

**The Influence of Stigma on Disclosure Decision-Making in  
People Affected by Dementia**

Jemini Bhatt

Research Department of Clinical, Educational and Health Psychology

University College London (UCL)

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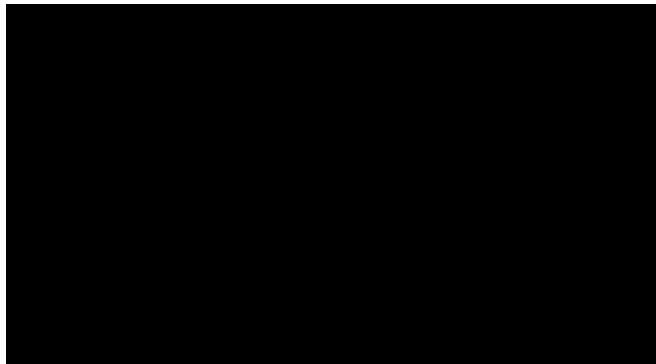
## **DECLARATION**

I, Jemini Bhatt, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Date:

15/07/2020

Jemini Bhatt:



## Impact statement

In this thesis, I provide the first insight into the influence of stigma on disclosure decision-making in people affected by dementia, with findings that have implications for the way stigma and disclosure decision-making in dementia are conceptualised, investigated and addressed in any intervention.

People affected by dementia experience stigma and are subject to the negative psychological and social consequences. It is necessary to build stigma measurement into initial assessments (primary and community care, memory service assessments) with people affected by dementia, and critical for professionals to be aware of the impact of stigma when delivering a diagnosis. Voluntary and health sector organisations seeking to support people affected by dementia need to intervene the consequences of stigma for carers but also support disclosure decision-making for correct, timely support to be provided.

The “Who to tell, how and when?” intervention, developed and tested in this thesis, is a beneficial addition to the post-diagnostic pathway, in which no specialised support for disclosure decision-making currently exists. The intervention will require further testing and therefore the work of this thesis has laid the foundation for future research that has direct public health benefit in our NHS.

As one of Alzheimer’s Society’s [Dementia Research Leaders](#), I have presented the work of this thesis at 14 national, and international conferences, designed and run three workshops for people affected by dementia and continuously engaged and consulted with people affected by dementia throughout my PhD. I was an author on the [World Alzheimer Report 2019](#) that presented the

first stigma prevalence data across the globe for dementia, which has over 1,200 reads. The report featured data from measures developed within my thesis and the “Who to tell, how and when” intervention. In addition to this, my systematic review was published in 2018 and has over 700 reads and three citations. Chapter 4 and Chapter 6 have also been submitted for publication and one of these have been accepted. I was awarded an [INTERDEM Fellowship](#) to investigate the stigma experiences of people living with dementia in the UK and the Netherlands, data has been collected, and findings from this Fellowship will be published in academic journals.

It is fundamental to create health information materials from the findings of this thesis for professionals, on how to uphold meaningful participation as an exercise of supporting the rights and provisions of people living with dementia. People living with dementia can remain in the centre of choices that affect them, if professionals have sufficient knowledge and training on how to support decision-making and importantly have an understanding of factors that disrupt this process.

## **ABSTRACT**

### **Background**

Disclosure decision-making refers to the way in which people affected by dementia choose to conceal or reveal their diagnostic status to others. Dementia is a stigmatised condition; the presence of stigma may generate reluctance to disclose a dementia diagnosis for fear of the consequences.

### **Aims**

The aim of this thesis is to understand the influence of stigma on disclosure decision-making in dementia, to (1) establish the motivations for diagnostic secrecy and the barriers to disclosure in dementia, utilising literature on stigma, stigma reduction and decision-making; (2) test measures of stigma with people affected by dementia; (3) develop and test an intervention to support disclosure decision-making for people affected by dementia.

### **Methods**

Robust methodology was employed to gather an initial understanding of the influence of stigma on disclosure decision-making through one conceptual and one systematic review, followed by adaptation and statistical analysis of psychometric instruments quantifying stigma in people affected by dementia. Intervention development and evaluation was conducted using Medical Research Council guidelines to create the first support group focussed on disclosure decision-making in dementia. Public and patient involvement was used throughout, ranging from the adaptation of psychometric instruments to intervention production being informed by coproduction principles.

### **Results**

Stigma exacerbates the existing complexities in the nature of decision-making in dementia. Stigma measures for people living with dementia (N = 40) and carers (N = 70) were acceptable and suitable with adequate psychometric properties with some exceptions. Intervention development procedures resulted in a novel, 3-session, group based, dyadic (pairs of people living with dementia and their carers) approach heavily endorsed by stakeholders. Preliminary evaluation of the “who to tell, how and when?” intervention (N = 14; 7 dyads) is presented along with recommendations for further iterations.

### **Conclusion**

Stigma negatively influences disclosure decision-making in dementia. Outputs of this thesis, with further testing, can help change this.

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## Glossary and Abbreviations

ADI	Alzheimer's Disease International
BAME	Black, Asian, minority ethnic
BPSD	Behavioural or psychological symptoms of dementia
CBT	Cognitive behavioural therapy
CD-ROM	Computer Disk Read Only Memory
CFA	Confirmatory factor analysis
CFI	Comparative Fit Index
CINAHL	Database for nursing and applied health research
DEEP	Dementia Engagement and Empowerment Project
DPM	Disclosure Process Model
DRDS	Disclosure Related Distress Scale
EbE	Experts by Experience
EBSCOHost	Online reference platform with full text publications from a number of databases
EWGPWD	European Working Group of People with Dementia
FAMSI	The Family Stigma Instrument
FINIS	The Framework Integrating Normative Influence on Stigma
FS-ADS	Family Stigma in Alzheimer's Disease Scale
GP	General practitioner
HAPI	Health And Psychological Interventions
HDDM	Health Disclosure Decision-Making
HIV/AIDS	Human immunodeficiency virus/ Acquired immune deficiency syndrome
HOP	Honest Open Proud
ICC	Intraclass correlation coefficient
INTERDEM	A Pan-European Research Network for Timely and Quality Psychosocial Interventions in Dementia



## Stigma and Disclosure Decision-Making in Dementia

JDR	Joint Dementia Research
LD	Learning Disabilities
MCAR	Missing Completely At Random
MeSH	Medical Subject Headings
MRC	Medical Research Council
MSc	Master of Science
MSNAP	Memory Services National Accreditation Programme
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIMHE	National Institute for Mental Health in England
PFS	Perceived Family Stigma
PLWD	Person living with dementia
PPI	Public and Patient Involvement
PRIDE	Promoting Independence in Dementia
PRISMA-P	Preferred Reporting items for Systematic review and Meta-Analysis Protocols
RCT	Randomised controlled trial
RMSEA	Root mean square error of approximation
RSES	Rosenberg Self-Esteem Scale
SDM	Shared Decision-Making
SIS	Stigma Impact Scale
SPD	Stereotypes, Prejudice and Discrimination framework
SPSS	Statistical Package for the Social Sciences
SSS	Stigma Stress Scale
UCL REC	University College London Research Ethics Committee
UK	United Kingdom

## 1 Introduction

### 1.1 Dementia

Dementia is a syndrome that comprises a collection of symptoms characterised by a decline in, and ultimately a loss of, cognitive functions such as decision-making, attention and awareness, planning, inhibition, learning, memory and language. Dementia is categorised as a major neurocognitive disorder in the Diagnostic and Statistical Manual of Mental Disorders 5<sup>th</sup> Edition (DSM-V; American Psychiatric Association, 2013). There are a number of underlying neuropathologies or neurodegenerative illnesses that ultimately lead to dementia, for example Alzheimer's disease and vascular disease.

Cognitive decline influences functional status in dementia, typically defined as a person's ability to carry out activities of daily living, which may include, but are not limited to, organisational skills (financial affairs, planning activities), decision-making abilities (clothing to wear, healthcare choices), speech and language (reading, conversing with others), ambulatory abilities (moving around) and personal care (bathing, dressing, toileting; Lee & Chodosh, 2009).

Diagnosing dementia is a process of elimination, whereby a diagnosis is given if no other potential illnesses or diseases might explain a person's symptoms. There is not one simple or absolute test to aid clinicians in diagnosing dementia. Typically, the diagnostic process for dementia is initiated through primary care services (e.g. General Practitioner; GPs), where those who are suspected of having dementia are referred to specialist dementia diagnostic services (e.g. Memory Clinics) after all potential causes for cognitive decline that

may be reversible have been investigated (National Institute for Health Care Excellence (NICE), 2019; Dementia Quality Standard QS184). Before dementia is considered, other potential causes investigated pre-referral include delirium, depression, sensory impairments such as hearing or vision loss, and side effects of existing medications, such as anticholinergic drugs known to be associated with symptoms of cognitive decline in older adults (NICE, 2019; Dementia Quality Standard QS184).

Dementia can be broadly categorised into early onset (>65 years of age) and late onset (<65 years of age), and, although dementia can be diagnosed in adults of all ages, it is more common for individuals over the age of 65 (Prince et al., 2014). The duration of dementia can span up to and over a decade but many other factors such as when a diagnosis was made, baseline cognition, medical comorbidities (e.g. pulmonary and cardiovascular diseases), type of dementia and neuropsychiatric symptoms (e.g. hallucinations or aphasia) can influence its duration (Auer & Reisberg, 1997; Burgener & Berger, 2008; Lee & Chodosh, 2009).

Seven stages are used to classify the severity of dementia, with the Global Deterioration Scale or the Functional Assessment Staging System being common instruments used by clinicians when establishing dementia severity (Auer & Reisberg, 1997; Reisberg, Ferris, De Leon, & Crook, 1982). Stages 1 and 2 represent no, or very mild, cognitive decline (normal function to some memory problems), stage 3 and 4 represent mild to moderate cognitive decline (reduced organisational capacity or ability to perform complex tasks such as planning dinner), stage 5 to 6 represent moderate severe to severe cognitive decline

(requiring assistance dressing, incontinence), while stage 7 represents very severe cognitive decline or late stage dementia where verbal and psychomotor abilities are lost (Auer & Reisberg, 1997).

