreditation Programme, was chosen to potentially be included as a 'spotlight' case linked to the Bristol Dementia Wellbeing Service. The classification 'hospital-based services' was renamed to 'specialist services' to enable clearer identification of the services included in the category. This left 14 services who were contacted to review their write-ups and add further details as required (table 7.5).

The next steps involve the full write-up of all services in the first full draft of the guidance (completed in September 2025), followed by a consultation and revision process through the DIAN (October-November 2025). This revision process will draw on the knowledge and expertise of experts and stakeholders around the world, including academics, national and

international organisations, and people with lived experience of dementia. Following this, the final document will be prepared for publication and is expected to be launched by the WHO in Spring 2026.

Table 7.5

The final 14 community dementia services for inclusion in the guidance organised by WHO region

WHO Region	Initially found	Income country	Service classification
African = 1 The Americas = 1 Eastern Mediterranean = 1 European = 7 South-East Asia = 1 Western Pacific = 3	Google = 5 Scholar = 2 Survey = 7	HIC* = 11 LMIC* = 3	Peer support = 2 Specialist = 2 Support and respite = 2 Crisis = 1 Community health = 3 Supported living accommodation = 3 Palliative/end-of-life care = 1

*HIC=high-income countries, LMIC=low- to middle-income countries

7.5 Conclusion

This work package involved the evaluation and validation of good human rights-based practice in community dementia services. Using reliable and valid methods, we identified a range of services that provide good practice in the desired approaches, although no service was rated as perfect. Some services suggested their care practices align with human rights standards, but, in actuality, they do not. The guidance, once completed, can provide recommendations for future policy and practice, as well as how the services can interact with other sectors to ensure the human rights of people living with dementia are respected, protected, and promoted.

8. Discussion and conclusion

This was the first in-depth study to investigate the global picture of human rights in dementia care, with the aim to develop good practice guidance for community dementia services. Previous research has determined that people with dementia can experience various infringements on their human rights as protected by the Convention on the Rights of Persons with Disabilities (CRPD; Cahill, 2018; Harding & Taşcıoğlu, 2018; Steele et al., 2020; Steele & Swaffer, 2022; WHO, 2017), a human rights standard developed with people with disabilities and other disability advocates involved in the drafting (Mittler, 2015). This means that they also experience infringements on their human rights protected by the Universal Declaration of Human Rights, the European Convention on Human Rights and other such Treaties, Charters, and Constitutions. This work adds to the current knowledge, demonstrating both historical and current care practices, attitudes of the general public towards the human rights of people with dementia, and the global picture of human rights in dementia policies. This research has also identified services that demonstrate good practice that upholds the human rights of people receiving their support, which will be showcased in the WHO good practice guidance document.

As a result, this doctoral work provides a holistic picture of human rights in dementia, examining the historical context for human rights in dementia care today, and the current attitudes, policies, and practices. This is important, because stigmatising attitudes towards dementia and personal, economic, cultural, systemic, political, and organisational barriers are some of the main reasons why people with dementia, as well as their family supporters, can experience infringements on their human rights within dementia care settings.

8.1 Main findings of the current study in the context of previous research

8.1.1 A conceptual history of human rights in dementia care

This review examined the care of people with dementia and vulnerable older people throughout history, to determine how their human rights were either upheld or disrespected. Past attitudes and practices towards dementia and similar symptoms have significantly influenced beliefs and practices in dementia care today. As far back as the Roman empire and Ancient Greece, old age has been synonymous with mental and cognitive decline, a belief still significantly present today. Reason and cognition were argued to be the main attribute of what made a person a person, and once people reached a certain age, then thought to be 60, they could no longer be given adequate respect as persons. They were also deemed to no longer be legally responsible for their actions, but the magistrate Solon later stated that they were legally able to declare wills, as long as their intellect and cognition was not affected by old age.

These beliefs had significant consequences for the care and treatment of older people and those with symptoms of dementia. Texts from the 16th and 17th century noted how people with dementia were regarded as 'mad', and were subsequently treated within lunatic asylums, sometimes living in prison-like conditions, and bound to beds and walls with the use of chains and shackles. Vulnerable older people with dementia could be admitted to these institutions without their consent and segregated, not only from the wider community, but others within the same institutions. They could be treated with dehumanising and patronising care, whereby staff would ignore their capabilities and treat them as those they were passive recipients of care. From the 19th century, there were movements towards more humanitarian treatments, which argued for reductions in the use of mechanical restraints, and communicating with and listening to the person about their wants, needs, and stories. From the 1960's onwards, with a growing societal emphasis on social and psychological factors influencing the onset and experience of dementia, community-based practices emerged. The review showed that the rights to legal capacity, freedom from coercion, participation, and community

inclusion have been infringed since ancient times, and have only improved in the last 60 years.

This work has supported previous historical studies. Firstly, the investigation into the historical concepts of human rights in dementia identified philosophical writings from Ancient Greece and Roman times regarding dementia and conceptualisations of what made a person a person, particularly regarding cognition and reason. These ideas are still considered today in Westernised cultures, which have been called 'hyper-cognitive' cultures, placing significance on cognition (Hughes, 2014; Low & Purwaningrum, 2020). This hyper-cognitivism downplayed other elements of what it means to be a person, including psychological, social, and emotional aspects (Hughes, 2014), and led to depictions and thoughts of people with dementia as not fully human and therefore unable to have basic human rights (Low & Purwaningrum, 2020; Swaffer, 2014).

Ethical considerations about how best to treat people with dementia and vulnerable older persons were based on these philosophies, and laws and practices were put in place that included what would now be considered denials of legal capacity and freedom from coercive practices under the CRPD (UN, 2006). Throughout history, coercive practices were primarily identified in institutional settings. Sashidharan et al. (2019) reports that measures to restrict freedom of movement, including restraints and involuntary admissions, can also be seen in community-based dementia services. Additionally, in the mid-20th century people with dementia were subject to depersonalising treatment, with staff in residential settings reported to ignore the capabilities of people with dementia and speaking down to them (Townsend, 1962). These practices indicate infringements on the rights of recovery-oriented and person-centred care. Tuntland et al. (2025) assert that the attitudes towards people with dementia would restrict recovery-oriented practices and the results have shown that attitudes towards and practices in dementia have influenced the attitudes and practices seen today (Bosco et al., 2019).

8.1.2 Predictors of attitudes towards human rights in dementia

The study found that attitudes towards the human rights of people with dementia often did not comply with international rights standards, including the CRPD. Older people had more negative attitudes, while females were more likely to hold more positive attitudes than males. People with professional experience in dementia, such as service providers, healthcare staff, or academics, had more positive attitudes than all other groups, including people with dementia and family supporters. Positive attitudes towards dementia correlated with better attitudes towards human rights in dementia, and more positive attitudes towards ageing were associated with more positive attitudes towards human rights in dementia.

Farina et al. (2021), Kim et al. (2023), and Nguyen and Li, (2020) all found similar results to the current study, whereas Herrmann et al. (2018) found younger people held more negative attitudes towards dementia. These studies did not investigate human rights attitudes, but attitudes towards the condition. Younger people have been found to make more personhood-related statements in dementia and have higher levels of knowledge of dementia, particularly knowledge of recent developments (Brookman et al., 2025; Zhang et al., 2023). Additionally, females may be socially positioned as family supporters of people with dementia compared to males and pay more attention to the emotional and care-related tasks, while males are reported to be more focused on functional aspects of supporting someone (Fletcher, 2021; Poisson et al., 2023).

Furthermore, the analyses of current attitudes towards human rights in dementia found that those with professional experience of working with dementia were more likely to report positive attitudes towards the human rights of people with dementia in comparison to people with dementia, family members and supporters, people who know or knew someone with dementia, and those with other experiences, including none. Training, knowledge, and experience acquired by professionals in the field of dementia, as well as the regulations of healthcare contexts which provide policies and procedures to follow, could make attitudes more positive (Brear et al., 2024; Cheston et al.,

2019). Although this study suggests that many people no longer see dementia as a normal consequence of ageing, other studies have shown that this misconception remains common today (Bosco et al., 2019; Cipriani & Borin, 2015; De Jager et al., 2015). In fact, global findings recently showed that since 2019, more of the general public, and more concerningly, healthcare professionals, believe that dementia is a normal part of ageing (Alzheimer's Disease International [ADI], 2024).

8.1.3 Preliminary psychometric examinations of the WHO QualityRights Attitudes towards Dementia scale (QRAD)

Overall, the QRAD scale showed adequate reliability and validity as a measure of attitudes towards human rights in dementia. The whole scale had good internal consistency, while the three subscales, relating to attitudes towards the services approach, attitudes towards coercive practices, and attitudes towards people with dementia as decision-makers and full members of society, had poor, acceptable, and questionable reliability respectively. Items of the Dementia Attitudes Scale with underlying concepts arguably comparable to human rights principles correlated with items on the QRAD, albeit weakly. Additionally, there were several weak correlations between items measuring unrelated concepts. These results suggest that the QRAD has adequate convergent and divergent validity. Furthermore, a three-factor structure was confirmed through factor analysis.

These results are in line with Moro et al. (2024), identifying the three factors reported by these authors as well as identifying good internal consistency. However, the current study identified three items that could be removed to slightly improve the internal reliability of the QRAD, a finding not reported by Moro et al. (2024). The subscale internal consistency scores using the Cronbach's alpha were also different between the two studies. Moro et al. (2024) reported face validity of the original QualityRights Attitudes questionnaire, and due to the limited adaptations made to create the QRAD, it can be said the adapted measure appears to measure human rights in accordance with the CRPD principles on which the scale was based. The CRPD was endorsed by several experts in dementia as a quality standard for

human rights in dementia (Panagiotidou et al., 2024), and thus, the QRAD can be said to have adequate face validity.

8.1.4 A content review of national dementia plans: are human rights considered?

The content analysis of 40 national dementia plans identified considerable variation in how far the CRPD is covered. Ninety percent (36) mentioned the term 'rights' or 'human rights', 11 (27.5%) mentioned the CRPD specifically, and 10 (25%) mentioned the WHO's global action plan. Most of the plans mention human rights principles in passing rather than providing specific actions and implementation plans to respect, protect, and promote the human rights of people with dementia within their countries. With regards to the specific human rights principles, 39 plans (97.5%) mentioned elements related to community inclusion, 31 (77.5%) mentioned aspects of recovery-oriented and person-centred care, while 28 (70%) acknowledged or provided actions to uphold the right to legal capacity. However, only 24 plans (60%) mentioned aspects relating to the right to participate in the design and delivery of services, policies, and research that would affect people with dementia. Twenty-four plans also acknowledged or provided actions to protect the right to freedom from coercion.

If attitudes towards dementia influence practices in dementia care, they might also influence policies (Benbow & Jolley, 2012). The study identified that human rights principles, as protected by the CRPD, are not necessarily considered during the development of national dementia plans around the world, particularly freedom from coercive practices and participation in the design and delivery of services, research, and policies. Specifically, even if mentioned, action plans to ensure the respect, protection, and promotion of human rights of people with dementia were lacking. The right to be included in the community was identified as a significant goal of almost all national dementia plans analysed, particularly through the increase of dementia-friendly communities, defined as supportive and enabling environments for people with dementia.

However, previous research has reported that these communities, despite the intention, could be unconsciously paternalistic and patronising, especially the use of the term 'dementia-friendly' (Rahman & Swaffer, 2018; Shakespeare et al., 2019). Moreover, people with dementia may be rarely involved in the design and implementation of dementia-friendly communities (Mathie et al., 2022), indicating denials of the right to participation. Participation within the design, development, and implementation of dementia plans was also found to be lacking in our review, strengthening the argument put forward by Cahill (2018), who stated that the goals, visions, and aims of national dementia plans do not match the lived experiences of people with dementia. However, most of the plans in this review were from high-income countries. This is important, because research suggests that the right to participation is an issue globally, but is particularly reported in low- to middle-income countries, since the dementia care system, services, and policies may be fragmented or absent (Benoist et al., 2024; Breuer et al., 2022; Brooke & Ojo, 2020; Mwendwa et al., 2022).

8.1.5 Work packages 1 and 2 of the good practice guidance methodology

Robust methodology was developed to inform the production of good practice guidance for community dementia services in relation to recovery-oriented, person-centred, and rights-based care. Literature and internet searches, as well as the utilisation of networks and contacts at the WHO Collaborating Centre for Mental Health, Disability, and Human Rights (WHO-CC) at the University of Nottingham, identified 1015 services around the world for potential inclusion in the guidance as case studies. Through a systematic screening process involving valid and reliable methods against service and human rights criteria, previously developed by the WHO, nearly 1000 services were excluded. The remaining services (n=22) were assessed based on the CRPD principles and previous WHO criteria. Two services were excluded by this process, leaving a total of 20 services remaining which showcased good recovery-oriented, person-centred, and rights-based practices in dementia care to be considered for the WHO guide.

Out of 1015 services found, 758 were from high-income countries. The lack of services from low- to middle-income and low-income countries reiterates the potential barriers experienced within these countries to develop services for dementia, including lack of funding, attitudinal barriers, and a lack of access to advances in technological, pharmaceutical, psychological, and social developments (Brooke & Ojo, 2020; Kupeli et al., 2018; Mussie et al., 2022). Services may not have access to computers or other networks who could provide support. Outside of high-income countries, services to support family members and supporters were few. This is significant because supporters are important in ensuring and enabling the independence and autonomy of people with dementia, but they themselves require support to do this (McQueen, 2022). In fact, Fletcher (2021) reported that the emotional impact and practical aspects of their lives were the biggest concern of family members and supporters, rather than the condition of dementia itself; therefore, services and support systems should be in place to meet the needs of family members and supporters.

Human rights in dementia services might not be purposefully infringed. Duffy et al. (2024) argue that practices that deny the full realisation of human rights exist on a spectrum, and many inadequacies in care occur due to systemic flaws. For example, care settings, such as residential homes, are subject to controls and policies (Backhouse et al., 2018), and there can be difficulties in maintaining the balance between the safety of the person receiving care, adhering to policies, and the protection of the person's human rights (Backhouse et al., 2018; Evans et al., 2018).

Furthermore, healthcare professionals wish to adhere to principles of recovery-oriented, person-centred, and rights-based care, but are unable to do so due to practical obstacles, such as a lack of resources, staff, and competing priorities (Courtright et al., 2020; Love & Femia, 2015; Midtbust et al., 2018). The information provided by one service within the rating process also demonstrated the different standards and laws that services contend with; the service stated that they abide by 'best interests' principles, with mental capacity advocates making decisions for the person based on their

understanding of their best interests. This practice is legislated by a law within the country the service is located in, but denies the right to legal capacity protected by the CRPD (UN Committee on the Rights of Persons with Disabilities, 2016), indicating the difficulties services face between meeting the standards and legalities set by governments, and upholding the human rights of people with dementia.

8.2 Methodological challenges

The methodological challenges identified in this doctoral research were both conceptual and practical. In the review of historical concepts of human rights in dementia, for example, there were no empirical or scientific writings about how people in Ancient History would have thought about dementia and human rights. Early accounts took a more philosophical approach and the laws and ethical issues that developed thereafter were often in response to the need for legal interventions and what would be best for the person with dementia and the whole community.