As a result of a diagnosis and symptomatic changes of dementia, a person's outlook on life can be negatively affected where one's identity may be defined through disability and impairment rather than retained abilities (Husband, 1999). Individuals may feel increased symptoms of anxiety because of gradual loss in abilities, coupled with fear and symptoms of depression due to the loss that is to come as dementia progresses (Husband, 1999, 2000; Pratt & Wilkinson, 2003). The presence of unaccommodating social contexts, such as the lack of acceptance from others, reduces one's ability to construct a positive social identity with consequences such as reduced self-esteem, anxiety, depression, social withdrawal and hypervigilance of displaying symptoms of cognitive decline (Husband, 2000). Many people living with dementia have awareness and insight into symptomatic changes during early and mild stages of severity, and therefore are able to mask symptoms by restricting social activities and avoiding members of one's social network to prevent being 'found out', or explaining evidence of cognitive decline as part of normal ageing and encouraging those who do know of the diagnosis to remain secretive (Husband, 2000). The focus of this thesis will be on people living with early to mild dementia, when it is still possible to conceal symptoms of dementia and attribute them to normal ageing or adapting to the stress and complexities of modern living.

## **1.2 United Kingdom (UK) Context**

### ***1.2.1 Epidemiology***

There are approximately 850,000 people living with dementia in the UK, with the number projected to rise to 2 million by 2050 (Prince et al., 2014). Annually, the death of approximately 60,000 over 65 year olds could have been averted if dementia were not present in the population (Knapp et al., 2008). There are 210,000 new cases of dementia each year, of which 74,000 are in men and 135,000 are in women (Matthews, et al, 2016). In 30-65 year olds, the prevalence rate for dementia is 0.01% - 0.16%, however amongst those aged 65 years and older the prevalence rate is 1.7% - 41.1% (Prince et al., 2014).

The most common type of dementia is Alzheimer's disease, which accounts for 62% of the UK population living with dementia (Prince et al., 2014). In Alzheimer's disease, there is typically a steady decline in cognitive impairment, whereas this differs in other types of dementia (e.g. vascular dementia) which can cause sudden bouts of noticeable decline over time. Vascular dementia is the next most prevalent type of dementia, accounting for 17% of the UK population living with dementia (Prince et al., 2014). Mixed dementia, dementia with Lewy Bodies, frontotemporal dementia, Parkinson's dementia and other rarer types of dementia collectively account for the remaining 21% of the UK population living with dementia (Prince et al., 2014).

### ***1.2.2 Economic impact***

The current cost of dementia to the UK economy is approximately £26.3 billion, which is a 24% increase since 2007 and is attributed mainly to the number of increasing cases of dementia (Prince et al., 2014). These costings take into

account health and social care costs, and also the value of the time given by unpaid family carers who support people living with dementia. More specifically, £4.3 billion is spent on health costs covered entirely by the National Health Service (NHS), £10.3 billion on social care costs covered by a combination of local authorities and self-funding, and an estimated £11.6 billion represents the work of unpaid carers of people living with dementia (Prince et al., 2014).

Healthcare costs account for 10.8% of the overall costs for caring for people living with dementia in the community. On average, these costs amount to £5,285 per year but differ based on the severity of dementia (Prince et al., 2014). For example, average healthcare costs for community dwelling people living with mild and moderate dementia are considerably lower (£2,695 and £2,751 per year), than costs for people living with severe dementia (£11,258 per year). The same pattern of increasing costs based on dementia severity exists for average social care costs, which are lower in mild and moderate dementia (£3,121 and £7,772 per year) in comparison to severe dementia (£10,321 per year) and account for 13.8% of overall care costs for people living with dementia (Prince et al., 2014).

The average cost of unpaid care for people living with dementia is £21,956 per year, accounting for 74.9% of the overall cost. However, the average cost of unpaid care also varies depending on the severity of dementia (Prince et al., 2014). More specifically, for community dwelling people living with mild dementia, the cost of unpaid care is an average of £19,714 per year, while for people living with moderate and severe dementia unpaid care costs an average of £32,237 and £33,482 per year respectively (Prince et al., 2014).

The cost of dementia is projected to rise to £59.4 billion by 2050 and this, coupled with an increasing life expectancy in the UK, means that age is the single largest risk factor for developing dementia. As the UK population ages, more people will receive a diagnosis of dementia, contributing to a greater burden on the UK health and social care system, which will be required to provide care. Dementia, therefore, can be framed as a financial, health and social care issue.

### ***1.2.3 Health and Social Care Policy***

Dementia is one of the leading healthcare challenges the world faces (Frankish & Horton, 2017). The growing economic impact of dementia has resulted in a surge of interest from the UK Government, an injection of finances (£13 million to research councils in 2012 for public awareness initiatives) and a policy driven approach. This began with the National Dementia Strategy for England that outlined a strategic framework for local services to deliver health and social care provision (Department of Health, 2009). The Strategy contained guidance for the planning, development and monitoring of provisions to address inequalities, deliver evidence-based practice and guide the content of high-quality services. Early diagnosis was a key component of the National Dementia Strategy, taking the perspective that timely diagnoses would increase the value of treatment opportunities (Department of Health, 2009). This policy priority was reinforced in the Prime Minister's Challenge on Dementia 2020, where health and social care targets to be achieved from 2015 to 2020 were developed, of which earlier diagnoses and raising societal awareness of dementia were outlined as two key targets requiring immediate attention (Department of Health, 2015).

### ***1.2.4 Development, Utility and Monitoring of Memory Services***

To achieve the target of earlier and timely diagnoses, specialist diagnostic services were utilised across the UK, many of which are based on the Croydon Memory Service Model (CMSM) developed and evaluated by Banerjee and colleagues (2007). The CMSM was set up to increase the capacity to diagnose dementia within the London borough of Croydon through earlier assessments, timely diagnoses and treatment for people living with dementia and carers (Banerjee et al., 2007). The CMSM was based on a generic team-working model where referrals could be initially assessed by all members of the team who had undergone the necessary training regardless of clinical background, which led to faster processing of initial referrals. Following formal assessments and diagnosis, a multidisciplinary team collectively created care management plans after which further referrals were made to more specialised services.

Banerjee and colleagues (2007) conducted a quantitative evaluation using referral data, sociodemographic characteristics of people living with dementia and outcome measures (behavioural disturbance, depression and quality of life; at baseline when attending the service and 6 months later). Quantitative results found lower than expected rates of service refusal (5%) and inappropriate referrals defined as no objective or subjective memory problems or having severe dementia (6%), and higher than expected rates of dementia (increase by 63%; Banerjee et al., 2007). In terms of service engagement, all results surpassed what was originally predicted by the study. There was adequate representation of ethnic minority groups (18%, greater than 11% represented in the population at time the study was conducted), those with early to mild dementia severity (77%) and younger people under the age of 65 (18%; Banerjee et al., 2007). There were



statistically significant improvements in behavioural disturbance and quality of life, and some improvement seen in depressive symptoms from baseline to follow-up for people living with dementia.

The CMSM met the aim of accelerating diagnostic rates, engaging individuals in early and mild stages and building tailored plans of care, including earlier and timely treatment. Following the successful results of the CMSM, the model was implemented across the UK. To monitor the quality of memory services the Royal College of Psychiatrists launched the Memory Services National Accreditation Programme (MSNAP) with the UK Government requesting all memory services to become accredited members (Doncaster, McGeorge, & Orrell, 2011). Accreditation required memory services to meet a number of standards which ensure best practice both before (pre-diagnostic counselling, information provision) and after (post-diagnostic counselling, access to psychosocial interventions) diagnosis (Doncaster et al., 2011).

There are several stages of the accreditation process, beginning with self-review where services are asked to submit data using audit tools (e.g. patient, carer, and staff questionnaires), followed by an external peer review where five multidisciplinary professionals visit the memory service to validate previously submitted self-review data. Every accreditation is then decided upon by a committee consisting of nominated professionals from organisations involved in diagnosing and assessing dementia (Doncaster et al., 2011). Accreditation is recognised by the Royal College of Psychiatrists' Centre for Quality Improvement at four levels: accredited as excellent, accredited, accredited deferred and not accredited. As of September 2019, 92 memory services were part

of MSNAP, where 51 were accredited, 31 were in review, 5 were deferred and 5 had affiliate status, meaning that the services agreed to engage in the MSNAP accreditation process in the near future (Royal College of Psychiatrists, 2019).

Before assessment and diagnosis, 62% of memory service staff said they delivered pre-diagnostic counselling to carers and people living with dementia and almost all staff members reported that they had enough time to communicate important information about dementia and the potential consequences of engaging in assessments (Royal College of Psychiatrists, 2019). The MSNAP report stated that 51-96% of memory services offered psychosocial interventions including cognitive stimulation therapy (CST), cognitive rehabilitation and group reminiscence therapy as part of the post diagnostic pathway and MSNAP accreditation criteria. It is important to note that within the MSNAP standards there is no requirement for memory services to provide interventions to support people affected by dementia to share a diagnosis with others in their social networks.