Additionally, conceptual issues were noted in the questionnaire study. A few participants stated to the researchers that they felt they could not answer some of the statements properly due to the varying impact of dementia each day as well as the different stages and types of dementia someone might be living with. These issues reflect everyday experiences of people affected by dementia and highlight the limits of the human rights questionnaire in relation to everyday experiences. Furthermore, attitudes are complex and can change depending on different factors, such as personal histories, levels of prior knowledge, and lived experience. Consequently, it is difficult to reduce explorations of attitudes into forced choice responses when several underlying factors could be contributing to the participants' thinking.

Practical difficulties included some participants saying that they had difficulties answering due to inabilities to see all available options for some statements on their devices, meaning the results may be inaccurate. In addition, the statistical tests for normal distribution suggested a deviation from normality in all analyses, despite all other assumptions being met. Due to the

large sample size in the study, the principles of the Central Limit Theorem (Kwak & Kim, 2017) were used to justify the continuation of analyses with all valid cases, but it is possible that the violation of normal distribution could increase the likelihood of a Type 1 error.

Practical methodological challenges could also have influenced the results in the review of national dementia plans. We were unable to download all known plans of countries due to the absence of a link to the plan in a few cases. Moreover, not all plans were amenable to translation into English, particularly those outside of Europe. Additionally, the translation matrices used (Google Translate and OnlineDoc) might not have translated accurately, causing potential misinterpretations or missed content altogether. Furthermore, there is a lack of information about how far national dementia plans have been implemented; a recent review by Ancidoni et al. (2025) examined the implementation and actions taken to ensure the Italian national dementia plan is meeting the targets of the WHO's global action plan, but as far as this author knows, this is the only academic study that reports on the implementation of national dementia plans. The Global Dementia Observatory, which monitors the actions taken by countries to meet targets set in the WHO's global action plan on the public health response to dementia 2017-2025, reports on whether countries have a national dementia plan in existence, as well as whether the countries have included targets or milestones that will be checked during the implementation phases of their dementia plans (WHO, 2021b). However, the Observatory does not examine how far each action has been implemented and has also not been updated since 2021. The global action plan also received an extension to 2031 due to the world falling significantly short of the targets (WHO, 2025a).

Finally, many services did not fill in the human rights survey or did not provide the necessary details or the depth required for a full rating. This could have been due to a lack of capacity on the service behalf, such as a lack of staff availability to complete questionnaires. Much of the information provided or gathered during the early phases of the methodology was promotional in nature, and some services did not talk about the specific

support they provided. Moreover, the searches conducted for services initially could have missed services that do not have an internet presence in any way, including mentions in published literature.

8.4 Limitations

Firstly, before conducting the review into the historical concepts, it was theorised that not much information regarding dementia, especially as a brain disease, would be identified in early periods of history, such as Classical Antiquity or the Middle Ages. This is because much of the early writings of dementia were philosophical, and less information has been identified by others during the period of the Middle Ages (Berchtold & Cotman, 1998; Bosco et al., 2019). However, although the review was able to demonstrate a timeline of how human rights are conceptualised in dementia care throughout history, many periods of history are either lacking in detail or missing entirely.

Additionally, the historical searches identified information from mainly European countries, and less than 3% of participants in the attitudes study were not White. Consequently, there is a lack of diverse representation in these studies, and conclusions cannot be generalised to these communities, because cultural differences and beliefs may play a role in attitudes and stigma about dementia and their practices in dementia care may be different to those of westernised cultures. Plus, the majority of the national dementia plans downloaded and examined were from the European WHO region, with none identified from Africa. Moreover, most of the services identified for potential inclusion in the WHO guidance were from high-income countries, with no services from low-income countries included in the rated pool. The lack of geographically diverse dementia plans and services may reflect barriers reported in the literature to providing care for people with dementia in these circumstances.

Also, particularly for the study exploring attitudes towards human rights for people with dementia, a cross-sectional, self-report, online research design was used. The use of Join Dementia Research (JDR) means that the study was not an epidemiological sample, as the participants all had an interest

in dementia and dementia-focused research. Furthermore, JDR is an online platform, and therefore potentially interested participants were possibly missed due to a lack of internet access or internet literacy. Additionally, due to the cross-sectional nature of the study, we cannot determine whether attitudes change over time. Reasons for attitudes also cannot be ascertained due to the quantitative, cross-sectional nature of the study. Finally, the use of self-report measures means that there is a risk of socially desirable answers being provided by the participants, especially because they may have a vested interest in dementia.

8.5 Future directions and implications

8.5.1 Recommendations for research

Future research could further investigate global attitudes towards human rights in dementia. Although the ADI recently published a report on global attitudes towards dementia, updating the results from 2019 (ADI, 2024), they did not specifically focus on the human rights of people with dementia or the CRPD principles. The results have suggested that human rights are an important concept that must be looked at more widely. Furthermore, qualitative investigations of attitudes towards human rights in dementia could provide significant detail and context to our results, as well as those of other studies that examine dementia-related stigma. Moreover, several pieces of research have been conducted regarding attitudes towards the human rights of people with mental health conditions and psychosocial disabilities (Harden et al., 2023; Poynton-Smith et al., 2023; Wang et al., 2025); additional research could investigate how these attitudes compare to attitudes explicitly towards people with dementia and their human rights.

Attitudes could also be investigated at different time points to ascertain if there is any change over time, particularly after any training has been undertaken. The Knowledge, Attitudes, and Practices theory posits that by expanding knowledge, negative attitudes can be changed, leading to improved behaviours and practices (Bettinghaus, 1986), and previous research has identified that training to improve knowledge and attitudes towards the human

rights of people with mental health conditions and psychosocial disabilities has been successful (Poynton-Smith et al., 2023; Wang et al., 2025). Full psychometric examinations of the QRAD could also be undertaken within a similar population, perhaps examining criterion validity against other questionnaires based on the CRPD.

Also, the results of the historical review have referred to the role of older people in society during the Roman period, and the concept of citizenship has received more recognition in dementia in recent years (Baldwin & Greason, 2016; Bartlett, 2016; Bartlett & O'Connor, 2007). As a result, future research could investigate the current roles of older people with dementia in society and within different cultures. Cultural influences are a common theme identified within this doctoral research, despite a lack of diversity within several studies. and other pieces of literature, and further work could be developed from the studies conducted to enable explorations in different cultural contexts.

Additionally, further updates and evaluations of national dementia plans could be conducted. During the review reported in this thesis, several plans were in the development phase, including updated plans from Australia and Uruguay. Moreover, the ADI have reported that countries in Africa are beginning to develop national dementia plans (ADI, 2025), and therefore, there may be the opportunity to examine these plans in relation to their human rights content. This is important considering the WHO's global action plan has been extended to 2031 (ADI, 2025).

8.5.2 Implications for practice

This work has highlighted the need for awareness campaigns of human rights in dementia. The percentage of participants who gave 'neutral' or 'don't know' answers in the attitudes study suggests a potential lack of knowledge of the human rights of people with dementia as protected by the CRPD. The QualityRights initiative launched by the WHO (WHO, 2022a) is one such initiative that could help deliver awareness sessions and trainings about how the CRPD related to dementia and the human rights of people with dementia.

The attitudes of society and people involved in the care of people with dementia can influence care practices, a conclusion also noted by Bosco et al. (2019), and therefore, one such way to improve care for dementia is to reduce and remove dementia-related stigma.

8.5.3 Implications for policy

The review into the human rights content of national dementia plans has significant implications for policy. The results highlighted how government ministries have fallen short of incorporating and implementing the CRPD principles into their policies, and therefore, governments and other policymakers can use the results of this work to ensure their national dementia plans, or health strategies with dementia incorporated, become more focused on the human rights of their citizens with dementia. Governments and other policymakers have a substantial responsibility to ensure that their national dementia plans are implemented, renewed, and kept updated. Additionally, governments should involve people with lived experience of dementia within the development and implementation of their plans to make sure that the plans meet the needs of people with dementia and their family members and supporters. Involving people with dementia and their families in the production of national dementia plans is also a human right in accordance with the CRPD. Doing this encompasses the practice of co-design, which emphasises the collaboration and joint process of design (Niedderer et al., 2024). In dementia, co-design often involves a person-centred approach and a participatory design, taking account of and valuing the voices of people living with dementia (Layton et al., 2024). The WHO guidance produced should also show governments and policymakers how they can respect, protect, and promote the human rights of people with dementia and their families, ensuring services provide recovery-oriented, person-centred, and rights-based care.

8.6 Reflexivity statement

I had an interest primarily in human rights in mental health before this PhD, due to my Masters dissertation work, but have since grown to become passionate about dementia specifically. With a little lived experience, both

personally and in my previous clinical role, I began to understand the importance of improving the quality of life for people affected by dementia and how human rights frameworks pertain specifically to people affected by the condition. The human rights of people with mental health conditions and psychosocial disabilities (including dementia) are often overlooked within both research and practice, and to be able to contribute further knowledge and enhance the field has been a pleasure. Working with the WHO has brought its challenges, particularly with methodological constraints and timescales, but has also been a fantastic experience, because I have gained further insight into how international organisations work to produce change.

The PhD has enhanced my knowledge and passions to improve the quality of life for people with dementia and their families, and I am looking forward to being able to throw this passion into my new role on the 'Lived Experience Narratives in Dementia' (LEND) programme. This programme has the quality of life and the voices of people affected by dementia at the forefront of its activities, and I believe I can bring my knowledge and perspectives of human rights into the programme to help develop the intervention. It has also helped me to develop more rigorous organisation and management skills, both of myself and others, which I can take into both my professional and personal life. I have grown as a person and I look forward to immersing myself into a career as a researcher.

8.7 Conclusion

In conclusion, the work presented has provided a holistic view of the previous and current picture of human rights in international dementia care. The study shows the development of human rights concepts in dementia care through history, such as wills being invalid if the mind is impaired due to old age stemming from ancient times, but also practices that demonstrate the use of coercive methods, such as involuntary admission and restraints, denying the right to legal capacity and the right to freedom from coercion. It has also demonstrated current attitudes towards human rights in dementia in a UK context, using a valid measure to explore this, and providing a political context of human rights within national dementia plans worldwide,

demonstrating whether governments are doing enough to ensure the full respect, protection, and promotion of human rights for people with dementia. Throughout, the research has identified denials of human rights for people with dementia, despite work to reduce stigma and move community dementia services to a rights-based care approach.

This work has formed the foundation for WHO guidance on rights-based care in community dementia services. The WHO guidance will showcase community dementia services from different geographical, legal, and financial contexts that provide good practice in relation to human rights. This guidance is due to be launched in 2026, and will inform governments, non-governmental organisations, and service providers how they can make improvements to ensure the full enjoyment of human rights for people with dementia. The guidance can also show people with dementia and their families what their rights are and help them locate services and supports near them which may provide the required support to meet their needs. Future work can focus on the global attitudes towards human rights in dementia and evaluate the human rights content of future national dementia plans, as well as their implementation, and evaluate the adoption of the guidance once launched to determine any improvements in rights-based care for people with dementia.

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Appendices

Appendix 1 Historical review search strategy

Platform and database: Ovid Medline® ALL <1946 to July 9, 2024>		
Link to run search: https://access.ovid.com/custom/redirector/wayfless.html?idp=https://idp.eng.nhs.uk/openathens&url=http://ovidsp.ovid.com/ovidweb.cgi?T=JS&NEWS=N&PAGE=main&SHAREDSEARCHID=4l7wZyzy84nx1ZldgfpRXm4j7DHLWGsiYzR6Ze4Zukg4JPEhS7koVpbgmRmbbKwuN		
1	exp *Dementia/	185245
2	(dement* or alzheimer*).ti,ab.	293100
3	1 or 2	323165
4	Cognitive Dysfunction/	41141
5	(cognitive and (impair* or disorder* or declin* or dysfunction* or deteriorat*)).ti,ab.	271054
6	(morosis or stupidity or senility or senile or memory).ti,ab.	345688
7	4 or 5 or 6	553260
8	exp Geriatrics/ or exp Aged/	3552785
9	(elder* or eldest or frail* or geriatri* or older or oldest or old or senior*).ti,ab.	2163951
10	8 or 9	5035881
11	7 and 10	147820
12	3 or 11	416005
13	exp *Human Rights/	86519
14	((human or equal) adj right*1).ti,ab.	13446
15	or/13-14	95189
16	12 and 15	961
17	History, 16th Century/ or History, Ancient/ or History, 17th Century/ or History, Medieval/ or History, 21st Century/ or History/ or History, 18th Century/ or History, 20th Century/ or History, Early Modern 1451-1600/ or History, 19th Century/ or "History of Medicine"/ or History, Modern 1601-/ or History, 15th Century/	377978
18	hi.fs.	308143
19	(historic or ancient or history or historical).ti.	142201
20	17 or 18 or 19	486297
21	12 and 20	2330
22	Dementia/hi [History]	189
23	Alzheimer Disease/hi [History]	304
24	or/21-23	2371
25	16 or 24	**3326**
Platform and database: ProQuest ASSIA (Applied Social Sciences Index and Abstracts)		

S1	MAINSUBJECT.EXACT("Dementia") OR MAINSUBJECT.EXACT("Alzheimer's disease") OR ti,ab(dement* OR alzheimer*)	19864
S2	(MAINSUBJECT.EXACT("Cognitive disorders") OR MAINSUBJECT.EXACT("Cognitive impairment")) OR ti,ab(cognitive AND (impair* OR disorder* OR declin* OR dysfunction* OR deteriorat*))	24970
S3	ti,ab(morosis or stupidity or senility or senile or memory)	25171
S4	[S2] OR [S3]	46038
S5	MAINSUBJECT.EXACT("Elderly people") OR ti,ab(elder* OR eldest OR frail* OR geriatri* OR old OR older OR oldest OR senior*)	135784
S6	[S4] AND [S5]	10533
S7	[S1] OR [S6]	27628
S8	MAINSUBJECT.EXACT("Human rights") OR ti,ab("human right" OR "human rights" OR "equal right" OR "equal rights")	8486
S9	[S7] AND [S8]	82
S10	(MAINSUBJECT.EXACT("Prehistory") OR MAINSUBJECT.EXACT("Colonial period") OR MAINSUBJECT.EXACT("Nineteenth century") OR MAINSUBJECT.EXACT("Tudor age") OR MAINSUBJECT.EXACT("Interwar period") OR MAINSUBJECT.EXACT("History") OR MAINSUBJECT.EXACT("Victorian era") OR MAINSUBJECT.EXACT("Social history") OR MAINSUBJECT.EXACT("Stuart age")) OR (ti,ab(historic OR ancient OR historical))	25014
S11	[S7] AND [S10]	148
S12	[S9] OR [S11]	**230**
Platform and database: Scopus Elsevier		
1	(((TITLE ("human right" OR "human rights") OR ABS ("human right" OR "human rights"))) AND (((TITLE (dementia OR alzheimer) OR ABS (dementia OR alzheimer))) OR (((TITLE (elder OR eldest OR frail OR geriatric OR older OR oldest OR old OR senior) OR ABS (elder OR eldest OR frail OR geriatric OR older OR oldest OR old OR senior))) AND (((TITLE ((morosis OR stupidity OR senility OR senile OR memory)) OR ABS ((morosis OR stupidity OR senility OR senile OR memory)))) OR ((TITLE (("cognitive impairment" OR "cognitive disorder" OR "cognitive decline" OR "cognitive dysfunction" OR "cognitive deterioration")) OR ABS (("cognitive impairment" OR "cognitive disorder" OR "cognitive decline" OR "cognitive dysfunction" OR "cognitive deterioration"))))))) OR ((TITLE (historic OR ancient OR historical)) AND (((TITLE (dementia OR alzheimer) OR ABS (dementia OR alzheimer))) OR (((TITLE (elder OR eldest OR frail OR geriatric OR older OR oldest OR old OR	**699**

	senior) OR ABS (elder OR eldest OR frail OR geriatric OR older OR oldest OR old OR senior))) AND (((TITLE ((morosis OR stupidity OR senility OR senile OR memory)) OR ABS ((morosis OR stupidity OR senility OR senile OR memory)))) OR ((TITLE (("cognitive impairment" OR "cognitive disorder" OR "cognitive decline" OR "cognitive dysfunction" OR "cognitive deterioration")) OR ABS (("cognitive impairment" OR "cognitive disorder" OR "cognitive decline" OR "cognitive dysfunction" OR "cognitive deterioration"))))))))	
Platform and database: ProQuest APA PsycInfo®		
1	(((MAINSUBJECT.EXACT.EXPLODE("Dementia") OR ti,ab(dement* OR alzheimer*)) OR (((MAINSUBJECT.EXACT("Cognitive Impairment") OR ti,ab(cognitive AND (impair* OR disorder* OR declin* OR dysfunction* OR deteriorat*))) OR (ti,ab(morosis OR stupidity OR senility OR senile OR memory))) AND ((MAINSUBJECT.EXACT.EXPLODE("Aging") OR MAINSUBJECT.EXACT.EXPLODE("Geriatrics")) OR ti,ab(elder* OR eldest OR frail* OR geriatri* OR old OR older OR oldest OR senior*)))) AND ((MAINSUBJECT.EXACT("Civil Rights") OR MAINSUBJECT.EXACT("Right to Treatment") OR MAINSUBJECT.EXACT("Freedom") OR MAINSUBJECT.EXACT("Autonomy") OR MAINSUBJECT.EXACT("Empowerment") OR MJMAINSUBJECT.EXACT("Human Rights")) OR ti,ab("human right" OR "human rights" OR "equal right" OR "equal rights"))) OR (((MAINSUBJECT.EXACT.EXPLODE("Dementia") OR ti,ab(dement* OR alzheimer*)) OR (((MAINSUBJECT.EXACT("Cognitive Impairment") OR ti,ab(cognitive AND (impair* OR disorder* OR declin* OR dysfunction* OR deteriorat*))) OR (ti,ab(morosis OR stupidity OR senility OR senile OR memory))) AND ((MAINSUBJECT.EXACT.EXPLODE("Aging") OR MAINSUBJECT.EXACT.EXPLODE("Geriatrics")) OR ti,ab(elder* OR eldest OR frail* OR geriatri* OR old OR older OR oldest OR senior*)))) AND (MAINSUBJECT.EXACT("History") OR (ti,ab(historic OR ancient OR historical))))	**1674**

Appendix 2 Unconstrained matrix for content analysis

Human rights information	Included?	Evidence:
Equal recognition before the law / respect for legal capacity		
Non-coercive practices		
Living independently and being included in the community / community inclusion		
Health / access to care		
Participation in political and public life		
Recovery approach to care		
Person-centred care		
Empowerment		
Agency		
Citizenship		
Dignity		
Autonomy		
Milestones in dementia care		
Legislation		
Where people with dementia were cared for		
The self / person concepts		
Control		
Industrialisation		
Social changes		
Legislation		

Appendix 3 Word version of the attitudes online survey

Attitudes to Dementia

We are looking at attitudes towards dementia, and whether they are linked to attitudes towards ageing or human rights, quality of life, and wisdom. We have a set of 5 questionnaires, plus a demographics questionnaire. You can finish this survey at a later point if you would like to, and can withdraw your answers by not submitting the questionnaire.

PLEASE NOTE: Depending on the size of your screen, not all answers may be visible. Please make sure you are able to see all available answers (either by scrolling sideways or making the questionnaire smaller on your device).

While completing the survey, you can withdraw your data by closing the browser window. After completing the survey and submitting your answers, and you change your mind and want to withdraw your data, please email the researchers (Swapneel - msxsm47@nottingham.ac.uk OR Briony - msxbh4@nottingham.ac.uk) with the passcode you provided on the survey so your data can be located and withdrawn.

Welcome to our survey.

Here you can find our information sheet which details our study, and what we hope you can help us with.

Summary of Research Study

We are inviting you to take part in a research study about attitudes relating to dementia. Negative attitudes about dementia can deter people from seeking help or affect the care they receive. We are aiming to look at attitudes about dementia and human rights and see if anything can predict these attitudes.

What is the purpose of the study?

We would like to ask about your views on wisdom, their quality of life, attitudes to ageing, attitudes to dementia, and attitudes towards the human rights of people with dementia. This would be done using an online survey of standard measures.

Do I have to take part?

It is up to you if you would like to take part in this survey or not. You can start to complete the survey and then close the browser if you change your mind. The decisions you make about whether you participate will not affect your care.

What will I be asked to do?

If you choose to take part, you will be asked to give your consent on the first page of the survey. Afterwards, you can work through the survey at your own pace, with the added option of finishing later if it becomes too tiring.

Are there any possible disadvantages in taking part in the study?

There will be no disadvantages to talking part in the study. You may feel tired from looking at the screen for a while; this is why we have added a finish later option. Some of the questions could cause upset. If this is the care, the student researchers will be happy to provide you with some support services. The contact details of the team are available further down this page.

We also know that some of the concepts within this study may be unknown to you, or you would like some extra information on this, we have made a glossary that has been looked at by people with dementia ready for this study. You can download the glossary here: https://docs.google.com/document/d/e/2PACX-1vTooEHAObANuym87pzX63ufofHROaZ3FjZozN6beL7XOnW3FzEm-A_DRf-0dmnGKQ/pub

What will happen to the information I give?

The information you give on the survey will be kept confidential and anonymous. The research team, or anyone else, will not be able to identify you or your answers. You can find out more about how we use your information and details of privacy notice at: https://www.nottingham.ac.uk/utilities/privacy/privacy.aspx

PLEASE NOTE: We cannot change the wording of the questionnaires in this study. This is because these scales are standardised and should not be changed for the validity of the study.

Extra information can be provided by:

Briony Harden (PhD student) - msxbh4@nottingham.ac.uk Swapneel Mirani (Masters student) - msxsm47@nottingham.ac.uk Prof. Martin Orrell (Supervisor) - m.orrell@nottingham.ac.uk

1. I have read and understood the above information, I confirm that I am 18 years old or older and by clicking "yes" and then NEXT to begin the online questionnaire, I give my consent to provide answers to the questions in this survey. If you do not wish to partake in the survey, please exit the window.

Yes

2. Please choose a unique code that we can use to find your data if you choose to withdraw at a later date.

Demographics

1. Age
2. Gender:
    a. Female
    b. Male
    c. Prefer not to say
    d. Other:
        i. _____
3. Experience:
    a. Person with dementia
    b. Family member
    c. Formal care partner

d. I know someone who lives with dementia

e. Service provider

f. Service volunteer

g. Service worker

h. Other

4. Ethnicity (according to 2021 UK Census):

    a. Asian or Asian British, or Asian Welsh

    b. Black, Black British, Black Welsh, Caribbean or African

    c. White:

        i. English

        ii. Welsh

        iii. Scottish

        iv. Northern Irish

        v. British

    d. White Irish

    e. White:

        i. Gypsy or Irish Traveller

        ii. Roma

        iii. Other White

    f. Mixed or Multiple ethnic groups

    g. Other ethnic group

Dementia Attitudes Scale

Items	Strongly disagree	Disagree	Slightly disagree	Neutral	Slightly agree	Agree	Strongly agree
1. It is rewarding to work with people who have dementia	1	2	3	4	5	6	7
2. I am afraid of people with dementia	1	2	3	4	5	6	7
3. People with dementia can be creative	1	2	3	4	5	6	7
4. I feel confident around people with dementia	1	2	3	4	5	6	7
5. I am comfortable touching people with dementia	1	2	3	4	5	6	7
6. I feel uncomfortable being around people with dementia	1	2	3	4	5	6	7
7. Every person with dementia has different needs	1	2	3	4	5	6	7
8. I am not very familiar with dementia	1	2	3	4	5	6	7

9. I would avoid an agitated person with dementia	1	2	3	4	5	6	7
10. People with dementia like having familiar things nearby	1	2	3	4	5	6	7
11. It is important to know the past history of people with dementia	1	2	3	4	5	6	7
12. It is possible to enjoy interacting with people with dementia	1	2	3	4	5	6	7
13. I feel relaxed around people with dementia	1	2	3	4	5	6	7
14. People with dementia can enjoy life	1	2	3	4	5	6	7
15. People with dementia can feel when others are kind to them	1	2	3	4	5	6	7
16. I feel frustrated because I do not know how to help people with dementia	1	2	3	4	5	6	7
17. I cannot imagine taking care of someone with dementia	1	2	3	4	5	6	7

18. I admire the coping skills of people with dementia	1	2	3	4	5	6	7
19. We can do a lot now to improve the lives of people with dementia	1	2	3	4	5	6	7
20. Difficult behaviours may be a form of communication for people with dementia	1	2	3	4	5	6	7

Adapted World Health Organization QualityRights questionnaire

Items	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. Nothing can be improved within dementia services without additional resources	1	2	3	4	5
2. The service environment has little to do with people with dementia's mental health and wellbeing	1	2	3	4	5
3. People with dementia should always live in group homes where staff can take care of them	1	2	3	4	5

4. People with dementia and related psychosocial disabilities should not be hired in work requiring direct contact with the public	1	2	3	4	5
5. Taking medication is the most important factor to help reduce the impact of the symptoms of dementia	1	2	3	4	5
6. You cannot inspire hope once a person is experiencing symptoms of dementia	1	2	3	4	5
7. People using dementia services should be empowered to make their own decisions about their treatment	1	2	3	4	5
8. Following the advice of other people who have lived experience of dementia (people with dementia and their family members and care partners) is too risky	1	2	3	4	5
9. The opinions of health practitioners about care and treatment should carry more weight than those of a person with dementia	1	2	3	4	5
10. It is acceptable to pressure people using dementia services to take treatment they don't want	1	2	3	4	5
11. People with dementia should not be given important responsibilities	1	2	3	4	5

12. When people with dementia experience a crisis, health practitioners of families should make decisions based on their ideas about what is best for the person	1	2	3	4	5
13. People with dementia have the right to make their own decisions, even if I don't agree with them	1	2	3	4	5
14. Controlling people using dementia services is necessary to maintain order	1	2	3	4	5
15. The use of seclusion and restraint is needed if people using dementia services become threatening	1	2	3	4	5
16. People at risk of harming themselves or others should be isolated in a locked room	1	2	3	4	5
17. Involuntary admission to services does more harm than good	1	2	3	4	5

Attitudes to Ageing Questionnaire

Items	**Strongly disagree**	**Disagree**	**Uncertain**	**Agree**	**Strongly agree**
1. As people get older they are better able to cope with life	1	2	3	4	5

2. It is a privilege to grow old	1	2	3	4	5
3. Old age is a time of loneliness	1	2	3	4	5
4. Wisdom comes with age	1	2	3	4	5
5. There are many pleasant things about growing older	1	2	3	4	5
6. Old age is a depressing time of life	1	2	3	4	5
7. It is important to take exercise at any age	1	2	3	4	5
	Not true at all	**Slightly true**	**Moderately true**	**Very true**	**Extremely true**
8. Growing older has been easier than I thought	1	2	3	4	5
9. I find it more difficult to talk about my feelings as I get older	1	2	3	4	5
10. I am more accepting of myself as I have grown older	1	2	3	4	5
11. I don't feel old	1	2	3	4	5
12. I see old age mainly as a time of loss	1	2	3	4	5
13. My identity is not defined by my age	1	2	3	4	5
14. I have more energy now than I expected for my age	1	2	3	4	5
15. I am losing my physical independence as I get older	1	2	3	4	5

16. Problems with my physical health do not hold me back from doing what I want to	1	2	3	4	5
17. As I get older, I find it more difficult to make new friends	1	2	3	4	5
18. It is very important to pass on the benefits of my experiences to younger people	1	2	3	4	5
19. I believe my life has made a difference	1	2	3	4	5
20. I don't feel involved in society now that I am older	1	2	3	4	5
21. I want to give a good example to younger people	1	2	3	4	5
22. I feel excluded from things because of my age	1	2	3	4	5
23. My health is better than I expected for my age	1	2	3	4	5
24. I keep myself as fit and active as possible by exercising	1	2	3	4	5

CASP-12

Items: How often do you feel or think...	**Often**	**Sometimes**	**Rarely**	**Never**
1. Your age prevents you from doing the things you would like to do?	1	2	3	4
2. That what happens to you is out of your control?	1	2	3	4

3. Left out of things?	1	2	3	4
4. That you can do the things that you want to do?	1	2	3	4
5. That family responsibilities prevent you from doing what you want to do?	1	2	3	4
6. That shortage of money stops you from doing the things you want to do?	1	2	3	4
7. Look forward to each day?	1	2	3	4
8. That your life has meaning?	1	2	3	4
9. Look back on your life with a sense of happiness?	1	2	3	4
10. Full of energy these days?	1	2	3	4
11. That life is full of opportunities?	1	2	3	4
12. That the future looks good for you?	1	2	3	4

Three-Dimensional Wisdom Scale (3D-WS-12)

Items	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
1. A problem has little attraction for me if I don't think it has a solution	1	2	3	4	5
2. I try to anticipate and avoid situations where there is a likely chance I will have to think about in depth about something	1	2	3	4	5
3. I prefer just to let things happen rather than try to understand why they turned out that way	1	2	3	4	5
4. I am hesitant about making important decisions after thinking about them	1	2	3	4	5
5. When I am confused by a problem, one of the first things I do is survey the situation and consider all the relevant pieces of information	1	2	3	4	5
6. Sometimes I get so charged up emotionally that I am unable to consider many ways of dealing with my problems	1	2	3	4	5

7. When I look back on what has happened to me, i can't help feeling resentful	1	2	3	4	5
8. I either get very angry or depressed if things go wrong	1	2	3	4	5
9. I can be comfortable with all kinds of people	1	2	3	4	5
10. Sometimes I feel a real compassion for everyone	1	2	3	4	5
11. I don't like getting involved in listening to another person's troubles	1	2	3	4	5
12. I'm easily irritated by people who argue with me	1	2	3	4	5

Appendix 4 Glossary attached to the survey

Term	What does it mean?
Dementia	Alzheimer's Disease and Related Dementias
'psychosocial disabilities'	when someone with a mental health condition or disability interacts with a social environment that presents barriers to their equality with others
Empower(ed/ment)	the process of becoming stronger and more confident, especially in controlling one's life and claiming one's rights.
Carer	also known as 'care partner', 'supporter', 'caregiver'
Seclusion	being shut away or kept apart from others (Merriam-Webster dictionary)
Questionnaires	**Information**
Control, Autonomy, Self-Realization, and Please (CASP-12)	This scale measures quality of life, and has been used in several research studies looking into quality of life in older age. CONTROL refers to the perception of being able to shape your own life; AUTONOMY refers to being in charge of your own lives and having the freedom to make choices; SELF-REALIZATION refers to the achievement of everything possible that you can achieve in relation to your character and personality; PLEASURE refers to the pursuit of enjoyable activities.
Three-Dimensional Wisdom Scale (3D-WS-12) (a.k.a Wisdom Scale)	Wisdom is considered an important part of quality of life. There are three elements to wisdom – cognitive wisdom, affective wisdom, and reflective wisdom. COGNITIVE wisdom refers to the ability to understand life and the meanings of deeper events; AFFECTIVE wisdom is about positive feelings and behaviours towards others and the absence of negative feelings and behaviours. REFLECTIVE wisdom refers to looking at events from different perspectives.