In summary, the prevalence of dementia in the community is increasing and the economic burden dementia places upon the UK economy is on the rise. UK policy has encouraged a shift to diagnose dementia earlier that includes, but is not limited to, the use of memory services. The anticipated benefits of early diagnoses of dementia were to promote timely access and engagement with post-diagnostic support, thus allowing people living with dementia and their families to make decisions about the future in a timely fashion (Nicholl, 2009). Other benefits of a diagnosis include timely access to care, reduced consequences such as social exclusion and discrimination, and encouraging appropriate help-seeking

behaviour (Department of Health, 2009). GPs have also noted that earlier and timely diagnoses are of benefit to patients (Milne et al., 2005; Milne et al., 2000; Fox et al., 2014; Pathak & Montgomery, 2015). It is important to note that accreditation with MSNAP is encouraged but not mandatory, and therefore the standard of care (pre-diagnostic counselling, assessment procedures, diagnostic procedures, sharing a diagnosis and post-diagnostic support) may vary considerably across various memory service models, with currently no support for people affected by dementia to share their diagnosis with others (Low, McGrath, Swaffer, & Brodaty, 2019).

### **1.3 Attitudes towards Dementia**

Dementia is a complex condition and has been studied by many researchers from a range of different academic disciplines. Influential perspectives include the medical model, biopsychosocial models, the Disability Rights Movement and selfhood perspectives. I will now consider each of these perspectives in turn to understand the implications for attitudes towards dementia.

#### ***1.3.1 Medical Model***

The medical model attributes dementia to physical changes in the brain that cause behavioural and psychiatric symptoms contributing to an overall progressive global decline in cognition, which presents initially as memory loss particularly for learning new information (National Collaborating Centre for Mental Health, 2007). Symptoms of dementia can be explained through anatomical atrophy (death of neurons) in areas of the brain such as the medial temporal lobe and hippocampus, which are primary sites for pathological change in dementia. As dementia progresses, atrophy is seen in cortical brain areas

responsible for executive functioning where individuals experience greater behavioural and psychiatric symptoms, referred to as behavioural and psychological symptoms of dementia (BPSD; Banerjee, 2009).

Many diseases can cause dementia with each characterised by a unique neurological pathology. Alzheimer's disease is caused by a build-up of amyloid beta deposits ( $A\beta$ , plaques) around neurons and accumulated amounts of tau (tangles, an abnormal protein), which develops within neurons over time causing a reduction in synaptic neuronal activity and eventual atrophy (Knapp et al., 2008). Medical model interventions for Alzheimer's disease include pharmacological drugs that slow and reduce the atrophy (NICE, 2018). In vascular dementia, atrophy is caused by vascular events such as microscopic bleeding or vessel blockage in the brain. Medical model interventions for vascular dementia therefore include pharmacological drugs that reduce the occurrence of vascular brain events (NICE, 2018).

Attributing dementia to physical changes in the brain (for which some interventions exist but none that cure Alzheimer's disease, vascular dementia or any other form of primary progressive dementia), has attitudinal implications. From the medical model perspective, attitudes towards dementia may be hopeful if early diagnoses are made and pharmacological treatment is started to delay atrophy. Yet, in the absence of an early diagnosis, or if individuals are not eligible for pharmacological interventions (e.g. diagnosed with other forms of dementia for which no drugs exist), the medical model carries little hope for people living with dementia and carers. This leads to attitudes where people living with

dementia are seen as being beyond help, leaving carers with the burden of support.

The medical model of dementia places at its centre the physical changes in the brain, rather than the person with dementia themselves. Based on this, there is little regard for the active role people living with dementia play in managing and improving symptoms. Consequently, a deep-rooted attitude from the medical model is that people living with dementia are not capable of understanding the world around them due to a lack of insight or awareness of deficits. There is seldom consideration in medical discourse of a person living with dementia's sense of self, how this is sustained through social relationships and how it can be of symptomatic benefit. This can undermine the autonomy of people living with dementia and impede their ability to participate in meaningful decision-making (Avari & Meyers, 2018).

### ***1.3.2 Biopsychosocial Models***

Broadly speaking, biopsychosocial models consider not only the underlying biology but also psychological and social factors that may explain symptoms of illness, and presents ways in which interventions across these categories can benefit individuals. Building on the subjective experiences of people living with dementia, Kitwood, (1993a) attributed dementia to biology (physical changes in the brain causing cognitive impairment) and also to the individual's personality, biography and physical health, all in the context of the social environment and relationships. Kitwood explained these factors through an equation where the clinical manifestation of dementia (SD) could be understood through the interaction between five discrete factors:

$$SD = P + B + H + NI + SP$$

An individual's personality (P) can be explained through social learning and the development of coping styles (in events of loss, change or crisis) which may dictate the readiness to receive help from others. The biography (B) of an individual involves an understanding of previous life events and whether structures that are stabilising are still in place or have been lost due to demoralising life changes. Physical health (H) status includes other physical illnesses that may affect mental health. Also considered is neurological impairment (NI) as previously defined by the medical model and, finally, social psychology (SP), which represented the underlying social context of everyday life and how this may support or hinder a person living with dementia and compromise their safety, personal value or sense of self.

Operationalising Kitwood's work, Spector and Orrell (2010) introduced a biopsychosocial model of dementia to be used as a clinical tool. Within this clinical tool a multitude of factors could be adapted with interventions to improve symptoms. The model was comprised of biological (e.g. age) and psychosocial (e.g. personality traits) fixed factors, which were unchangeable personal aspects or characteristics, and biological (e.g. physical health) and psychosocial (e.g. environment) 'tractable' factors, which were changeable aspects suitable for intervention.

Biopsychosocial models explain why dementia manifests differently across individuals (e.g. differences in personality or biography), and thus why psychosocial interventions work for some but not all people living with dementia.

Kitwood's explanation of the clinical manifestation of dementia remains one of the most influential shifts away from attributing ill-being to cognitive impairment alone, providing a more holistic, hopeful and positive understanding of dementia, and opening potential avenues to improve symptoms by keeping the person living with dementia at the centre of their own care (Kitwood, 1993b). The tractable factors outlined by Spector and Orrell (2010) were used to inform clinical practice and introduced optimistic and ability-driven attitudes towards dementia, rather than those focussing narrowly on cognitive deficits and decline.

### ***1.3.3 Disability Rights***

The Disability Rights Movement began globally from the late 21<sup>st</sup> century as a retaliation to medical explanations of disability and damaging social forces marginalising disabled individuals whose rights, provisions and protections were systematically threatened (Mehta & Thornicroft, 2013; Winter, 2003). The Movement began a campaign to empower individuals with disability and make political changes to support the integration of individuals with disabilities into mainstream society (Mehta & Thornicroft, 2013). The subsequent disability rights campaign sought to secure equality and rights that were no different to those rights bestowed upon non-disabled individuals. The medical perspective attributes disability to biological impairment; however, the Disability Rights Movement describes disability as separable from impairment. More specifically, impairment is a biological or physical state whereas disability is constructed by one's social environment. For example, a left-handed child in a classroom with only right-handed scissors is disabled but not impaired, whereas a wheelchair-bound person in a building with lifts is impaired but not disabled. Therein lies the premise that

impairment and disability are separately formed with different aetiologies but each can be equally debilitating.

The Disability Rights Movement sought to redefine the attributes of disability to create attitudinal changes on societal and institutional levels. The primary focus was on diminishing the negative attitudes (e.g. disabled people are incompetent) that caused the marginalisation of disabled individuals, described as the process through which individuals are labelled, discredited and kept in the periphery of mainstream activities. In response to the growth of the Disability Rights Movement, the United Nations Department of Economic and Social Affairs published the Convention on the Rights of Persons with Disabilities (CRPD) in December 2006 (MacKay, 2006). The purpose of the CRPD was to ensure that its signatories upheld the fundamental human rights and freedoms of disabled people who were defined as those with long-term mental, physical, and/or sensory impairments.

The manifestation of dementia can be attributed to the maintenance of rights, provisions and protections of people living with dementia (Gilliard, Means, Beattie, & Daker-White, 2005; Gove et al., 2019). In Alzheimer Europe's position paper, co-produced with the European Working Group of People with Dementia, the strengths and limitations associated with categorising dementia as a disability were summarised (Gove et al., 2019). In this position paper, the definition of disability outlined by the Disability Rights Movement was adapted to not only explain the experiences of people living with dementia, but also to identify recommendations to reduce excess disability (e.g. dementia friendly environments, responsible media reporting). More specifically, the position paper



outlined that disability in dementia is the product of tractable social factors (environment and relationships) as well as physical or biological factors (cognitive impairment; Gove et al., 2019). When these rights, provisions and protections are denied, excess disability can occur. For example, an awareness of unaccommodating social relationships and environments, despite intact ability for social engagement, leads to excess disability in social relationships (e.g. being cut off from friends or family) and environments (e.g. negative societal language portrayed in the media).

An example of damaging social forces that propagate the excess disability of dementia can be seen in media outputs. The media are systematically responsible for creating unaccommodating social environments, exacerbating excess disability for people living with dementia. Media representations have depicted dementia in terms of panic and catastrophe ('the living death of Alzheimer's', Revoir 2011), where dementia is associated with social death (Sweeting & Gilhooly, 1997) or 'death in life' (Kastenbaum, 1988). People living with dementia can be seen as living reminders of frailty and dependence that can happen to any ageing person (Kitwood, 1997). Media reports likening people with Alzheimer's disease to zombies have perpetuated this view being applied to people living with dementia across all stages of severity, where dementia is seen as a lethal threat which should be avoided and socially oppressed, generating attitudes of fear and disgust (Behuniak, 2011).

A framing analysis conducted on newspaper articles, movies, documentaries and health care literature about dementia consisted predominantly of negative frames, where dementia represented fear of death and degeneration

unsuited to Western societal expectations of self-fulfilment and individualism (Van Gorp & Vercruyse, 2012). Furthermore, in 350 UK newspaper articles from October 2010 to September 2011, headlines emphasising fear (“Cancer and Alzheimer’s most feared of diseases”; p 890) and the catastrophic nature of dementia (“A bomb ready to explode”; p 890) were commonplace (Peel, 2014).

Such media depictions create fearful public attitudes towards dementia (Behuniak, 2011; Peel, 2014; Van Gorp & Vercruyse, 2012) that manifest as acts of avoidance or social distancing (Devlin, MacAskill, & Stead, 2006).