Appendix 5 Regression sensitivity analyses between the DAS and the QRAD (*italics represent extreme scores removed*)

The model indicated that the predictor explained 27.2% of the variance (R2=.272, F(1,3142)=1172.575, p<.001). Attitudes towards dementia significantly predicted attitudes towards people with dementia as human rights holders (b=-.291, p<.001, 95% CI [-.308, -.275]).

The model indicated that the predictor explained 28.8% of the variance (R2=.288, F(1,3130)=1267.859, p<.001). Attitudes towards dementia significantly predicted attitudes towards people with dementia as human rights holders (b=-.298, p<.001, 95% CI [-.314, -.281]).

The model indicated that the predictor explained 12.4% of the variance (R2=.124, F(1,3142)=446.487, p<.001). Attitudes towards dementia significantly predicted attitudes towards mental health/dementia services approach(b=-.069, p<.001, 95% CI [-.076, -.063]).

The model indicated that the predictor explained 13.7% of the variance (R2=.137, F(1,3125)=498.099, p<.001). Attitudes towards dementia significantly predicted attitudes towards the mental health services approach (b=-.071, p<.001, 95% CI [-.078, -.065]).

The model indicated that the predictor explained 19.6% of the variance (R2=.196, F(1,3142)=766.911, p<.001). Attitudes towards dementia significantly predicted attitudes towards people with dementia as human rights holders (b=-.127, p<.001, 95% CI [-.136, -.118]).

The model indicated that the predictor explained 20.9% of the variance (R2=.209, F(1,3131)=828.745, p<.001). Attitudes towards dementia significantly predicted attitudes towards involuntary and coercive practices (b=-.130, p<.001, 95% CI [-.139, -.121]).

The model indicated that the predictor explained 22.2% of the variance (R2=.222, F(1,3142)=898.736, p<.001). Attitudes towards dementia significantly predicted attitudes towards people with dementia as decision makers and full members of society (b=-.095, p<.001, 95% CI [-.101, -.089]).

The model indicated that the predictor explained 23.8% of the variance (R2=.238, F(1,3123)=973.191, p<.001). Attitudes towards dementia significantly predicted attitudes towards people with dementia as decision makers and full members of society (b=-.097, p<.001, 95% CI [-.103, -.091]).

The model indicated that the two predictors explained 28.2% of the variance (R2=.282, F(2,1341)=615.796, p<.001). It was found that both dementia knowledge (b=-.412, p<.001, 95% CI [-.452, -.372]) and social comfort (b=-.222, p<.001, 95% CI [-.248, -.195]) significantly predicted attitudes towards people with dementia as rights holders.

The model indicated that the two predictors explained 29.6% of the variance (R2=.296, F(2,1333)=657.662, p<.001). It was found that both dementia

knowledge (b=-.425, p<.001, 95% CI [-.464, -.386]) and social comfort (b=-.224, p<.001, 95% CI [-.250, -.197]) significantly predicted attitudes towards people with dementia as rights holders.

The model indicated that the two predictors explained 13.0% of the variance (R2=.130, F(2,1341)=235.563, p<.001). It was found that both dementia knowledge (b=-.102, p<.001, 95% CI [-.118, -.087]) and social comfort (b=-.050, p<.001, 95% CI [-060, -.040]) significantly predicted attitudes towards the mental health/dementia services approach.

The model indicated that the two predictors explained 14.1% of the variance (R2=.141, F(2,1329)=256.023, p<.001). It was found that both dementia knowledge (b=-.105, p<.001, 95% CI [-.120, -.090]) and social comfort (b=-.052, p<.001, 95% CI [-062, -.041]) significantly predicted attitudes towards the mental health/dementia services approach.

The model indicated that the two predictors explained 19.9% of the variance (R2=.119, F(2,1341)=389.885, p<.001). It was found that both dementia knowledge (b=-.159, p<.001, 95% CI [-.181, -.138]) and social comfort (b=-.108, p<.001, 95% CI [-.123, -.094]) significantly predicted attitudes towards involuntary and coercive practices.

The model indicated that the two predictors explained 20.9% of the variance (R2=.209, F(2,1332)=416.096, p<.001). It was found that both dementia knowledge (b=-.163, p<.001, 95% CI [-.184, -.141]) and social comfort (b=-.110, p<.001, 95% CI [-.125, -.096]) significantly predicted attitudes towards involuntary and coercive practices.

The model indicated that the two predictors explained 23.8% of the variance (R2=.238, F(2,1341)=491.615, p<.001). It was found that both dementia knowledge (b=-.151, p<.001, 95% CI [-.165, -.136]) and social comfort (b=-.063, p<.001, 95% CI [-.073, -.053]) significantly predicted attitudes towards people with dementia as decision makers and full members of society.

The model indicated that the two predictors explained 25.0% of the variance (R2=.250, F(2,1330)=522.976, p<.001). It was found that both dementia knowledge (b=-.155, p<.001, 95% CI [-.170, -.141]) and social comfort (b=-.062, p<.001, 95% CI [-.072, -.053]) significantly predicted attitudes towards people with dementia as decision makers and full members of society.

Appendix 6 AAQ regression results (n=1344)

AAQ REGRESSIONS

The model indicated that the predictor explained 3.1% of the variance (R2=.031, F(1, 3142)=98.89, p<.001. It was found that attitudes towards ageing significantly predicted attitudes towards the mental health/dementia services approach (b=-.04, p<.001, 95% CI [-.05, -.03]).

The model indicated that the predictor explained 3.1% of the variance (R2=.031, F(1, 3142)=99.83, p<.001. It was found that attitudes towards ageing significantly predicted attitudes towards involuntary and coercive practices (b=-.06, p<.001, 95% CI [-.07, -.05]).

The model indicated that the predictor explained 3.0% of the variance (R2=.030, F(1, 3142)=98.89, p<.001. It was found that attitudes towards ageing significantly predicted attitudes towards people with dementia as decision makers and full members of society (b=-.04, p<.001, 95% CI [-.05, -.03]).

AAQ Subscales

The model (R2=.056, F(3, 3140)=61.59, p<.001) found that psychosocial loss (b=-.13, p<.001, 95% CI [-.15, -.11]) and psychological growth (b=-.04, p<.001, 95% CI [-.06, -.02]) significantly predicted attitudes towards the mental health/dementia services approach, but physical change did not (b=.02, p=.053).

The model indicated that the three predictors explained 3.3% of the variance (R2=.033, F(3, 3140)=35.66, p<.001). The model identified that all three predictors, psychosocial loss (b=-.09, p<.001, 95% CI [-.12, -.06]), physical change (b=-.03, p=.047, 95% CI [-.06, .00], and psychological growth (b=-.07, p<.001, 95% CI [-.11, -.04]) significantly predict attitudes towards involuntary and coercive practices.

The model indicated that the three predictors explained 3.9% of the variance (R2=.039, F(3, 3140)=42.67, p<.001. It was found that psychosocial loss (b=-.05, p<.001, 95% CI [-.07, -.03]) and psychological growth (b=-.10, p<.001, 95% CI [-.12, -.07]) significantly predicted attitudes towards people with dementia as decision makers and full members of society, but physical change did not (b=.005, p=.645).

Appendix 7 Sensitivity analyses for selected psychometric tests

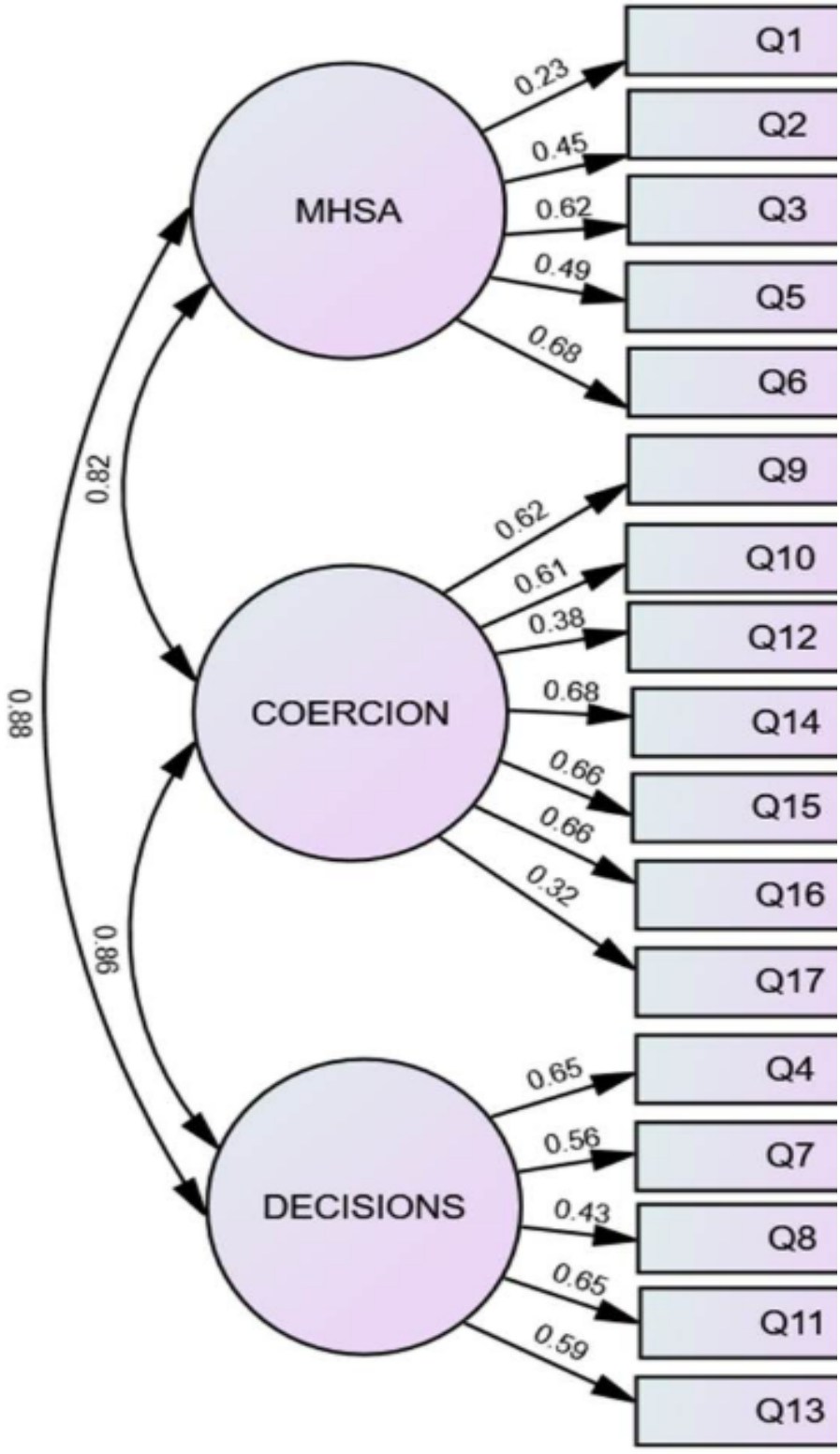
Internal consistency (n=2288)

All 17 items had good internal consistency, α=.828. Item 1 ('nothing can be improved within dementia services without additional resources'), if removed, would slightly improve the reliability score to α=.838. Once removed, items 2 ('the service environment has little to do with people with dementia's mental health and wellbeing') and 17 ('involuntary admission does more harm than good'), if removed, would not change the reliability score.

Confirmatory factor analysis

After the removal of outliers, the data included in the CFA came from 2288 participants. We hypothesised, as previous research had shown (Moro et al., 2024), that there would be three latent factors in the scale: 1) attitudes towards the mental health/dementia services approach, 2) attitudes towards involuntary and coercive practices, and 3) attitudes towards people with dementia as decision-makers and full members of society. The Chi-Square value for the default model was significant, $X^2(116)=795.22$, $p=.000$, with a CMIN/DF ration of 6.86, suggesting a poor fit. The CFI and TLI were .72 and .67 respectively, indicating a poor model fit. However, the RMSEA was .05, 95% Confidence Intervals (CI) [.047, .054], suggesting the model fits well regarding error approximation. Upon inspection of the model, we identified that one item (Q1) did not meet the threshold for factor loadings (0.3). As a result, we removed the item to determine if there would be any model improvement. Using weighted least squares, the Chi-Square value for the new default model was significant, $X^2(101)=744.63$, $p=.000$, with a CMID/DF ratio of 7.37, suggesting a poor model fit. The CFI and TLI were .72 and .67 respectively, against suggesting poor fit. The RMSEA was .05, 95% CI [.049, .056], suggesting the model fits well regarding error approximation.