Collectively, utilising the Disability Rights perspective, it is evident that people living with dementia are subject to excess disability, perpetuated by the media and grounding attitudes towards dementia in pessimism and fear.

#### ***1.3.4 Selfhood in Dementia***

Thus far, attitudes of others towards people living with dementia have been explored. 'Self' can be conceptualised in dementia through a number of ways (Caddell & Clare, 2010). In the current section and the one which follows, two contrasting perspectives on the self will be presented where the former outlines constructions of the self based on the world around the person (Sabat, 1994) and the latter understands self through one's knowledge, self-representation and self-regulation (Clare, Quinn, Jones, & Woods, 2016).

This section will describe a model, which considers attitudes of people living with dementia towards themselves. It is important to note that selfhood in dementia is based on the premise outlined by Kitwood (1993a) that people living with dementia have insight and awareness of the effect of the condition on their experiences. Sabat (1994, 2002) attributed the manifestation of dementia through

social constructionism by outlining three types of 'self' that are differentially affected when a person develops dementia. First, personal identity, the autobiographical self that is constructed from an individual's ownership of their experiences and understandings (Sabat, 2002). Second, the self that is constructed from physical (e.g. eye colour, height) and mental (e.g. educational achievements) attributes which could be viewed positively or negatively by others, and are built over time with some more recent (e.g. receiving a diagnosis of dementia) than others (e.g. graduating from university). Third, social identity, the self that is defined by the social environment (relationships and interactions with others), which is the most vulnerable of the three types of self as one's social identity depends on the recognition, reaction and treatment from others. For example, negative attitudes from others (e.g. burdensome or defective) lead to people living with dementia experiencing a loss of self or social identity, which is not due to neurological changes but the social environment. Evidence of negative attitudes from others towards dementia is presented in the section above detailing media depictions, and the selfhood model importantly provides a link to how these attitudes may exacerbate the negative experiences of dementia.

Historically it was assumed that people living with dementia lacked selfhood or awareness (Burgener & Berger, 2008; Sabat, 1994; Sabat, 2002). As mentioned previously, dementia has a lengthy disease course where many individuals can spend a number of years in the early or mild stages, during which there is awareness of symptomatic impact (e.g. the changes occurring and in and around a person) and the attitudes of others (Burgener & Berger, 2008). Awareness as well as the length of the disease process in dementia makes individuals vulnerable to the negative attitudes of others over elongated periods,

with the risk of negatively affecting the way people living with dementia see themselves (Burgener & Berger, 2008; Sabat, 1994; Sabat, 2002).

In summary, The selfhood perspective posits that clinical manifestations of dementia are attributed to others seeing the limitations (e.g. deficit or disease attributes) rather than retained abilities of individuals, causing anger or frustration in the person living with dementia, otherwise described as the excess disability of dementia (Sabat, 1994; Sabat, 2002) as previously noted in the Disability Rights perspective.

### ***1.3.5 Illness Representation***

The selfhood explanation overlooks the way in which people living with dementia self-regulate representations of the diagnosis (e.g. dementia as an illness) and the consequences this may have for the clinical manifestation of dementia (e.g. lower mood; Clare, Quinn, Jones, & Woods, 2016). Additionally, the selfhood explanation of dementia focusses on social context but does not explicitly outline the psychological construction (e.g. internal cognitive processes) of attitudes people living with dementia may develop towards themselves.

Moving beyond the selfhood explanation, illness representations of dementia through the lens of self-regulation (Diefenbach & Leventhal, 1996), can be used to understand how attitudes towards dementia (illness representations) held by people living with the syndrome can shape clinical manifestation (Clare, Goater, & Woods, 2006; Clare et al., 2016; Quinn, Jones, & Clare, 2017). The self-regulatory model can be used to understand how individuals make sense of dementia and develop new or build on existing beliefs about health and illness

(Clare et al., 2006). The way in which people living with dementia represented dementia led to differences in self-regulation such as the ability to evaluate their own memory problems, mood and awareness of performance or functioning (Clare et al., 2016). Participants who viewed dementia as an “illness”, used medical language to describe dementia, were able to accurately appraise their own cognition, had higher meta-cognitive awareness and greater perceived practical consequences such as lowered mood (Clare et al., 2016). It is important to note that the aforementioned study had a cross-sectional design and for this reason, causality cannot be inferred. Yet findings suggest that people living with dementia who self-represent their diagnostic label through the lens of illness harbour greater levels of awareness that is linked to greater consequences of the disease label such as lowered mood. This has implications for how people living with dementia may frame their abilities and **position in society as a result of experiencing greater practical challenges.**

### **1.4 Well-being in Dementia**

In the previous section, different models along with their implications for attitudes towards dementia were presented. In the same way that clinical manifestations of dementia may be affected by factors beyond physical brain changes, well-being in dementia can be attributed to factors other than neurodegeneration or cognitive impairment. In the rest of this section, I shall summarise perspectives that separate well-being from cognitive impairment in people living with dementia, followed by the consequences of receiving a diagnosis of dementia on well-being. This thesis as a whole will aim to draw on conceptualisations that provide an opportunity to improve the well-being of people living with dementia and carers.

### *1.4.1 Attributions of Well-being*

In the medical model, the well-being of people living with dementia and carers is linked intrinsically to neurodegeneration for which there is no cure, leaving little regard for the active role an individual with dementia plays in society (G. J. Mitchell, Dupuis, Kontos, & Mitchell, 2013). A medical perspective alone, therefore, cannot explain findings from psychosocial research that speaks to people living with dementia playing active roles in society, with the ability to sustain identity, meaningfully participate and improve well-being (Birt, Poland, Csipke, & Charlesworth, 2017; Higgs & Gilleard, 2017). In a key shift away from pathologising the individual with dementia, Kitwood (1993a, 1993b) proposed that individuals with dementia were aware and responsive to their surroundings and factors separable from cognitive impairment negatively affected the well-being of a person living with dementia (Kitwood, 1993b). Psychosocial tractable factors such as mental stimulation, reaction to life events, mood, social and personal psychology and environment, are of particular interest in this thesis as they can be targeted as part of psychosocial interventions to improve the well-being of people living with dementia, even when the underlying pathology remains unchanged (Spector & Orrell, 2010).

The Disability Rights Movement can be used to understand how well-being in people living with dementia is negatively affected. More specifically, if a person living with dementia is surrounded by negative societal attitudes (exacerbated by media depictions), their rights, provisions and protections may be denied thus causing excess disability not attributable to the underlying neurological cause (Gilliard et al., 2005; Gove et al., 2019). Fearful attitudes towards dementia increase negative social behaviours, such as avoidance by

others, which lead to reductions in well-being as people living with dementia feel rejected and withdraw from unaccommodating social environments (Burgener & Berger, 2008). Furthermore, a reduced sense of well-being may also be maintained in dementia through the loss of one's social identity which, again, might occur as the result of unaccommodating social contexts in which the person living with dementia may experience excess disability.

### ***1.4.2 Receiving a Diagnosis of Dementia***

A sanctioned labelling system, otherwise known as the process through which one receives a diagnosis of dementia, initiates the social processes of labelling where negative attitudes compromise the well-being of people living with dementia. There are benefits to early and timely diagnoses that I have discussed previously in this Chapter. This section will now explore the unintended consequences of increased diagnostic rates in the UK and how clinicians share diagnoses of dementia and implications for the well-being of people affected by dementia.

#### **1.4.2.1 Rationale for Early and Timely Diagnoses**

In an attempt to achieve increased diagnostic rates with limited staff and resources to carry out continued post-diagnostic support, an unintended and complex issue emerged whereby many received a diagnosis of dementia with little scope for individualistic and tailored support (British Psychological Society, 2014). This complex issue of continuing support for people living with dementia raised concerns around the benefits of early and timely diagnosis in the absence of sufficient uptake of post-diagnostic support (Alzheimer's Society, 2012; Manthorpe, 2011, Iliffe & Manthorpe 2010; National Audit Office, 2007).

The benefits of early diagnosis of dementia have been argued to be limited for several reasons. For example, dementia is untreatable and post-diagnostic options may be limited (Fox et al., 2014), early diagnosis has no positive medical or therapeutic consequences (Kaduszkiewicz, Bachmann et al., 2008; Kaduszkiewicz, Wiese et al., 2008) and an increased number of people living with dementia place a burden on resources with limited positive outcomes (Pathak & Montgomery, 2015).

### **1.4.2.2 Clinicians sharing the diagnosis**

Historically, people who were diagnosed with dementia were not always told their diagnosis by clinicians. This may be because a diagnosis was typically made when individuals were at the later stages with higher cognitive impairment at the point of presenting to clinicians and that disclosure was deemed by clinicians as too distressing (Husband, 2000). Another explanation was that a diagnosis of dementia often symbolised the end rather than the beginning of an individual's journey to accessing health and social care support (Kitwood, 1993a). During this time, the dementia care pathway was sparsely populated with provision therefore rendering diagnosed individuals and their families lacking in service support and hope (Kitwood, 1993a). Historically, the conceptualisation of dementia as a medical problem left individuals at the periphery of their own care, due to the assumption that people with dementia lacked the capacity to make informed and meaningful decisions about their healthcare once diagnosed.

It was not until recently that the British Psychological Society published a series of four papers in the *Clinical Psychology in Early Stage Dementia Care Pathway* publication outlining good practice guidance for clinicians when disclosing a diagnosis (British Psychological Society, 2014). The guidance



outlined recommendations on how to share a diagnosis, including pre-diagnostic counselling where appropriate, so that the future engagement of post-diagnostic support could be maximised. Sharing a diagnosis of dementia called for clinicians to consider an individual's personality, coping style and attitudes towards dementia, which translated into clinicians performing thorough assessments, considering family involvement and responding to patients in terms of their perspectives and their anticipated reaction to receiving a diagnosis of dementia (British Psychological Society, 2014).

In a systematic review based on 25 quantitative and 21 qualitative studies published before September 2016, 34.2% - 48.3% of GPs or specialists disclosed a diagnosis of dementia directly to the person living with dementia, while 89% - 97% routinely disclosed a diagnosis with a carer present (Low et al., 2019). Clinicians were more likely to use euphemisms ("cognitive problems", "confusion", "slowing down due to ageing"; p2885) rather than medical language ("dementia", "Alzheimer's disease"; p2885; Low et al., 2019). In addition, clinicians were more likely to endorse barriers (e.g. social stigma, reducing hope, psychological distress) as opposed to facilitators (e.g. person's right to know, allow for planning) for communicating the diagnosis, with the awareness of a person living with dementia increasing the likelihood of disclosure by clinicians. There was also a range of other factors that influenced clinicians' decisions to directly share a diagnosis of dementia, such as patient circumstances, (awareness, familial support), benefits to clinicians (treatment efficacy, confidence in communication), health and social care (availability of services), and cultural aspects (attitudes towards dementia in the community, psychological distress of labelling; Low et al., 2019)

The current strategies for diagnostic delivery do not fully acknowledge how the negative attitudes associated with the label of dementia affect the way people share the diagnosis with their social networks. Now that the process and standards of delivering a diagnosis have been outlined, it is necessary to understand the consequences of receiving a diagnosis of dementia.

### **1.4.2.3 Consequences of Receiving a Diagnosis on Well-being**

In a systematic review of 59 studies, Bamford and colleagues found inconsistencies in the approach to medical professionals telling people living with dementia and their carers about a diagnosis (Bamford et al., 2004). Findings indicated that people living with dementia experienced increased anxiety, negative effects on self-esteem, hypervigilance or preoccupation with the diagnosis and a crisis period following being told the diagnosis. Clinicians were also criticised for not dealing with recipients' emotional reactions when delivering a diagnosis of dementia as well as providing insufficient information about the diagnosis and post-diagnostic opportunities (Bamford et al., 2004).

However, positive effects of receiving a diagnosis were also reported, such as ending uncertainty, greater understanding of one's problems and avenues of support, an opportunity to develop positive coping strategies and, by doing so, the opportunity to effectively plan for the future. Carers, similar to clinicians, have found it difficult to have discussions about the diagnosis with people living with dementia, however getting a diagnosis meant that carers were also better able to access the relevant support for themselves (Bamford et al., 2004).

A systematically overlooked consequence of the recent policy drive to increase diagnosis is the also increasing levels of negative attitudes towards

dementia felt by many of those who are labelled in numbers greater than before, giving rise to ill-being in people affected by dementia without any support provided on how to share the diagnosis with others in one's social network. As discussed above, devaluation and ill-being can begin to manifest from the point of diagnosis, yet little acknowledgement is given for how this impacts the way people affected by dementia share the diagnosis.

### **1.5 Rationale and Aims for this Thesis**

Different perspectives attribute dementia differently, and, where attributes are of discreditation, the attitudes associated with dementia are negative and have consequences for the well-being of people living with dementia. Attitudes consist of affective, cognitive and behavioural components. However, the role of society, social processes and relationships and power are not included in the definition of attitudes, speaking to the limitations of aforementioned perspectives (Stedman, 2002). Attitudes are interwoven and embedded in complex social processes and relationships, this coupled with the limited use of biological explanations in understanding well-being in dementia, highlights the value of psychological and psychosocial factors that can not only be influential but tractable. The limitations of attitudinal research presented earlier in this Chapter lays the foundation for the work of this thesis. The medicalisation and fear of dementia discussed in Chapter 1 has led to negative societal attitudes towards people living with dementia and their families. Negative societal attitudes will be now explored as one part of a larger and more complex psychosocial phenomenon, namely, stigma. There is a considerable body of work on the stigma experience in relation to mental health problems (Corrigan, Larson, & Rüsch, 2009; Roe, Lysaker, & Yanos, 2011; Thornicroft, Rose, Kassam, & Sartorius, 2007), HIV/AIDS and sexuality (Bekalu

& Eggermont, 2015; Brouard & Wills, 2006; Frye et al., 2019; Herek, 2014; Parker & Aggleton, 2003; Schrimshaw, Downing, & Cohn, 2016). However, the application of ‘stigma’ conceptualisations in dementia has been understudied. The study of attitudes does not encapsulate the issues of power and psychological and social processes, therefore the concept of stigma will now be used instead of attitudes.

Aligned to the shift of dementia discourses from medical to psychosocial, the introduction of person-centred care placed people affected by dementia at the centre of their care. This includes the consensus in the health service that people living with dementia should be told their diagnosis by clinicians. There is training and support for clinicians on how to sensitively deliver a diagnosis of dementia and deal with potential reactions (British Psychological Society, 2014). However, as reviewed in the previous section, although guidelines are available for clinicians who shared diagnoses of dementia with patients and carers, inconsistencies in practice remain.

People living with dementia and carers do not have the same support as clinicians, and interventions and guidance on how people share their diagnosis with others remains an understudied area. Telling others about a diagnosis of dementia or associated difficulties presents serious challenges, and is often avoided through secrecy and concealment whilst symptoms can be hidden in early to mild stages (Alzheimer’s Disease International, 2019). People living with dementia and their families are not given any training or support on how to tell others within their social network (e.g. family, friends, and neighbours), and the intended benefits of a timely diagnosis may therefore not transfer to timely social

support. Negative attitudes towards dementia previously covered within this Chapter can further contribute to complexities when sharing a diagnosis.

Dementia can to an extent be a concealable diagnosis in the early to mild stages, and therefore individuals wishing to tell others have a series of decisions to make about disclosure such as, who, how and when to tell others about a diagnosis. Knowing and being able to talk about one's diagnosis can empower people to access services and support, to plan for the future, or become activists or advocates (Department of Health, 2015). On the other hand, many individuals in the early stages, whose symptoms are mild, worry about telling others, and how and when to do so (O'Connor et al., 2018).

The capacity for people living with dementia to maintain daily obligations and fulfil their potential (concept of social health; Huber et al., 2011) is influenced by social factors, such as the presence or absence of a social network. The Social Health Taskforce of a pan-European research network for timely and quality psychosocial interventions in dementia (INTERDEM) suggested focusing interventions around decision-making to protect and promote the competencies and rights of people living with dementia. (Dröes, Chattat, et al., 2017). A recent INTERDEM manifesto called for the development of psychosocial interventions to promote dignity and autonomy through enhancing social integration for people living with dementia and their families. (Vernooij-dassen et al., 2019). An example of such would be a decision-making intervention that seeks to empower people in reaching decisions about disclosing a diagnosis of dementia, however, interventions of this nature are not included in current service provisions.

### ***1.5.1 Aims of the Thesis***

In accordance with National Policy, dementia in the UK is being diagnosed earlier in the course of neurological decline than was once the case, and there are initiatives in place to enhance dementia awareness with the aim to reduce negative societal attitudes. However, prevailing attitudes towards dementia remain negative and some people with dementia and their carers avoid social contact or mask symptoms in order to keep the condition a secret. Social withdrawal and isolation hamper the ability to remain cognitively, socially and physically active, with associated adverse consequences for well-being. The aim of this thesis is to better understand the motivations for diagnostic secrecy and the barriers to disclosure. Literature on stigma, decision-making and stigma reduction will be reviewed, and measures of dementia-related stigma will be developed. The development and preliminary evaluation of an empowerment intervention will be described, considering both feasibility, acceptability and implementation.

This thesis is organised into three sections, each with two chapters, followed by a general discussion and conclusions. The first section provides detailed reviews of stigma (Chapter 2) and decision-making in dementia (Chapter 3). Chapter 2 is a conceptual review of stigma models and their application to dementia, followed by a selective review of approaches to stigma reduction. Chapter 3 is a systematic review of decision-making in dementia, followed by an overview of disclosure-decision making models and their potential application to dementia. The second section of the thesis describes measures developed to assess stigma, with psychometric explorations of tools for use with people with dementia (Chapter 4) and family carers (Chapter 5). The third section of the thesis covers the development and evaluation of a brief intervention to empower people

affected by dementia who are fearful or worried about disclosing the diagnosis to others. Intervention development issues are covered in Chapter 6, with a qualitative evaluation described in Chapter 7.

## **2 Stereotyping, Prejudice and Discrimination: the Stigma of Dementia**

Understanding dementia-related stigma has become a global priority (Alzheimer's Disease International, 2019) yet, in the field of dementia, the term 'stigma' is under-defined (Livingston & Boyd, 2010; Nguyen & Li, 2018) and there is no established model of dementia-related stigma. I start this Chapter by outlining the historic context of stigma in the social sciences before providing definitions of stigma used in contemporary research. Following this, I summarise theories and frameworks of stigma alongside dementia-related stigma literature. Finally, I present an overview of stigma reduction initiatives and interventions in dementia.

### **2.1 Stigma: A brief history**

In ancient Greece, the word *Stigma* described a physical mark, cut or burn inflicted upon the human body. This mark denoted poor moral status to one's identity (e.g. a person who was a criminal or slave) and alerted society to avoid the person. Although many parts of the world have moved on from burning or cutting marks into those who are of low *moral status*, the concept of stigma still exists in the absence of a physical mark. Goffman (1963) has been the foundation for most contemporary stigma literature.

In the social sciences, evolutionary and social psychologists posit that the stigma process arises from the human need to survive (Major & O'Brien, 2005; Neuberg, Smith, & Asher, 2000) and controlling the social environment is one way through which survival is assured. Social environments are controlled through the exclusion of others who may be different from the rest of the group.



This process of exclusion allows group members to assume preferential social statuses that ultimately allow individuals within a group to stigmatise others.