Figure below shows the CFA path diagram (n=2288)



Appendix 8 Unconstrained matrix for the national dementia plans review

Country: Plan launch date: Researcher name: Date information collected:

Summary of National Dementia Plan/Strategy (Abstract/Contents page/Key points):

……
……

Is the CRPD mentioned within the plan?: ☐ Yes ☐ No

If yes, where is the CRPD mentioned?:
……
……

Human rights factors	Included? Yes/No	Evidence:
CRPD Articles:		
A. Equality and non-discrimination		
B. Accessibility		
C. Awareness raising		
D. Equal recognition before the law (QualityRights aspect=respect for legal capacity)		

E. Liberty and security of person		
F. Freedom from torture or cruel, inhuman or degrading treatment or punishment (QualityRights aspect=Non-coercive practices)		
G. Freedom from exploitation, violence, and abuse (QualityRights aspect=Non-coercive practics)		
H. Living independently and being included in the community (QualityRights aspect=community inclusion)		
I. Health		
J. Work and employment		
K. Adequate standard of living and social protection		
L. Participation in political and public life (QualityRights aspect=participation)		
Additional QualityRights aspects		
M. Recovery approaches to care		
Relevant rights		
N. Empowerment		
O. Agency		

P. Citizenship		
Q. Dignity		
R. Dementia-friendly		
S. Supported decision-making (QualityRights=respect for legal capacity)		
T. Autonomy		
Any other relevant rights:		

Appendix 9 Glossary for human rights aspects for the national dementia plans review

QualityRights terms glossary:

Term	Definition
Respect for legal capacity	The right to make decisions for oneself and to have those decisions respected by others
Non-coercive practices	Practices that do not involve the use of involuntary admission, involuntary treatment, seclusion, and physical, chemical, or mechanical restraint
Participation	People living with dementia are able to participate in making decisions about society as a whole, such as the design and delivery of services that care for them and the development of policies regardless of their expertise and experience in the area
Community inclusion	Services respect the right of people with dementia to remain free and independent, receive services in the place of their own choosing, enable people with dementia to live independently, and participate in their communities
Recovery-oriented care	Enabling people living with dementia to identify what recovery means to them; helping people with dementia to gain or regain control over their life, have hope for the future, and live a life that is meaningful for them
Person-centred care	Person-centred care involves tailoring a person's care to their interests, abilities, history and personality

CRPD Articles Glossary:

CRPD Articles	Definition
Equality and non-discrimination (Article 5)	Countries agree that everyone is equal and that discrimination against people with dementia is not allowed; reasonable adjustments within society are made to enable people with dementia have access information, services, activities and opportunities[1].
Awareness raising (Article 8)	Countries help everyone realise that people with dementia: have equal rights; combat ideas and practices that hurt people with dementia, and; show that people with dementia can and do contribute to society. They should do this with campaigns, education, supporting awareness programmes, and encouraging the media to talk positively about people with dementia[1].
Accessibility (Article 9)	Countries make it possible for people with dementia to be with others in society and do the same activities as others, giving them access to transport, buildings, information and other relevant services/items to do this. Countries should remove all obstacles that make it difficult for people with dementia to be included in society[1].
Equal recognitions before the law (Article 12)	The law must recognise that people with dementia are human beings with rights and responsibilities like everyone else. People with dementia must be able to use their rights. People with dementia must have appropriate support to help them make decisions when it is difficult for them to do so. People with dementia must be protected against possible abuse as a

	consequence of their decisions. Countries must protect the following rights of people with dementia: to have or be given property; control their money; borrow money, and; not have homes or money taken away from them[1].
Liberty and security of person (Article 14)	People with dementia have the right to be free like other people and not be detained or imprisoned on the grounds that they have dementia. If people with dementia are detained or imprisoned, they must be protected by international human rights law and treated in a way that respects the objectives and principles of the CRPD[1].
Freedom from torture or cruel, inhuman or degrading treatment or punishment (Article 15)	People with dementia must not be tortured or treated cruelly. They cannot be experimented on by doctors or scientists unless they give informed consent. Countries should do everything possible to ensure people with dementia are not tortured or treated cruelly[1].
Freedom from exploitation, violence, and abuse (Article 16)	Countries must make laws and rules to ensure people with dementia are protected within and outside their home from violence, and from being exploited or abused. Countries must prevent abuse by providing support, information, and training to people with dementia, their families, and caregivers, with extra support for women and children. Countries should ensure services are reviewed by independent bodies. People with dementia that have been abused must be provided with help and support to help keep them safe and help them recover. Laws should be created to find out if abuses occur often, investigate them, and take abusers to court[2].

Living independently and being included in the community (Article 19)	People with dementia have the right to live like other people and have the same choices in life. Countries should make sure people with dementia: can choose where they want to live and who with; have access to a wide variety of community services to help them live within the community, and; have access to the same community services as all others[2].
Health (Article 25)	People with dementia should have the same chance as others to be in good health and countries should provide full access to health services. This also means making sure services are accessible close to the person's home. Health professionals should give the same quality of service to people with dementia as they do others, including obtaining fully informed consent. People with dementia s[3]hould not be discriminated against when it comes to health and life insurance. People with dementia should not be refused care, treatment, food, or fluids[2]. Palliative care protected under the right to health.
Work and employment (Article 27)	People with dementia have a right to work, right to earn money, and right to choose their job. Countries must respect these rights. This includes not allowing discrimination, providing good and safe working conditions, ensure equal chances of getting jobs, equal pay, and making sure they are not abused at work. People with dementia should not be forced to undertake unpaid work[2].
Adequate standard of living and social protection (Article 28)	People with dementia have an equal right to satisfactory and acceptable standards of living and living conditions. This includes food, clean water, housing, and clothing. They should be protected by the state from poverty and bad living conditions[2].
Participation in political and public life (Article 29)	Countries must ensure people with dementia are able to participate in politics on the same basis as everyone else. This includes being able to vote and to be elected. Voting should be made accessible (easy for those who may find it hard), secret, and free. People with dementia should be allowed to choose someone to vote for them/help them vote. People with dementia

	must also be encouraged to participate in public affairs, including joining non-governmental organisations and associations, as well as creating and joining organisations of persons with disabilities[2].

Rights synonyms glossary:

Term	Definition
Empowerment	"The state of being empowered to do something; the power, right or authority to do something"[4]
Agency	A multifaceted term; "Agency is embodied, emotional, international, and socially situated. It encompasses the feeling of control we have over our actions, making decisions, and the sense of being responsible for our actions"[5]
Citizenship	Involves having rights as well as responsibilities; citizenship has been equated with opportunities for growth and being able to participate in meaningful ways[6]
Dignity	A multifaceted term; providing support that validates the self-worth of the individual, including their experiences and opinions[7]
Dementia-friendly (societies / communities)	A society/community that possesses an inclusive and accessible community environment, optimising opportunities for health, participation and security for all people[8]

Supported decision-making	Can take several forms: appointing a trusted person who can support persons with dementia in weighing up different options, help communicate the wills and preferences of the person with dementia, and/or support the person living with dementia to exercise their legal capacity to the greatest extent possible, or; through the use of advanced care planning[9]
Autonomy	People living with dementia are in charge of their own lives and have the freedom to make their own choices[10]

Appendix 10 Screenshot of the combined dementia plan data

COUNTRY	DATE	TITLE	ACCESSED?	TRANSLATED?	ADI	CHECKED	CRPD?	RIGHTS?	WHO-GAP?
Australia	2015	National Framework for Action on Dementia 2(	YES	YES	Has new on	YES		YES	
Austria	2015	Dementia Strategy: Living well with dementia	YES	YES	Yes	YES	YES	YES	
Belgium (Flanders)	2022	Dementia plan 2021-2025	YES	YES	No	YES			
Belgium (Wallonia)	2010	The Alzheimer Wallon Action Program	YES	YES	No	YES			
Bonaire	2019	On the way to one dementia-friendly society: N	YES	YES	Yes	YES			
Canada	2020	A Dementia strategy for Canada: Together We /	YES	YES	Yes	YES	YES	YES	YES
Chile	2017	National Dementia Plan 2017	YES	YES	Yes	YES	YES	YES - 3: We highlight the need to have timely diagnoses, reduce the stigmas associated with dementia and aging, reduce the bu	
Costa Rica	2014	plan nacional para la enfermedad de alzheimer y	YES	YES	Yes	NO			
Cuba	2013	Estrategia Cubana para le enfermedad de Alzhe	YES	YES	Yes	YES	YES	YES	
Curacao	2021	Beleidsplan dementie 2021-2025 Curacao	YES	YES	Yes	YES		YES	
Cyprus	2012	National action plan for treatment of dementia i	YES	YES	Has new on	YES		YES - 37: 4.6.1 Review of the Legislative Framework To enforce the rights of patients with dementia with an appropriate legis	
Czechia	2020	NAPAN: Narodni akcni plan pro Alzheimerovu	YES	YES	Yes	YES		YES - several times but is a full strategic goal: V. The rights	YES
Denmark	2017	A safe and dignified life with dementia: nationa	YES	YES	Yes	YES		YES	
Dominican Republic	2020	Plan de respuesta a las demencias en la republic	YES	YES	Yes	YES	YES	YES	YES
England	2016	Prime Ministers Challenge on Dementia 2020: I	YES	YES	Has new on	YES		YES	
Finland	2023	National programme on ageing 2030: For an ag	YES	YES	Yes	YES		YES	
France	2021	Roadmap diseases neurodegenerative 2021-202	YES	YES	No	YES		YES	YES
Germany	2020	National Dementia Strategy	YES	YES	Yes	YES	YES	YES	
Gibraltar	2023	Gibraltar National Dementia Society 2023-2028	YES	YES	Yes	YES	YES	YES	YES
Greece	2014	National action plan for dementia - alzheimer's	YES	YES	Yes	YES		YES	
Iceland	2020	action plan for services to persons with dementi	YES	YES	Yes	YES		YES	YES
Indonesia	2015	national strategy: Management of alzheimer an	YES	YES	Yes	YES		YES	
Iran	2021	dementia country program in view to exectue in	YES	YES	Yes	YES		YES	YES
Ireland (Rep)	2014	the irish national dementia strategy	YES	YES	Yes	YES		YES	
Israel	2013	addressing alzheimer's and other types of deme	YES	YES	Yes	YES		YES	
Italy	2014	the united conference (today's session 30.10.20	YES	YES	Yes	YES		YES	
Japan	2015 (Upd	The Orange Plan implementation status AND a	YES	YES	Yes	YES			
Kuwait	2017	national plan for dementia in the elderly Kuwai	YES	YES	Yes	YES		YES	YES
Luxembourg	2013	Demenz: Final report of the steering committee	YES	YES	Yes	YES	YES	YES	
Macau SAR		Ten Year action plan for elderly services from 2016-2025		NO	Yes				
Malta	2015	Empowering change: A national strategy for de	YES	YES	Yes	YES		YES	
Mexico	2014	Plan de accion alzheimer y otras demencias, me	YES	YES	Yes	YES		YES	
Netherlands	2021	National Dementia Strategy 2021-2030	YES	YES	Yes	YES		YES	

Appendix 11 Dementia plans included in the review

Included

Country	Date(s)	Name	Leader	WHO Region
Australia	2015-2019	National Framework for Action on Dementia 2015-2019	Department of Health and Aged Care	Western Pacific
Austria	2015	Dementia Strategy: Living Well with Dementia	Federal Ministry Labour, Social Affairs, Health and Consumer Protection	European
Belgium (Flanders)	2022	Dementia Plan 2021-2025	Flemish Ministry of Welfare, Public Health, an Family	European
Belgium (Wallonia)	2010	The Alzheimer Wallon Action Program	Wallonia Government	European
Canada	2020	A Dementia Strategy for Canada: Together We Aspire	Public Health Agency of Canada	Americas
Chile	2017	National Dementia Plan 2017-2025	Ministry of Health	Americas
Cuba	2013	Strategy for Alzheimer Disease and Dementia Syndromes	Ministry of Public Health	Americas
Cyprus	2012	National Actional Plan for Treatment of Dementia in Cyprus 2012-2017	Ministry of Health	European
Czechia	2020	National Alzheimer's Disease Action Plan and Similar Diseases 2020-2030	Ministry of Health and Ministry of Labor Social Affairs	European
Denmark	2017	A safe and dignified life with dementia: national action plan on dementia 2017-2025	Danish Ministry of Health	European
Dominican Republic	2020	Dementia response plan in the Dominican Republic 2020-2025	Ministry of Public Health	Americas
England	2016	Prime Ministers Challenge on Dementia 2020: Implementation Plan	Department of Health	European

Finland	2023	National Programme on Ageing 2030: For an age-competent Finland	Ministry of Social Affairs and Health	European
France	2021	Roadmap for neurodegenerative diseases 2021-2022	Ministry of Social Affairs, Health and Women's Rights	European
Germany	2020	National Dementia Strategy	Federal Ministry for Family Affairs, Senior Citizens, Women and Youth AND Federal Ministry of Health	European
Greece	2014	National Action Plan for Dementia - Alzheimer's Disease (2016-2020)	Ministry of Health	European
Iceland	2020	Action Plan for Services to Persons with Dementia	The Government Council of Iceland Ministry of Health	European
Indonesia	2015	National Strategy: Management of Alzheimer and Other Dementia Diseases: Towards Healthy and Productive Older Persons	Ministry of Health	South-East Asia
Iran	2021	Dementia Country Program with a view to execute in a period of time	Ministry of Health	Eastern Mediterranean
Ireland	2014	The Irish National Dementia Strategy	Department of Health	European
Israel	2013	National Program for Addressing Alzheimer's and other types of Dementia 2013: Israeli National Strategy	Ministry of Health	European
Italy	2014	National Dementia Strategy 2014	Ministry of Health	European
Japan	2015 (Update 2020)	The Orange Plan 2015: Implementation Status	Ministry of Health, Labor and Welfare	Western Pacific
Kuwait	2017	National Plan for Dementia in the	Department of Health Services for the Elderly	Eastern Mediterranean

		Elderly Kuwait 2017-2020		
Luxembourg	2013	Dementia: Final report of the steering committee for the establishment of a national action plan "dementia"	The Government of the Grand-Duchy of Luxembourg Ministry of Family and Integration and Ministry of Health	European
Malta	2015	Empowering change: A national strategy for dementia in the Maltese Islands 2015-2023	Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing	European
Mexico	2014	Plan of Action for Alzheimer's and other Dementias Mexico 2014	National Institution of Geriatrics, Secretary of Health	Americas
Netherlands	2021	National Dementia Strategy 2021-2030	Ministry of Health, Welfare and Sport	European
New Zealand	2014	Improving the lives of people with dementia	Ministry of Health	Western Pacific
Northern Ireland	2011	Improving dementia services in Northern Ireland: A regional strategy	Department of Health, Social Sciences and Public Safety	European
Norway	2021	Dementia plan 2025	Norwegian Ministry of Health and Care Services	European
Portugal	2018	The Health Strategy in the Area of Dementia	Secretary of State for Health	European
Qatar	2018	Qatar National Dementia Plan 2018-2022 Summary	Ministry of Public Health	Eastern Mediterranean
Scotland	2023	Dementia in Scotland: Everyone's Story	Scottish Government	European
Slovenia	2016	Dementia Management Strategy in Slovenia until 2020	Ministry of Health	European
Spain	2019	Comprehensive Plan for Alzheimer's and other Dementias 2019-2023	Ministry of Health, Consumption and Social Welfare	European
Sweden	2018	National Strategy for Care of People with Dementia	Ministry of Social Affairs	European

Switzerland	2016	National Dementia Strategy 2014-2019: Results achieved in 2014-2016 and priorities for 2017-2019	Federal Department of Home Affairs and Federal Office of Public Health	European
USA	2022	National Plan to Address Alzheimer's Disease: 2022 update	U.S. Department of Health and Human Services	Americas
Wales	2018	Dementia Action Plan for Wales 2018-2022	Welsh Government	Eurpean