### **2.2 Defining and Categorising Stigma**

The term ‘stigma’ in relation to dementia is often overused. Dementia is referred to as being a stigmatised condition, but the type of stigma is not typically defined. The resulting narrative may not communicate the complexities of stigma across contexts and levels (individual, interpersonal, public, and institutional). Definitional issues exist in stigma literature where several stigma terms are used interchangeably even though they may not mean the same thing. A lack of definitional specificity can cause critical issues in the operationalisation of stigma constructs and the way in which the social sciences conceptualise dementia through the lens of stigma.

Commonly used terms in stigma research are presented in Table 2.1 adapted from Pescosolido & Martin, (2015). Table 2.1 is not an attempt to synthesise or summarise definitions across disciplines or various research designs, rather it aims to provide an overview of types of stigma and the consequences that have been studied. Drawing from the basic concepts of stigma outlined in Table 2.1, the concepts of public stigma, self-stigma, courtesy stigma and affiliate stigma are all of relevance to this thesis, and are defined below.

Table 2.1.

*Theoretical building blocks of stigma research adapted from Pescosolido and Martin (2015)*

Basic concepts Stigma	
Stigma	A deeply discrediting attribute; “mark of shame”; “mark of oppression”; resulting in a devalued social identity
Stigmatisation	A social process embedded in social relationships that devalues through conferring labels and stereotyping
Labels	Officially sanctioned terms applied to conditions, individuals, groups, places, organisations, institutions, or other social entities
Stereotypes	Beliefs and attitudes assigned to labelled social entities
Prejudice	Endorsement of negative beliefs and attitudes inherent in negative stereotypes
Discrimination	Behaviours that act to endorse and reinforce negative stereotypes, and disadvantage those labelled
Stigma characteristics	
Physical	Of the body, e.g., physical disabilities
Character	Indicating moral weakness, e.g., criminal, mental health problems
Status	A position in society; often used with ascribed characteristics, e.g., race/ethnicity
Discredited	Already known or immediately evident; “marks” that are visible or not concealable
Discreditable	Neither known nor immediately perceivable; “marks” that are invisible or concealable
Target variants	
Self-stigma	Internalised acceptance of stereotypes and prejudice
Courtesy stigma	Stereotypes, prejudice, and discrimination by association with marked groups
Public stigma	Stereotypes, prejudice, and discrimination endorsed by the general population
Provider-based stigma	Prejudice and discrimination voiced or exercised, consciously or unconsciously, by occupational groups designated to provide assistance to stigmatised groups
Structural stigma	Prejudice and discrimination by policies, laws, and constitutional practice; also called institutionalised stigma

### **2.2.1 Public Stigma**

The term ‘public stigma’ refers to the way in which lay persons react towards a stigmatised group of people, and has been found to be one of the primary experiences of people affected by dementia (Werner, Mittelman, Goldstein, & Heinik, 2011). It is generally agreed upon in stigma research that public stigma consists of the endorsement of negative attitudes or beliefs by members of the general public which manifest as behavioural acts of discrimination (Corrigan & Watson, 2002; Werner, 2012). To optimise the definition of public stigma, Pescosolido and Martin (2015) added the following dimensions:

- Social distance: desire to be detached from stigmatised individuals
- Traditional prejudice: unfavourable judgements towards stigmatised individuals
- Exclusionary sentiments: excluding stigmatised individuals from social roles
- Negative affect: anticipating negative emotional reactions from being around stigmatised individuals
- Treatment carryover: those who are in treatment for a stigmatised condition are of a reduced status
- Disclosure carryover: telling others about a stigmatised diagnosis produces negative societal responses
- Perceptions of dangerousness: fear that stigmatised individuals are violent

### **2.2.2 *Self-Stigma***

The concept of ‘self-stigma’ is defined as a cognitive process where an individual internalises negative stereotypes and prejudice related to their stigmatised identity (Corrigan & Watson, 2002). Based on mental health, homosexuality and HIV/AIDS literature, self-stigma may lead to reduced self-esteem (Corrigan & Watson, 2002; Rüsçh et al., 2014; Yang et al., 2013), disempowerment (Brouard & Wills, 2006; Corrigan & Watson, 2002), and experiences of anxiety and depression (Livingston & Boyd, 2010; Pachankis, 2007). Self-stigma is also referred to as internalised stigma and these terms will be used interchangeably throughout this thesis.

### **2.2.3 *Courtesy and Affiliate Stigma***

Courtesy stigma is defined as the stigma experienced because of being associated with a stigmatised individual, It is also referred to as ‘stigma by association’ (Ostman & Kjellin, 2002). Although individuals do not have the stigmatising characteristic or ‘mark’, they may care for, live with, work with or share proximity with someone who possesses a stigmatised identity (Pescosolido & Martin, 2015). Affiliate stigma is the internalisation (cognitive, affective and behavioural consequence) of courtesy stigma by those who are associated to someone with a stigmatised identity (Mitter, Ali, & Scior, 2018). There are definitional challenges in this area. For example, the term ‘family stigma’ has been used to refer to the combination of courtesy and affiliate stigma (Mitter et al., 2018). However, some literature has used the term family stigma to describe courtesy stigma only (Werner, Goldstein, & Buchbinder, 2010). The term family stigma for this reason will not be used in this thesis. Courtesy and affiliate stigma are explored further in Chapter 5.

## **2.3 Theories and Frameworks of Stigma**

There are no theories or frameworks to explain the initiation and maintenance of dementia-related stigma. This may explain why the limited empirical work that has been carried out is not theoretically grounded (Herrmann et al., 2018). Although this is the case, theories and frameworks from other populations such as mental health do have relevant aspects that can help to understand dementia-related stigma. In this section, I present four models and frameworks that aid the understanding of the initiation and maintenance of stigma in dementia.

### **2.3.1 *Modified Labelling Theory***

Advancing Goffman's work Link et al. (1989) introduced the Modified Labelling Theory, according to which stigma is initiated and maintained through three stages. Firstly, 'routine socialisation' where one develops conceptualisations of a 'mark'. Secondly, the development of a 'lay theory' so one can determine what it is like to have a 'mark'. Thirdly, 'expectation formation', which one uses to regulate behaviour in situations where this 'mark' is encountered.

Later work by Link and Phelan (2001), examined the social construction of stigma and emphasised the role of social power in the process of stigmatisation which goes beyond appraisal and includes status loss and discrimination. According to Link and Phelan (2001), stigma is the consequence of five components converging to create one overall stigma process. I will now outline these five components.

#### **2.3.1.1 Distinguishing and Labelling Differences**

The first component of the stigma process is the procedure of social selection, which leads to identifying and labelling human differences. This begins with oversimplification and results in the creation of groups (Link & Phelan, 2001). For example, skin colour is often assigned two overly simplified categories or labels such as ‘black’ and ‘white’, even though these labels have large degrees of variance within each and have no concrete boundaries. In addition, the social selection of human differences is performed in the context of time and place based on the salience of a label. For example, memory loss was commonly thought of as a part of normal ageing, but it is now a much more salient indicator of the label of dementia.

### **2.3.1.2 Associating Human Differences to Negative Attributes**

Once created, labels are linked to a set of undesirable characteristics that go on to form negative stereotypes. For example, in the case of mental health, many believe that patients with mental health problems are a risk to others around them. This can lead to the established stereotype of dangerousness being linked to the label of ‘mental health patient’ (Link & Phelan, 2001).

Human differences observed in people living with dementia have built the foundation for negative stereotypes. For example, the zombie metaphor has been used where the undesirable characteristics of the label ‘living with dementia’ are framed as death-like and include a loss of self, being an empty shell and the mind dying (Young, Lind, Orange, & Savundranayagam, 2019).

### **2.3.1.3 Separating “Us” From “Them”**

The third component of the stigma process describes how social labels are used in an effort to promote the separation of “us” from “them”. This effort can be seen easily from the nature of labels themselves and the language used (Link &

Phelan, 2001). For example, someone *is* schizophrenic and therefore not one of “us”, in contrast, when someone *has* cancer, they are still one of “us” but they happen to be affected by a serious health condition. Language used to describe people living with dementia such as “demented, sufferers, subjects, victims and not all there” (Swaffer, 2014, p.711) can be seen as an effort to promote the separation of “us” from “them”.

### **2.3.1.4 Status Loss and Discrimination**

The fourth component of the stigma process brings together components one to three where individuals are labelled, linked to undesirable characteristics and are set apart, leading to devaluation and exclusion (Link & Phelan, 2001). Status loss is the lowering of a person’s placement in the status hierarchy and discrimination (individual and institutional) is the behavioural reaction to the person’s label, undesirable characteristics and stereotypes (Link & Phelan, 2001).

Discrimination in the form of unfair treatment from others has been experienced in people living with dementia globally across domains such as social life, finances, housing, healthcare, intimate relationships, making or keeping friends and unfair treatment by children or family (Alzheimer’s Disease International, 2019).

### **2.3.1.5 Stigma Depends on Power**

The fifth component of the stigma process is power. Access to power allows the separation of individuals through the construction and application of stereotypes and the behavioural acts of disapproval, exclusion and rejection (Link & Phelan, 2001). Therefore, the existence of salient labels, undesirable characteristics and negative stereotypes alone do not result in stigmatisation. Instead, there must be a power imbalance for stigmatisation to be ‘felt’ by an

individual and initiated by society (Link & Phelan, 2001). Cognitive abilities are highly valued in contemporary societies and, as dementia is characterised by cognitive impairment over time, people living with dementia experience a loss of status and social capital and consequently a loss of power (Jones, 2017).