Removed during screening

Country	Date(s)	Name	Leader	WHY?
Bonaire	2019	On the way to one dementia-friendly society: National Policy Plan for Dementia Bonaire	Government of Bonaire	UN
Costa Rica	2014	National Plan for Alzheimer's disease and related Dementias shared efforts 2014-2024	CONAPAM	Translation
Curacao	2021	Dementia Policy 2021-2025 Curacao	Ministry of Social Development, Labor and Welfare and Ministry of Health, Environment and Nature	UN
Gibraltar	2023	Gibraltar National Dementia Strategy 2023-2028	Ministry of Health and Care	UN
Macao SAR	2016	Ten Year Action Plan for Elderly Services from 2016-2025	Macao SAR Government	Translate
New Zealand	2021	Improving Dementia Mate Wareware Services in Aotearoa New Zealand	Alzheimers New Zealand, Dementia New Zealand, New Zealand Dementia Foundation,	Not gov. plan

			Mate Wareware Advisory Rõpũ	
Puerto Rico	2015	Action plan for Puerto Rico: Strategies to improve care and the quality of life of people with Alzheimer's disease 2015-2025	Department of Health	UN
Rep. Korea	2016	The 3rd national dementia plan: Living well with dementia in the community	Ministry of Health and Welfare	Not most recent
Sweden	2017	National guidelines for care and care in dementia: support for governance and management	National Board of Health and Welfare	Not most recent
Taiwan	2018	dementia prevention and care policy and action plan 2.0 2018-2025	Ministry of Health and Welfare	UN

Unable to access

- Armenia
- China
- Rep. Korea 4th version
- Russia
- Singapore
- Thailand
- Vietnam
- Uruguay

Appendix 12 Contributions in the WHO guidance methodology

Team member	Affiliation (at time of involvement)	Dates involved (since Oct 2022)	Task(s) involved on
Briony Harden	IMH - WHO-CC	Oct 2022 -	ALL except write up of full document
Martin Orrell	IMH - WHO-CC	Oct 2022 -	ALL
Orii McDermott	IMH - WHO-CC	Oct 2022 -	Overseeing ; Creating algorithm ; Rating
Michelle Funk	WHO	Oct 2022 -	Overseeing
Natalie Drew	WHO	Oct 2022 -	Overseeing
Katrin Seeher	WHO	Oct 2022 -	Overseeing
Tarun Dua	WHO	Oct 2022 -	Overseeing
Thea Sobers	UON – WHO-CC	March 2023 - Nov 2023	Searches for services
Justin Weiss	Mailman School of Public Health	May 2023 - July 2023	Searches for services
Selina Hsuan	Mailman School of Public Health	May 2023 - July 2023	Searches for services
Rachel Orrell	N/A – WHO-CC	Dec 2023 - April 2024	Screen against minimum service criteria
Tanmay Nainwal	UON – WHO-CC	Oct 2023 - April 2024	Screen against minimum service criteria
Ira Makhijani	UON – WHO-CC	Oct 2023 - April 2024	Screen against minimum service criteria

Insha Merchant	Wellesley College	June 2024 - August 2025	Send out human rights survey ; Service classifications ; Find more information ; Find human rights information ; Rating
Zachary Smith	Mailman School of Public Health	May 2024 - July 2024	Send out human rights survey ; Service classifications ; Find more information
Abhisri Chadalavada	UON – WHO-CC	April 2024 - August 2025	Consensus work (service criteria) ; Find more service information ; Find services that fill gaps ; Find human rights information ; Rating
Sherryn Man	UON – WHO-CC	April 2024 - Oct 2024	Consensus work (service criteria) ; Find more service information ; Find services that fill gaps
Jack Cahill	UON – WHO-CC	Nov 2024 - Dec 2024	Find human rights information
Ella Kaye	UON – WHO-CC	Nov 2024 - August 2025	Find human rights information ; Rating

Appendix 13 Countries organised by WHO region

YES = complete, blank = not started, MORE = needs more indepth searching
*= Source is International Financial Reporting Standards 2023 https://www.ifrs.org/content/dam/ifrs/shop/world-bank-list.pdf

African Region

Country name	Income?*	Internet (Google) search	Literature (Scholar) search
Algeria	LMIC		
Angola	LMIC		
Benin	LMIC		
Botswana	UMIC		
Burkina Faso	LIC		
Burundi	LIC		
Cameroon	LMIC		
Cape (Cabo) Verde	LMIC		
Central African Republic	LIC		
Chad	LIC		
Comoros	LMIC		
Congo	LMIC		
Cote d'Ivoire	LMIC		
Democratic Republic of the Congo	LIC		
Equatorial Guinea	UMIC		
Eritrea	LIC		
Eswatini (Swaziland)	LMIC		
Ethiopia	LIC		
Gabon	UMIC		
The Gambia	LIC		
Ghana	LMIC		
Guinea	LMIC		
Guinea-Bissau	LIC		
Kenya	LMIC		

Lesotho	LMIC		
Liberia	LIC		
Madagascar	LIC		
Malawi	LIC		
Mali	LIC		
Mauritania	LMIC		
Mauritius	UMIC		
Mozambique	LIC		
Namibia	UMIC		
Niger	LIC		
Nigeria	LMIC		
Rwanda	LIC		
Sao Tome and Principe	LMIC		
Senegal	LMIC		
Seychelles	HIC		
Sierra Leone	LIC		
South Africa	UMIC		
South Sudan	LIC		
Tanzania (United Republic of)	LMIC		
Togo	LIC		
Uganda	LIC		
Zambia	LMIC		
Zimbabwe	LMIC		

The Americas

Country name	Income?	Internet (Google) search	Literature (Scholar) search
Anguilla	HIC		
Antigua and Barbuda	HIC		
Argentina	UMIC		
Aruba	HIC		
Bahamas	HIC		

Barbados	HIC		
Belize	UMIC		
Bermuda	HIC		
Bolivia	LMIC		
Brazil	UMIC		
Canada	HIC		
Cayman Islands	HIC		
Chile	HIC		
Colombia	UMIC		
Costa Rica	UMIC		
Cuba	UMIC		
Curacao	HIC		
Dominica	UMIC		
Dominican Republic	UMIC		
Ecuador	UMIC		
El Salvador	UMIC		
French Guiana			
Grenada	UMIC		
Guadeloupe			
Guatemala	UMIC		
Guyana	HIC		
Haiti	LMIC		
Honduras	LMIC		
Jamaica	UMIC		
Martinique			
Mexico	UMIC		
Montserrat	UMIC		
Netherlands Antilles			
Nicaragua	LMIC		
Panama	HIC		
Paraguay	UMIC		
Peru	UMIC		

Puerto Rico	HIC		
Saint Kitts and Nevis	HIC		
Saint Lucia	UMIC		
Saint Vincent and the Grenadines	UMIC		
Sint Maarten	HIC		
Suriname	UMIC		
Trinidad and Tobago	HIC		
Turks and Caicos Islands	HIC		
USA	HIC		
Uruguay	HIC		
Venezuela	UMIC		
British Virgin Islands	HIC		

Europe

Country name	Income?	Internet (Google) search	Literature (Scholar) search
Albania	UMIC		
Andorra	HIC		
Armenia	UMIC		
Austria	HIC		
Azerbaijan	UMIC		
Belarus	UMIC		
Belgium	HIC		
Bosnia and Herzegovina	UMIC		
Bulgaria	UMIC		
Croatia	HIC		
Cyprus	HIC		
Czechia	HIC		
Denmark	HIC		
Estonia	HIC		
Finland	HIC		
France	HIC		

Georgia	UMIC		
Germany	HIC		
Greece	HIC		
Hungary	HIC		
Iceland	HIC		
Ireland (Republic of)	HIC		
Israel	HIC		
Italy	HIC		
Kazakhstan	UMIC		
Kyrgyzstan	LMIC		
Latvia	HIC		
Lithuania	HIC		
Luxembourg	HIC		
Malta	HIC		
Moldova (Republic of)	UMIC		
Monaco	HIC		
Montenegro	UMIC		
Netherlands	HIC		
North Macedonia	UMIC		
Norway	HIC		
Poland	HIC		
Portugal	HIC		
Romania	HIC		
Russian Federation	UMIC		
San Marino	HIC		
Serbia	UMIC		
Slovakia	HIC		
Slovenia	HIC		
Spain	HIC		
Sweden	HIC		
Switzerland	HIC		
Tajikistan	LMIC		

Turkiye	UMIC		
Turkmenistan	UMIC		
Ukraine	LMIC		
United Kingdom of Great Britain and Northern Ireland	HIC		
Uzbekistan	LMIC		

Eastern Mediterranean

Country name	Income?	Internet (Google) search	Literature (Scholar) search
Afghanistan	LIC		
Bahrain	HIC		
Djibouti	LMIC		
Egypt	LMIC		
Iran	LMIC		
Iraq	UMIC		
Jordan	LMIC		
Kuwait	HIC		
Lebanon	LMIC		
Libya	UMIC		
Morocco	LMIC		
Oman	HIC		
Pakistan	LMIC		
Palestine (Territories of)	UMIC		
Qatar	HIC		
Saudi Arabia	HIC		
Somalia	LIC		
Sudan	LIC		
Syria	LIC		
Tunisia	LMIC		
United Arab Emirates	HIC		
Yemen	LIC		

South-East Asia

Country name	Income?	Internet (Google) search	Literature (Scholar) search
Bangladesh	LMIC		
Bhutan	LMIC		
India	LMIC		
Indonesia	UMIC		
North Korea (Democratic People's Republic of Korea)	LIC		
Maldives	UMIC		
Myanmar	LMIC		
Nepal	LMIC		
Sri Lanka	LMIC		
Thailand	UMIC		
Timor-Leste (East Timor)	LMIC		

Western Pacific

Country name	Income?	Internet (Google) search	Literature (Scholar) search
American Samoa	HIC		
Australia	HIC		
Brunei Darussalam	HIC		
Cambodia	LMIC		
China	HIC		
Cook Islands			
Fiji	UMIC		
French Polynesia	HIC		
Guam	HIC		
Hong Kong	HIC		
Japan	HIC		
Kiribati	LMIC		

South Korea (Republic of)	HIC		
Lao (People's Democratic Republic of)	LMIC		
Macao	HIC		
Malaysia	UMIC		
Marshall Islands	UMIC		
Micronesia	LMIC		
Mongolia	LMIC		
Nauru	HIC		
New Caledonia	HIC		
New Zealand	HIC		
Niue	UMIC		
Northern Mariana Islands	HIC		
Palau	UMIC		
Papua New Guinea	LMIC		
Philippines	LMIC		
Pitcairn Island			
Samoa	LMIC		
Singapore	HIC		
Solomon Islands	LMIC		
Tokelau	LMIC		
Tonga	UMIC		
Tuvalu	UMIC		
Vanuatu	LMIC		
Vietnam	LMIC		
Wallis and Futuna Islands	UMIC		

Countries not currently in WHO Regions

Country name	Income?	Internet (Google) search	Literature (Scholar) search
Antarctica			
Christmas Island			

Cocos (Keeling) Islands			
Falkland Islands			
Faroe Islands	HIC		
French Southern Territories			
Gibraltar	HIC		
Greenland	HIC		
Holy See/Vatican City			
Kosovo	UMIC		
Liechtenstein	HIC		
Mayotte			
Reunion Island			
Taiwan	HIC		
Tibet			
US Virgin Islands	HIC		
Western Sahara			

Appendix 14 Dementia Service Identification Questionnaire



WHO Collaborating Centre
for Mental Health,
Disabilities and Human Rights

Information sheet and consent

Developing Good Practice Guidance for International Dementia Care in collaboration with the World Health Organization

Thank you for participating in this survey. Following the launch of the "Guidance on community mental health services: Promoting person-centred and rights-based approaches" document by the World Health Organization in June 2021, they have been asked to create a similar document for dementia services. This is also in support of WHO's global mandate - the Global action plan on the public health response to dementia 2017-2025 (WHA A70/28) - which envisions a world in which dementia is prevented and people with dementia and their caregivers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy, and equality. This survey will enable us to collect as many details about dementia services from around the world to help us create this document.

We specifically would like to know the service contact details, the type of services they offer, and how they promote good practice in relation to human rights and person-centred approaches within these five areas: 1) respect for legal capacity; 2) non-coercive practices; 3) participation; 4) community inclusion, and; 5) person-centred approaches. We have attached our guide about these rights aspects to help explain these terms here and later on (click more info : https://docs.google.com/document/d/e/2PACX-1vTyykTZl4Iiw-7vfc2j7B3EWzgAmaraBBrHdd7FCRDwRdgIjnub2Cx5W4tyy1lMkAdu3zkFmy_-DjMB/pub

The whole questionnaire can take a while to complete, so we have enabled you to finish the questionnaire later if you so wish. The data, however, will only be uploaded by clicking FINISH on the final page. From this point, it will not be possible to withdraw or change your service answers.

After pressing FINISH to submit your answers, another page with the university team contact details will appear. There will also be another link that asks you to provide your contact details. This is so we are able to follow up with you if we cannot get hold of the service you have submitted. Please note your details will not be disclosed or published, and will be stored separately from the service details. We will only be able to match up your contact details and your survey response using a passcode or memorable word you will be asked to provide below. If you choose to provide your details, click the link which will send you to a different survey. For a more detailed information sheet, please click here: https://docs.google.com/document/d/e/2PACX-1vRZufAUDFbiYyzY-2y4OkP00UKrB7qQOcWzrRAKMGZYrSCj83rd8odHFZ7k2QWiFg/pub

This survey will close on 31st October 2023 at 23:45 GMT.

PLEASE NOTE: It is possible that the survey may be too long or complex to complete. Please be sure that the researchers are on hand if you wish to ask any questions or if you would like help completing the questionnaire. You can email or call the team on the contact details below. This questionnaire is being used for a PhD research project but also for an international WHO document. If you have any questions, please contact: Briony Harden (email msxbh4@nottingham.ac.uk) or if you have any concerns about any aspect of this study please contact the Research Supervisors: Professor Martin Orrell (email mszmwo@nottingham.ac.uk) or Dr Orii McDermott (email msxom1@nottingham.ac.uk). You can also contact Orii on 07811 940708. Please allow for 2-3 working days before a response; this phone is not monitored every day.

Acknowledgements

The University of Nottingham thanks the WHO for its continuous support through the research project.

1. Please provide your passcode or memorable word here. Add at least 1 number and 1 symbol to make it unique to you (e.g. elephant1!):

2. I have read and understood the above information and consent form, I confirm that I am 18 years old or older and by clicking "yes" and then NEXT to begin the online questionnaire, I give my consent to provide details of the service I wish to submit. If you do not wish to partake in the survey, please exit the window.