### **2.3.1.6 Modified Labelling Theory and Dementia**

Collectively, there is evidence to suggest the components of stigma outlined in the Modified Labelling Theory can explain stigma in dementia. Although the Modified Labelling Theory is a sociological explanation, Link and Phelan (2001) acknowledge that the stigma process is a psychosocial one, where individuals who build a lay theory through the above outlined components may well apply such lay theory inwards if one were to acquire an undesirable characteristic. The application of a lay theory inwards, otherwise known as self-stigma, is acknowledged by Link and Phelan (2001) to have serious negative consequences even in the absence of overt discrimination (e.g. fearing rejection as a lay theory suggests mental health patients are rejected by society). Link and Phelan (2001) acknowledge the notion of self-stigma but do not explore the underlying cognitive processes that may cause a labelled individual internal harm.

### **2.3.2 *Stereotypes, Prejudice and Discrimination (SPD) Framework***

The SPD framework developed by Corrigan and Colleagues has been the foundation for the majority of contemporary stigma research in mental health and dementia (Nguyen & Li, 2018; Thornicroft et al., 2016). Public and self-stigma are explained through three cognitive-behavioural levels in this framework (Corrigan & Watson, 2002; Corrigan, Kerr, & Knudsen, 2005; Figure 2.1 ): (1) stereotypes – consisting in this case of negative beliefs towards a group of people; (2) prejudice – emotional responses generated as a result of stereotypes; and (3)



discrimination – the behavioural manifestation of prejudice.

Figure 2.1.

*Stereotype, Prejudice and Discrimination Framework adapted from Corrigan et al., 2005; Corrigan & Watson, 2002*

Public Stigma	Levels	Self-Stigma
Negative belief about a group (e.g., dangerousness, incompetence)	Stereotype	Negative belief about the self (e.g., weakness, incompetence)
Agreement with the belief and/or negative emotional reaction (e.g., anger, fear)	Prejudice	Agreement with the belief, negative emotional reaction to themselves (e.g., upset, self-distrust)
Behavioural manifestation of prejudice (e.g., avoidance, help-withholding)	Discrimination	Behavioural response to prejudice (e.g., self-isolation)

### 2.3.2.1 SPD Framework: Public Stigma

In public stigma, an example of stereotypes, prejudice and discrimination in practice could be: (1) “I believe people with dementia are unpredictable”, (2) “all people with dementia make me feel uneasy”, and (3) “I always avoid people with dementia”. Strategies to reduce public stigma range from media campaigns, protest strategies, educational approaches such as flyers or videos targeting stereotypes, and reducing stigma through interpersonal contact with members of a stigmatised group (Corrigan et al., 2005). In mental health, education as a stigma reduction strategy has been found to produce short-term improvements in attitudes; however, participants with greater prejudice were less likely to benefit from educational materials (Corrigan et al., 2005). Contact with members of stigmatised groups yielded the most promising findings in mental health studies

but this was dependent on how strongly a layperson conformed to negative stereotypes (Corrigan et al., 2005).

The SPD Framework has been the most widely used to investigate public stigma in dementia through the use of vignette and questionnaire methodologies (Berwald, Roche, Adelman, Mukadam, & Livingston, 2016; Cheng et al., 2011; Cohen et al., 2009; Johnson, Harkins, Cary, Sankar, & Karlawish, 2015; O'Connor & McFadden, 2012; Wadley & Haley, 2001; Werner, 2005; Werner & Davidson, 2004; Werner & Werner, 2008). There are conflicting findings in dementia literature; in some research, negative stereotypes are associated with prejudice and discriminatory behaviours (Woo, 2017) but this is not always the case (Blay & Peluso, 2010; Johnson et al., 2015; Wadley & Haley, 2001).

Quantitative findings are consistent with the notion that dementia is associated with negative beliefs (Blay & Peluso, 2010; Woo, 2017), in that stereotypes of dementia are embedded in greater accessibility to death-related thoughts and lower levels of competence (O'Connor & McFadden, 2012). Qualitative work on dementia-related public stigma has found that participants often reported little knowledge of dementia yet still expressed dementia stereotypes that caused negative consequences. For example, a case vignette study in Black African and Caribbean communities of people without dementia found that dementia was stereotypically seen as a “white person’s illness” and help seeking was deferred as a result of the perceptions within Black African and Caribbean communities associated with having a diagnosis dementia (Berwald et al., 2016).

Based on the SPD framework, negative stereotypes consistently leading to negative discriminatory behaviours has been disputed by recent findings, where it is suggested that, even in the presence of negative stereotypes, the consequent feelings and behaviour are not always discriminatory. In a healthy population, greater prosocial behaviours (desire to help, be friendly) were exhibited towards people living with dementia, even though dementia was associated with negative beliefs (Blay & Peluso, 2010).

Wadley and Haley (2001) tested 221 undergraduate students using vignettes portraying a parent exhibiting socially inappropriate behaviours with a diagnostic label of either Alzheimer's disease, major depression or no label. Participants were asked to rate their emotions, attributions and willingness to help after reading each vignette. The vignettes of Alzheimer's disease produced greater levels of sympathy and willingness to help and reduced sense of blame towards the parent for their behaviour (Wadley & Haley, 2001). Similarly, another vignette study found that the label of Alzheimer's disease was not associated with stigmatising attitudes or attributions but the idea of disease progression resulted in higher stigmatisation (Johnson et al., 2015). This may lead to the conclusion that people living with dementia are not directly stigmatised but the idea of the diagnosis (the diagnostic label), disease progression and death-related concepts are.

Another point of contention for the application of the SPD Framework to dementia is the transference of public stigma reduction strategies. As suggested within the SPD Framework, education may be a key strategy in reducing public stigma (Corrigan et al., 2005). In a survey conducted on visitors to the 'People of

Dementia' blog, 79% of respondents agreed that they had a better understanding of dementia after reading the blog and 60% of respondents felt more comfortable around someone living with dementia (Harper, Dobbs, & Buckwalter, 2018). No measure of public stigma was taken from readers of the blog, therefore it is difficult to ascertain whether increased knowledge of dementia did lead to reduced stigmatisation, yet the evidence suggests increases social comfort around people living with dementia. In addition, Corrigan et al. (2005) suggest that the reduction in stigmatisation depends on the strength of an individual's prejudice and discrimination initially; Harper and Colleagues did also not measure this.

Corrigan et al. (2005) suggested that interpersonal contact with stigmatised individuals may reduce public stigma, however, findings around contact reducing stigmatisation in dementia are conflicting. In one study, those with a family history of dementia in comparison to those without, believed that people living with dementia are incapable of feeling the worries or concerns of others (Woo, 2017). Familiarity with dementia therefore, does not necessarily reduce stigmatising beliefs, contrary to the claims and efforts made by awareness raising campaigns. Findings from Woo (2017) must be interpreted with caution as the statistical analysis performed to compare those with and without a family history of dementia did not correct for multiple comparisons leaving room for type II error.

A recent systematic review synthesised evidence from 51 empirical papers investigating dementia-related stigma and concluded that stigmatising beliefs and behaviours are more prominent in populations who have little knowledge of dementia or contact with people living with dementia (Herrmann et al., 2018).

Although, Herrmann and colleagues also found that health-workers in the field of dementia (those who have a large amount of contact with people living with dementia), held stigmatising beliefs towards people living with dementia, which speaks against education and interpersonal contact with stigmatised individuals as a strategy to reduce stigma. Similarly, Nguyen & Li (2018) found two empirical papers concluding that the competence of healthcare professionals is affected when caring for someone living with dementia as a result of structural stigmatisation, for instance providing insufficient information and poor service delivery.

Collectively, it is possible that education and interpersonal contact are effective in reducing the stigma of mental health but not dementia, where increased contact with people with dementia may be associated with experiencing burden or it may result in more negative beliefs and behaviours. The theorised stigma-reducing role of contact, therefore, is not universal and cannot be assumed to have a similar effect across stigmatised populations.

### **2.3.2.2 SPD Framework: Self-Stigma**

An example of stereotypes, prejudice and discrimination in self-stigma, where an individual has internalised public stigma towards dementia, in practice could be: (1) *“Because I have dementia I am unpredictable”*; (2) *“I don’t trust myself to be around others”* and (3) *“I avoid being in social situations entirely”*. In mental health, strategies for reducing self-stigma have included educational programmes in which participants are encouraged to dispute and challenge negative stereotypes of mental health and approaches incorporating cognitive-behavioural therapy where self-stigma thoughts are framed as irrational (Corrigan, Kosyluk, & Rüsçh, 2013).

According to a recent review by Nguyen & Li, (2018), there were seven studies of self-stigma in dementia that are relevant to the SPD Framework. All seven papers were qualitative, and explored the three levels of stigma (stereotypes, prejudice and discrimination) outlined by Corrigan and colleagues (Devlin et al., 2006; Harris & Caporella, 2014; Morgan, Semchuk, Stewart, & D’Arcy, 2002; O’Sullivan, Hocking, & Spence, 2014; Peel, 2014; Walmsley & McCormack, 2016; Werner et al., 2010).

People living with dementia and carers felt that dementia-related negative images and emotions were predominantly death-related and focussed on the severe stages of dementia resulting in participants feeling isolated, and uncomfortable discussing the diagnosis within their social networks (Devlin et al., 2006; Harris & Caporella, 2014). People living with dementia felt frustration, anger, grief and fear due to patronising attitudes, promoting the stereotype that people living with dementia lack competence. Again this led to diagnostic secrecy, withdrawal from daily activities and an increase in depressive symptoms (O’Sullivan et al., 2014). From the perspective of healthcare professionals, a diagnostic label of dementia was associated with hurtful feelings of shame and embarrassment seen from family carers of people living with dementia (Walmsley & McCormack, 2016). Self-stigma was found to have lasting negative consequences for people living with dementia such as withdrawal from everyday activities or interactions, delays in help-seeking, loss of confidence or feeling inferior (Devlin et al., 2006; Morgan et al., 2002; O’Sullivan et al., 2014; Walmsley & McCormack, 2016; Werner et al., 2010).