About the service being submitted

3. Name of the service:

4. Address:

5. City/Town:

6. State/Province/County:

7. ZIP/Postal code:

8. Country of the service:

9. Phone number:

10. Any links to websites or other relevant documents about the service:

11. First name and last name:

12. Organisation or Place of Work:

13. Position, background, or experience:

14. City/Town:

15. State/Province/County:

16. ZIP/Postal code

17. Country:

18. Phone number (including area code):

19. Email address of the service contact person:

20. General service email address if the above is unavailable:

21. Does the service target a specific subtype of dementia?

I. Yes
II. No
III. Unsure

22. If yes to the above, which subtype of dementia?

I. Alzheimer's Disease
II. Vascular Dementia
III. Frontotemporal Dementia
IV. Young/Early-onset Dementia
V. Mixed Dementia
VI. Dementia with Lewy Bodies
VII. Mild Cognitive Impairment
VIII. Other

23. If you selected Other, please specify:

Here is a guide to help with the next question regarding service classifications if you are unsure: https://docs.google.com/document/d/e/2PACX-1vRPAFXGDxk-L1ROJ0WfueqTcIRR_CSKXL2sz8iRiA6X1x3aPCRxN-1z-x5f9TtH9A/pub

24. What service classification would the service fit? You can select more than one if necessary:

I. Peer support services
II. Social, cultural, recreational services
III. Hospital-based services
IV. Support and respite services
V. Crisis services
VI. Community health services
VII. Supported living accommodation
VIII. Palliative/End-of-life care services
IX. Unsure

25. If you have selected more than one, please state the primary classification:

26. In a few paragraphs, could you expand on the previous questions and provide us with a description of the service?* (What type of service? What does it provide? Who uses the service?).

27. Please highlight if the selected service provides care and support to people with dementia only or to families only or to both.

I. People with dementia only
II. Families/caregivers only
III. Both
IV. Other

28. If you selected Other, please specify:

29. Also indicate if the service provides supports in crisis or challenging situations - without resorting to force or coercion such as involuntary admission and treatment or the use of seclusion and restraints. Please describe these non-coercive measures used and also the service more generally and also include any weblinks that describe the service.

30. Provide a summary of any evaluations or research on the effectiveness of the service and provide full links and references to the evaluation where available. Here is the guide for the rights aspects: https://docs.google.com/document/d/e/2PACX-1vTyykTZl4Iiw-7vfc2j7B3EWzgAmaraBBrHdd7FCRDwRdgIjnub2Cx5W4tyy1lMkAdu3zkFmy_-DjMB/pub

31. Legal capacity (autonomy, independent decision making, fostering independence)

32. Non-coercive practices (explicit reference to implementing services without coercion, force, involuntary admission and treatment and the use of seclusion and restraint etc.)

33. Lived experience (peer support, users involved in the development or implementation of service)

34. Community inclusion (direct links to community, offers additional service, cultural practice inclusion, development of networks)

35. Person-centred approach (going beyond a focus on the condition and on treatment and symptom reduction, in order to support people live a meaningful life, based on their choices, goals, strengths, and abilities, empowering them to regain control of their lives and to make their own choices as well as promoting meaningful daily activities, relationships and social networks, and to have hope for the future)

36. Is there any additional information that you would like to share about the service (videos, publications, newspapers, articles, etc.)? If so, please include the link to the resources:

37. Please upload any documents on the service. You can upload pdf, png, gif, doc, odt, ppt, under 10240 KB each (Please upload at most 10 files)

By clicking finish below, you will submit the service details provided. Please read the last page carefully, as this includes the link to provide your contact details as previously mentioned.

Final page:

Thank you very much for submitting a service for consideration through this survey. You can revisit the survey by clicking on the link initially sent to

you to submit more services if you wish to. As mentioned at the beginning of the survey, we are asking for your contact details to help us follow-up with you for additional service information should we require it. We will contact the services first but if we cannot reach them, we hope to be able to contact you.

If you consent to provide your contact details, please click this link: https://nottingham.onlinesurveys.ac.uk/contact-details If you would not like to provide your details, you can close the browser window. If you have any questions, feel free to get in touch with Briony Harden (msxbh4@nottingham.ac.uk), Professor Martin Orrell (mszmwo@nottingham.ac.uk), or Dr Orii McDermott (msxom1@nottingham.ac.uk or 07811 940708). Should you use the phone number provided, please allow for 2 to 3 working days before we respond; this phone is not monitored every day.

Appendix 15 Email to DIAN members

Dear DIAN members,

On behalf of Martin Orrell we send you this request of WHO to complete a questionnaire on dementia services.

The WHO QualityRights initiative is working to improve access to quality mental health services globally and to promote the human rights of people with mental health conditions and psychosocial, intellectual, and cognitive disabilities. As part of this initiative, we are developing a good practice guidance document which will present information on dementia services that promote human rights and the recovery approach. This is also in support of WHO's global mandate - the Global action plan on the public health response to dementia 2017-2025 (WHA A70/28), that envisions a world in which dementia is prevented and people with dementia and their caregivers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality.

We are contacting you to help us identify people-centered services that you are aware of, that operate without coercion, and that respond to people's needs by promoting autonomy, inclusion in the community, and the involvement of people with lived experience at all levels of decision-making. This should include services that support people experiencing acute crises but that do not resort to force, coercion, involuntary admission and treatment or the use of seclusion and restraints.

By completing the questionnaire in the link at the bottom of this email, you will have the opportunity to submit any dementia services that you believe should be considered as a good practice. By participating, you can contribute to shaping the future of mental health services.

Anyone who is involved in providing a service, has experience of using a service, or knows of a service is welcome to complete the questionnaire so please pass this email on as needed.

Please note that we are not looking for services specifically focused on e-interventions, phone-based interventions, training programs, employment and housing programs, prevention programmes, or services focused on advocacy and/or system reform.

The online Consultation will close on 31st October 2023 at 23:45 GMT

You can access the consultation survey **in English** here: https://nottingham.onlinesurveys.ac.uk/dementia-service-identification-questionnaire

If you have any questions, please send an email to m.orrell@nottingham.ac.uk

Thank you in advance for your contribution,

Michelle Funk and Tarun Dua

Department of Mental Health and Substance Use

WHO Geneva

Martin Orrell and Briony Harden

WHO Collaborating Centre for Mental Health, Disabilities, and Human Rights

Institute of Mental Health, University of Nottingham, Triumph Road, Nottingham, NG7 2TU

http://www.institutemh.org.uk





Appendix 16 Guide to the human rights aspects

Human rights guide

Legal capacity

The right to legal capacity is guaranteed by the CRPD Article 12. People living with dementia have the right to make their own decisions. State parties and society should provide people living with dementia with the support they need to be able to exercise their right to legal capacity. The right to legal capacity includes the right to decide, the right to choose, the right to own property, and the right to enter agreements, including legal agreements. It also encompasses health and treatment decisions. These decisions must be respected by others.

In addition, if it becomes hard for people living with dementia to make decisions, they should have a trusted person who they choose to help them understand the options available, weigh up the advantages and disadvantages of the options and any actions they may take, as well as support the person to be assertive and communicate their wills and preferences. These trusted persons should not influence the person to make decisions they do nt want to make, and these decisions should be made in the best interest of the individual themselves, not others. State parties are expected to provide appropriate and effective safeguards to prevent abuse and enable exercise of legal capacity in accordance with international human rights law.

It is important to note that legal capacity is different to mental capacity; legal capacity is the right to hold rights and right to exercise the right. Mental capacity is used to refer to the decision-making skills.

Supported decision-making checklist

Do you?

- Provide relevant information:
  - ➢ Does the person have all the relevant information he or she needs to make a particular decision?
  - ➢ Does the person have all the information they are asking for?
  - ➢ Have they been given information on all available options?
- Communicate in an appropriate way:
  - ➢ Explain or present the information in a way that is easier for the person to understand (e.g. by using simple, clear and concise language or visual aids).
  - ➢ Explore different methods of communication if required, including nonverbal communication.

➢ Ascertain if anyone else can help with communication (e.g. a family member, support worker, interpreter, speech and language therapist or advocate) and that the person accepts this help

• Make the person feel at ease:

➢ Identify if there are particular times of day when the person's understanding is better.

➢ Identify if there are particular locations where the person may feel more at ease.

➢ Ascertain whether the decision could be put off to see whether the person can make the decision at a later time when circumstances are right for them.

• Support the person:

➢ Ascertain if anyone else can help or support the person to make choices or express a view.

Non-coercive practices

Coercive practices are those which include:

- involuntary admission,
- involuntary treatment,
- Seclusion (isolating an individual away from others; restricting the person's ability to leave a defined space [confinement]), and
- mechanical/physical (interventions taken with use of devices to immobilise the person or restrict movement, such as belts, ropes, chains, shackles), manual (such as holding, imposing restricted movement on a person), and/or chemical (using medication to control) restraint.

Violence is the intentional use of any physical force or power, threatened or actual, which either results in or has a high likelihood of resulting in injury, death, psychological harm or deprivation.

Coercion can be understood as any action or practice which goes against the wishes of the person being cared for. These actions or practices are used to make the person behave or stop behaving in particular ways. Violence and coercion are different but have distinct similarities/overlap. Coercive practices can feel violent, and generally acting coercively requires a degree of violence, no matter how small. Coercive practices also involves a denial of the right to exercise legal capacity.

Coercive actions also include controlling a person's resources such as money and belongings to force the person to do things they may not want to. It can also be more subtle; for example, giving someone medication unbeknownst to them, or making people think there will be negative repercussions or actions if the person does not comply with a treatment or care plan.

The rights relevant to coercion and violence in the CRPD are Article 10 (right to life), Article 12 (equal recognition before the law), Article 14 (liberty and security of the person), Article 15 (freedom from torture or cruel, inhuman or degrading treatment or punishment), Article 16 (freedom from exploitation, violence and abuse), and Article 17 (protecting the integrity of the person).

Appropriate strategies to diffuse any tense situations and avoid coercion/violence include: communicating with the person about how they want to be treated and supported; respecting the wishes of the person and treating them with empathy too; paying attention to any history of trauma or abuse; keeping calm and listening to the person carefully; be reassuring, patient and supportive, and; finding non-violent solutions. Staff can also be mindful and aware of any signs of distress, verbal and non-verbal. Key strategies to help with any distress include: communication techniques; supportive environments and the use of comfort rooms; creating a "yes" and "can do" culture; individualised plans to explore sensitivities and signs of distress, and; response teams.

Participation

There is an Article within the CRPD regarding the participation of individuals with disabilities in public and political life (Article 29). This includes being able to vote and to be elected. Voting should be made accessible (easy for those who may find it hard), secret, and free. People with dementia should be allowed to choose someone to vote for them/help them vote. People with dementia must also be encouraged to participate in public affairs, including joining non-governmental organisations and associations, as well as creating and joining organisations of persons with disabilities.

But people with lived experience of dementia, whether they have dementia or care for someone with the condition, are also excluded from decision-making processes within society as as whole. This includes making decisions about the design and delivery of services that care for them and the development of policies regardless of their expertise and experience in the area. For example:

- being able to provide feedback about the service;
- being part of the service as staff, volunteers, or consultants;
- taking part in the higher-level decisions about the service, such as funding/budget allocation, service development and implementation, service structure, policies, etc.

This is the element of participation we are interested in regarding services.

Community Inclusion

People living with dementia and often their carers are excluded from society. When people are excluded from society and therefore unable to participate in the stereotypical family and social life, they become excluded from

community overall. In turn, when people are under the care of services, including residential care, it can lead to further exclusion from the community.

Services respect the right of people with dementia to remain free and independent, receive services in the place of their own choosing, enable people with dementia to live independently, and participate in their communities. A critical role for mental health services is therefore to support people to access relevant services, supports, organizations and activities of their choosing, that can help them to live and be included in the community. Services should also help, for example, facilitate access to social welfare services and benefits, housing, employment, and educational opportunities.

Recovery-oriented and person-centred approaches to care

Services should provide recovery-oriented and person-centred care. By this, we mean supporting and providing care that meets the needs and wishes of people with dementia. Recovery here does NOT mean a curing of symptoms; we mean services that promote and ensure that people with dementia can regain control over their identity and lives, enable hope for the future, and live a life meaningful to them. Services should focus on what recovery means to each person in their care. Furthermore, care services should respect their dignity, legal capacity, and autonomy, from diagnosis to end of life. Person-centred care should ensure that people with dementia can fully participate in tailoring their care plans to suit their specific needs and preferences. Where necessary, this includes inputs from families and carers. Person-centred care should empower people with dementia to live longer in the community, maintain/regain control of their lives, promote meaningful relationships in life, foster engagement in life and the community, and engender hope for the future. It should enable people with dementia to live well with dementia.

Appendix 17 Contact details survey

You are here because you consent to provide the research team with your contact details. We are only asking for your contact details so we may be able to contact you if we need additional information about the service you are providing. These details shall not be disclosed or published. Your details will be stored separately from the service details you provide. We will only be able to match your responses via the password you created at the beginning.

1. Please state your passcode/memorable word here:

2. First name and last name:

3. Email address:

4. Organisation or Place of work:

5. City/Town:

6. State/Province/County:

7. ZIP/Postal code:

8. Country:

9. Phone number (including area code):

10. What is your connection with the service?:

I. I am a current service user
II. I am a former service user
III. I am a Service Provider
IV. I am a Policy Maker
V. I am a researcher/academic
VI. I am a family member/care partner or member of the social network of a service user
VII. I have heard of this service
VIII. Other

11. If you selected Other, please specify:

Final page:

Thank you very much for providing your contact details. If you have any questions, feel free to get in touch with Briony Harden (msxbh4@nottingham.ac.uk), Professor Martin Orrell (mszmwo@nottingham.ac.uk) or Dr Orii McDermott (msxom1@nottingham.ac.uk or 07811 940708). Should you use the phone number provided, please allow for 2 to 3 working days before we respond; this phone is not monitored every day.

Appendix 18 Definitions of the algorithm pathways

Is there sufficient/ok information?: Do we have a description of the service? Contact details

Google 3 ways: Use different key words for the service (e.g. country, name of service, type of service etc.)

Any good rights information OR is it recommended by the network?: Have you identified any good rights-based practices? OR Has the DIAN network (go through Briony) recommended this service?

Follow the links/network recommendations (mainly to get contact info): The links that have been found for the service OR provided by the DIAN network OR If we only have contact details, we can send them an email to gain more information.

SERVICE, ASSOCIATION, OR NETWORK?

Definition of NETWORK: A group of services that has one main hub and then several locations. Examples include: MSNAP, Care Farming, Memory services network. Can be regional, national, or international.

Business example: Bupa – has a variety of homes. Could be used if we have a specific home that demonstrates good practice, but we CANNOT evaluate Bupa as a whole company.

SERVICE	ASSOCIATION	NETWORK
Is it a single practitioner or psychosocial intervention?	Does the association have a range of advice/activities?	Is it a wider organisation or business?
• Is it one person who provides the service? E.g. a dementia specialist	• Does the association have specific ranges of services? E.g. does it have a memory cafe, advice centres, carer support groups, which could be	• For example, Bupa. Bupa is a wider organisation that owns several care

within a wider organisation. If yes, EXCLUDE • Is the "service" only a psychosocial intervention with no other services provided? E.g. is it CBT only? If yes, EXCLUDE	evaluated as standalone services? If yes, move forwards. • If the association, once you remove a support group, for example, the only things left are, say, handouts, EXCLUDE.	homes. It is a business, so cannot be considered a network. EXCLUDE • NOTE: If we find a good, specific care home that is run by Bupa, we can include it, but we **CANNOT** evaluate Bupa as a whole, because it is one organization, not a network of related/linked ones.
Does it fit with a service category? (see classifications help below)	If it has services (e.g. memory cafes), is it/are they standalone with the possibility to evaluate?	Is it a group of linked services with a common dementia-specific theme? (includes social, cultural, and recreational activities/provisions)
• https://uniofnottm-my.sharepoint.com/:w:/r/personal/msxbh4_nottingham_ac_uk/Documents/PhD/WHO%20Services%20project/Services%20-%20initial%20criteria_February2024/Service%20classifications%20help.docx?d=w1a32a7557b184058b7a1922b6f1cee2c&csf=1&web=1&e=V2wrs9	• Are the 'leftover' services from the associations (e.g. memory cafe, carer support groups) standalone and could be evaluated as a service?	• e.g. Care Farming, MSNAP, Meeting Centres network – these networks provide services with a common goal/link • Social, cultural, and recreational services can be a range of activities provided, by say, a local council, that ALL have a dementia-specific theme.
Is it dementia specific? (i.e. does the service have aspects specifically tailored to dementia?	If YES, go through services flow; if NO, exclude	If YES, keep the network. If NO, exclude

• The services can provide care for other conditions (e.g. cancer, depression), but must have aspects of care specifically tailored to dementia. • If a service only states that they care for people with dementia *too* within their description, but does not specify dementia-tailored care, it can be excluded. • If we need more information on the service to determine this, we can get in contact with the service.		
If YES, keep the service. If NO, exclude		

Appendix 19 Human rights survey [word version]



WHO Collaborating Centre for Mental Health, Disabilities and Human Rights

Human Rights in Community Dementia Services

At the WHO Collaborating Centre for Mental Health, Disabilities and Human Rights, we have been working to develop a good practice guidance document relating to rights-based and person-centred care in dementia. In our searches for potential services to include, we came across this service. We are reaching out to ask you some questions about how you promote and protect the human rights of people using your service. We have included a glossary which can be found on the human rights section. There are also smaller definitions further down the page. If you have any questions, please do not hesitate contact our team: Briony Harden (PhD student) - msxbh4@nottingham.ac.uk Prof. Martin Orrell (Principal Investigator) - m.orrell@nottingham.ac.uk

1. If you are happy to proceed, please press 'next':

Service information

We wish to validate the information we have gathered on your service. PLEASE NOTE: The service name, address, and contact details will be published in the good practice guidance document if the service meets our requirements.

1. Service name

2.Address

3.Country

4.Contact name

5.Email address

6.Telephone number

7.If you have more than one location (e.g. more than one care home), please choose only ONE location to provide the information on, and write the name and site location here (Some services/organisations we have found have several

locations. For the purposes of this document, we require ONE location to be evaluated**):**

8.What type of service do you provide? (see the link for a glossary of our categories - https://docs.google.com/document/d/e/2PACX-1vSjNqQFhA3_ka3G1w_KuxJklZG6PHlGXhBAu-k2yBC4frTg9Zme5eH6lzCqgRAlFg/pub)

i. Peer support services
ii. Hospital-based services
iii. Crisis
iv. Community health services
v. Support and respite services
vi. Supported living accommodation
vii. Palliative/End-of-life care
viii. Network of services

9.If you have selected more than one service type, please specify which type of service yours fits most:

10.Please provide a description of your service:

11.Do you provide dementia-specific care? (do you tailor care for people with dementia rather than provide people with dementia the same care you provide for anyone else?) - Please select an option:

i. Yes
ii. No

12.If yes, please describe what dementia-specific care you offer

13.Do you provide a service for people with a specific type of dementia? - Please select an option

i. Yes
ii. No

14.If you selected 'yes', please describe the type(s) of dementia you provide care for:

15.Who do you provide care for? - Please select an option

i. People with dementia ONLY
ii. Care partners and family members ONLY
iii. Both
iv. Other

16.If you selected 'other', please specify:

Care provided and human rights

17.Please indicate if the service provides support in crisis or challenging situations – without resorting to force or coercion such as involuntary admission and treatment or the use of seclusion and restraints. Please describe these non-coercive measures used and also the service more generally. ***(prompts: how are crises dealt with? What if a resident refused to eat or take medication?)***

18.Please provide a summary of any evaluations or research on the effectiveness of the service and provide full links and references to the evaluation where available:

Human rights

Here is a glossary of the human rights aspects we are asking about: https://docs.google.com/document/d/e/2PACX-1vR04Z30JTtFEuX7DHKbJl53fVs41oZR4ydbWFf-sKQWCIEVxC3wWi9FPtNbmi2AaQ/pub:

Can you provide information on how you protect, promote, and ensure the rights of people living with dementia?:

19.Legal capacity ***(autonomy, independent decision-making, supported decision-making, fostering independence) [prompts: how are residents supported to make decisions? How do the staff approach things if they find people have problems with autonomy?]*****:**

20.Non-coercive practices ***(explicit reference to implementing services without coercion, force, involuntary admission and treatment, and the use of seclusion and restraint etc.)*****:**

21.Participation ***(peer support, people with lived experience involved in the development or implementation of the service) [prompts: can residents/service users make suggestions for improvement of services? Are activities based on what***

***the residents want? Are residents involved in the running of activities and services?]*:**

22.Community Inclusion ***(direct links to the community, offers additional services, cultural practice inclusion, development of networks)*:**

23.Recovery-oriented and person-centred care ***(going beyond the focus on the condition, treatment, and symptom reduction, and instead focusing on helping people live a meaningful life to them, based on their choices, goals, strengths, abilities, and empowering them to regain control over their lives and to make their own choices. Services promote meaningful daily activities, relationships, and social networks, and to have hope for the future. The person receiving care is placed at the centre, is involved in their care plan, and care is tailored to the person's needs and desires)*:**

24.Is there anything else you wish us to know?

Appendix 20 Invite to respond to the human rights survey





SUBJECT LINE: [service name] WHO QualityRights Consultation 2 - Good Practices of Dementia Services

To Whom It May Concern,

We are a research team at the University of Nottingham in the United Kingdom collaborating with the World Health Organization. We are developing a 'good practice guidance' document of community dementia services around the globe that demonstrate good human rights-based and person-centred care.

In our initial searches, we came across this service and feel you may be eligible for inclusion in this document. As a result, we are reaching out to ask some questions about your service. These questions include a description of your service, whether you provide dementia-specific care, how you deal with crises and challenging situations, and how you promote and protect the rights of people with dementia and/or their carers using your services.

We have created an online survey for you to complete. Please note, most of these questions will be required for you to be selected for our next screening stage. If you are included within the final document, your address, contact name, and contact details will be published, but there will be no other personal identification included. The link to the survey is here: **https://app.onlinesurveys.jisc.ac.uk/s/nottingham/human-rights-in-community-dementia-services**

If you would like to be considered for further inclusion within this document, please complete our survey within 2 weeks of receiving this email.

If you have questions, please contact the principal investigator Prof. Martin Orrell on m.orrell@nottingham.ac.uk or PhD student Briony Harden on msxbh4@nottingham.ac.uk.

Thank you in advance for your contribution.

Yours faithfully,

Martin Orrell
Director, Institute of Mental Health, University of Nottingham
Director of Research & Development, Nottinghamshire Healthcare NHS Foundation Trust
NIHR Senior Investigator

Briony Harden
PhD student, Institute of Mental Health, University of Nottingham

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Appendix 21 Rating booklet for the dementia services

Rater initials: Date: Service name: Service category:

Rating guidelines for community dementia services

The CRPD has been validated as an appropriate standard for good practice in dementia care by an international, expert panel (Panagiotidou et al., 2024) so please review this paper before commencing your rating https://onlinelibrary.wiley.com/doi/full/10.1111/opn.12643. Hence, we will use CRPD principles to rate the services we have identified in our searches thus far as good practice.

This rating document is for every service potentially to go in the WHO guide on human rights and dementia care with pages for rating each aspect of the information against the CRPD criteria a) legal capacity, b) non-coercive practices, c) participation, d) community inclusion, and e) recovery-oriented & person-centred care). This follows the previous WHO guidance on *Community mental health services: Promoting person-centred and rights-based approaches*.

Go through the information on services and assess how well the services respect, protect, and promote the human rights of persons with dementia (and their families and care partners). Each rights aspect (a-e) is rated from 1 to 5. **For services to be included they need to score: no 2's (unsatisfactory); have at least one area with good or very good ratings; and have at least 2 areas which can be rated from 3 to 5.**

1 - No information available/found; 2 - Not met – unsatisfactory; 3 - Partially met/satisfactory;
4 – Good; 5 - Very good

Please also include some text to justify the validity your ratings. This can include quotes or comments related to the service document. Highly rated services from this phase will move forward for potential inclusion in the document. We currently have 3 groups: 1) services ready for this phase, 2) services that do require more information, and 3) services that could

potentially fill in our service and country gaps. The total number of services to review (as of 20.01.25) is 24. We will pilot this rating guide with 3 'ready' services *(document = **ServicesToReview**)*.

All of us will complete the rating for these services independently, before coming together to discuss our findings and any discrepancies. We need the piloting completed by **7th February** latest (as we will not be able to meet until the end of February at least). Save each copy as 'service name and country_date rated_initials of rater' e.g. "DementiaInterventionTeamMalta_20.01.25_BH". Please send Briony the completed ratings and she will upload them into a file. **All services will be rated by the end of March 2025**.

Unsatisfactory practices (red flags) for services: score 2 (highlight any criteria met here!)

- *Promotes medication as a primary/principal course of action*
- *Principles/how the service is delivered/outcomes contravene one or more international human rights standards*
  - *Involuntary admission/treatment allowed*
  - *Seclusion/restraint allowed in the service*
  - *Legal capacity is not recognised (decision-making lies with family member, staff, or others)*
  - *ECT (Electronic Convulsive Therapy) undertaken without informed consent*

a) Legal capacity

DEFINITION: the right to make decisions and have those decisions respected by others.

Take into consideration:

- people with dementia are enabled and encouraged to make decisions about their own care and other broader decisions
- people with dementia are provided with all of the information required to make informed decisions
- people with dementia are supported to make these decisions if struggling to make them by themselves
- when receiving support, people with dementia must be protected from possible abuse (including being manipulated/influenced by the supporter to make a decision they do not want)

RATING:

Rating	Score given
No information available/found = 1	
Not met = 2	
Partially met/satisfactory = 3	
Good = 4	
Very good = 5	

COMMENTS:

b) Non-coercive practices

DEFINITION: Coercive practices are any practices that make the person receiving care do something they do not want to do; methods can include restraints, seclusion, segregation, persuasion, involuntary admission and involuntary treatment

Take into consideration:

- People with dementia are free and have their freedoms protected
- People with dementia are NOT detained/imprisoned
- People with dementia are NOT treated cruelly or tortured
- People with dementia are protected from abuse and violence in their own home and other services

RATING:

Rating	Score given
No information available/found = 1	
Not met = 2	
Partially met/satisfactory = 3	
Good = 4	
Very good = 5	

COMMENTS:

c) Participation

DEFINITION: people with dementia are involved in the decision-making processes within society as a whole, including the design and delivery of services that affect them, as well as the development of policies and research.

Take into consideration:

- People with dementia are enabled and encouraged to join in and participate/start up organisations and associations
- People with dementia have the opportunity to be actively involved in decisions regarding policies and procedures, particularly those that concern them
- Services actively seek the involvement of people affected by dementia in their decision-making processes
- People with dementia are provided with opportunities and encouraged to participate in giving feedback and suggestions for service improvement

RATING:

Rating	Score given
No information available/found = 1	
Not met = 2	
Partially met/satisfactory = 3	
Good = 4	
Very good = 5	

COMMENTS:

d) Community inclusion

DEFINITION: People with dementia are supported to access relevant services, supports, organisations, and activities of their choosing which help them live and be included within the community. They can live independently where and with whom they choose.

Take into consideration:

- Services provide opportunities for community involvement and inclusion, facilitating access to the wider community
- People with dementia are free to be involved in the wider community
- People with dementia are given the same opportunities, activities, living conditions and treatment as others
- People with dementia have access to the same services as wider community members (i.e. not just dementia-specific services)

RATING:

Rating	Score given
No information available/found = 1	
Not met = 2	
Partially met/satisfactory = 3	
Good = 4	
Very good = 5	

COMMENTS:

e) Recovery-oriented and person-centred practices

DEFINITION: Practices that focus on supporting people to identify what recovery (personal recovery) means to them, helping them to gain or regain control of their identity and life, have hope for the future, remain connected with others, and empower them to live a life meaningful to them.

Take into consideration:

- Services ensure their care recipients are considered within the context of their entire lives and experiences.
- Services ensure that people with dementia are included in their community on an equal basis with others (could be through reconnecting with friends and family, peer support groups, developing new relationships
- Services work to encourage and instil hope in people with dementia, that living a full life is possible despite their symptoms
- Services encourage people with dementia to appreciate who they are, increase self-worth and strengthen their sense of self
- Services support people to rebuild and gain/regain control, meaning, and purpose according to their own choices and preferences
- People with dementia are placed at the centre of their care, and support is tailored to each individual rather than using a 'one-size-fits-all' process.

RATING:

Rating	Score given
No information available/found = 1	
Not met = 2	
Partially met/satisfactory = 3	
Good = 4	
Very good = 5	

COMMENTS:

f) Evaluations

Evaluations include some kind of assessment of the quality or outcomes of the services which can include surveys of patient or carer satisfaction. Types of evaluations for this service identified:

- Awards (given for quality of care, especially if an independent award with a judging panel
- External evaluation
- National/international reports relating to good practice, human rights, and good care
- Feedback from service users
- Independent feedback
- Research studies/papers
- Service audit with agreed standards
- Health/wellbeing/social outcomes
- Care Quality Commissions and/or equivalents
- Complaints – have services listened to any received complaints and subsequently improved?

Does the evidence base available demonstrate:

Good practice ***(robust, peer-reviewed evidence base in support of the effectiveness of the service. The service has produced consistent results across a number of different settings lending towards transferability:***

Notes:

Promising practice ***(early evidence, either quantitative or qualitative, that indicates the effectiveness of the service. However, the variety of settings of implementation may be limited, or the evidence base is still relatively small/early):***

Notes:

Emerging practice ***(limited evidence base available to demonstrate the effectiveness of the initiative at this stage):***

Notes:

No qualitative or quantitative data available but all principles are checked:

Notes:

More information required:

Notes:

g) Additional comments/notes:

Service categories (Service classifications help.docx)**:**

Peer support *(support groups, drop-in centres, advice, connection, share experiences, carer information)*

Hospital-based *(liaison services, medical care, specialist support)*

Support and respite *(home support, help with daily activities, assistive tech., overnight respite)*

Crisis *(helplines, crisis and home treatment teams, safe place schemes, services for protection from abuse/neglect)*

Community health *(memory services, assessment/diagnosis/interventions, referrals to specialists, counselling/information/education sessions)*

Supported living accommodation *(residential/nursing/care homes, supported housing)*

Palliative/end-of-life care *(care, medication, future, financial and legal advice, counselling)*

Networks *(services/projects with shared theme e.g. care farms and memory cafes, regional/national/international, could include social, recreation and cultural activities e.g. choirs, exercise groups, trips)*