Four of the seven qualitative studies exploring self-stigma in dementia

connected the stereotypes and prejudice experienced internally by people living with dementia and carers to the need for keeping the diagnosis a secret from their social network including family and friends (Berwald et al., 2016; Harris & Caporella, 2014; Morgan et al., 2002; O'Sullivan et al., 2014).

### **2.3.2.3 SPD Framework and Dementia**

The literature I have cited in the above sections provides evidence of public and self-stigma from the perspective of the three levels outlined in the SPD Framework, where stereotypes initiate prejudices leading to inward discrimination (e.g. secrecy about diagnosis), however, there are drawbacks to applying this framework that I will now consider.

Corrigan and colleagues do not acknowledge the consequences for individuals who carry more than one stigmatising mark. I have noted that Black African and Caribbean individuals are more likely to be secretive about symptoms as public stigma in these communities towards dementia is rife; this is compounded by the experience of persistent barriers to help seeking in the Health Service (e.g. dismissive GPs or unfair treatment by health professionals) due to systemic racism (Berwald et al., 2016; Myrie & Gannon, 2013). Therefore, not only is dementia stigmatised by the public but also specific characteristics (e.g. race) can create added layers of stigmatisation. Keeping with this, dementia related-stigma is heavily compounded by age-related fears and ageism, where dementia has been described as a stigma double-jeopardy (Birt et al., 2017).

If the building blocks of stigmatisation are dependent on stereotypes both in public and self-stigma contexts, it is important to acknowledge that negative stereotypes associated with given labels may be different. For example, unlike

stereotypes of mental health difficulties, those with a diagnosis of dementia are perceived to be less dangerous to society and more a danger to themselves (Cohen et al., 2009).

Furthermore, whilst the stereotype-prejudice and discrimination framework is the most widely used to explain stigma in health conditions (Corrigan et al., 2005; Nguyen & Li, 2018), not all ethnic groups share the same stereotypes of dementia (Cipriani & Borin, 2015). In a recent systematic review on the sociocultural climate of dementia-related stigma, Cipriani and Borin (2015) concluded that sociocultural conceptualisations of dementia shape the way in which symptoms are interpreted and dealt with. Whilst dementia in the Western world is seen as devastating, other parts of the world do not describe dementia like this. Differing from the Western conceptualisation of dementia that is based on a biomedical model of disease, in some Chinese communities dementia is interpreted as an imbalance between opposing forms of energy (Yeo & Thompson, 2014). If the basic conceptualisations of dementia differ across sociocultural contexts, stereotypes of dementia cannot be assumed universal and the “stigma” that is produced may therefore look very different.

### ***2.3.3 The Framework Integrating Normative Influence on Stigma (FINIS)***

Pescosolido & Martin (2015) suggest the stereotype-prejudice-discrimination framework reduces the complexity of stigma and that more specific stigma dimensions are required. They contend that stereotypes, prejudice and discrimination do not address the nuances in stigma experiences across populations and health conditions, do not elucidate what kinds of prejudice or discriminatory behaviours are associated with specific ‘marks’ and do not



consider whether there are unique ramifications to particular 'marks' (Pescosolido & Martin, 2015). Pescosolido and Martin (2015) proposed the FINIS (see Figure 2.2) which represents a systems science approach to stigma where the individual and society are interconnected and cannot be detached from each other. The FINIS begins with Goffman's notion that stigma is understood through the language of social relationships emphasising the integral interface between society and the individual.

### **2.3.3.1 The FINIS: The Individual**

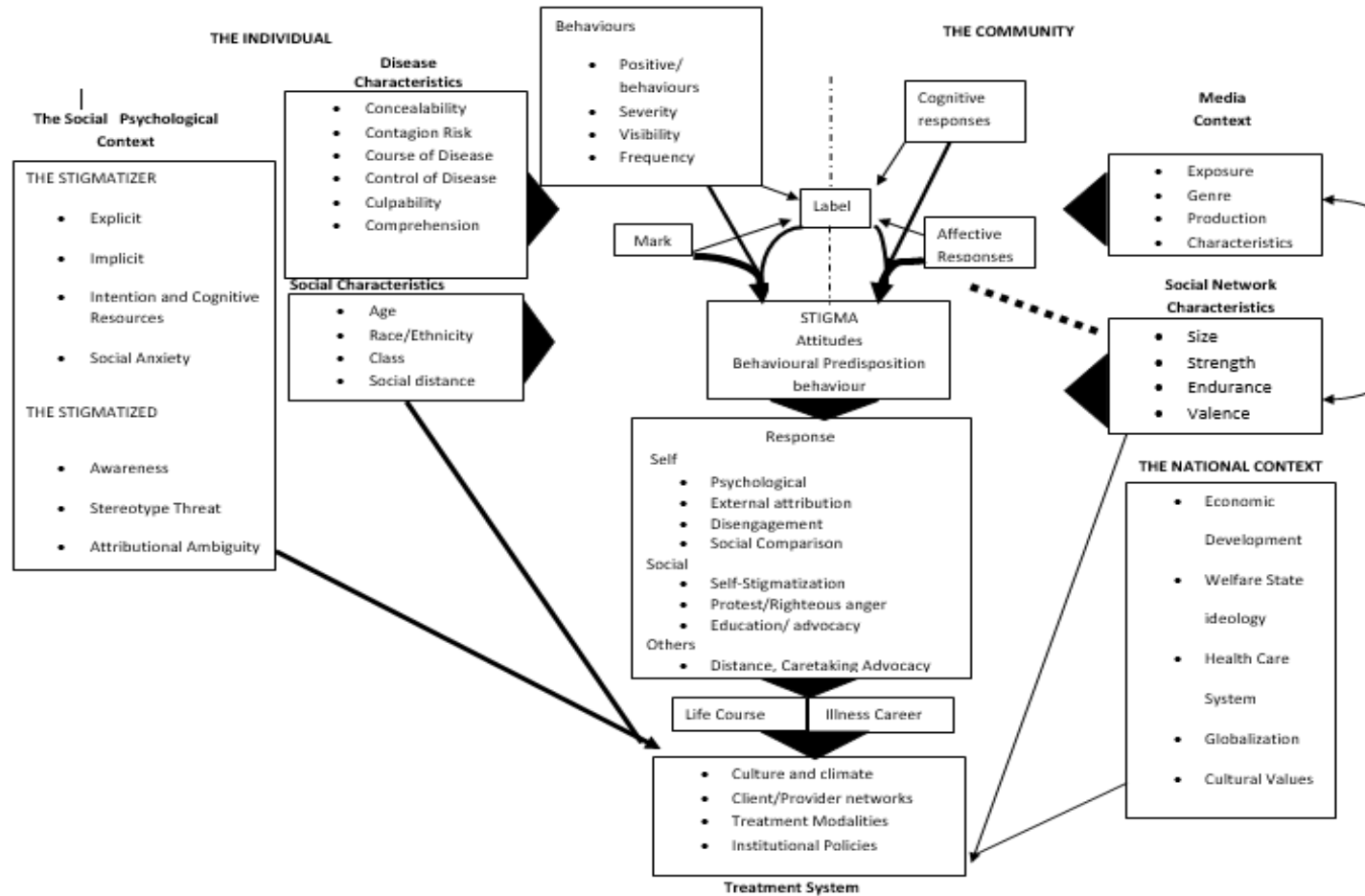
On the left hand side of the model, an individual's social (e.g. age, race) and disease (e.g. concealability, contagion) characteristics are combined to shape whether an individual is identifiable as someone with a stigmatised condition. The greater the extent to which an individual possesses a devalued status, the greater the chances are that they will experience stigmatising behaviour from others. This is also exacerbated if there is a greater social differentiation (race, age differences) between the stigmatised and the stigmatiser.

### **2.3.3.2 The FINIS: The Community**

The right hand side of the model represents the wider cultural context that surrounds both the stigmatised and the stigmatisers. This includes the stereotypes that may exist within a national context (e.g. cultural values) and how these may be based upon beliefs that are accepted, rejected or modified to aid the "othering" of individuals. To take an example, discourses around race have changed dramatically in the Western world from the time of Martin Luther Jr. However researchers argue that the stigma of 'being black' still exists, but overt racism has been transformed into other less explicit stigmatising behaviours (Launer, 2020; Rabinowitz, Sears, Sidanius, & Krosnick, 2009).

Figure 2.2.

The Framework Integrating Normative Influence on Stigma (FINIS) Pesolido & Martin (2015)



The media also play a critical part in the way stereotypes of mental health difficulties are endorsed, encouraging negative connotations of a diagnostic label to be communally accepted. The notion of encouraging individuals with stigmatising marks to “come out” to their social networks has been thought of as a source of change. However, this may also create further social distance from the wider community (Corrigan, Kosyluk, & Rüschi, 2013).

### **2.3.3.3 The FINIS and Dementia**

To some extent, the FINIS includes national and cultural contexts in which stigma exists. However the framework would require some adaptation if used in dementia due to the varying stereotypes and behaviours (negative and positive) elicited as a result (Berwald et al., 2016; Blay & Peluso, 2010; Woo, 2017). Stereotypes and discriminatory behaviours towards people living with dementia vary across sociocultural contexts, even though dementia is universally stigmatised (Alzheimer’s Disease International, 2019), the stereotypes of dementia are not universal concepts. The lack of universality of stereotypes can therefore create difficulties when generalising existing models and frameworks to explain stigma in dementia. A stigmatised label may cause very different portrayals of public and self-stigma; however, stigma frameworks neglect to consider this.

As I previously noted, although the SPD framework is the most widely used, it does not accommodate individuals who carry more than one stigmatising mark (Corrigan & Watson, 2002; Corrigan et al., 2005). The FINIS importantly outlines that a label is placed on an individual based on the visibility of a ‘mark’ (e.g. symptoms akin to a diagnosis of dementia) and therefore an individual may carry more than one of these marks. For example, racial identity, economic status,

gender and vocation can lead to an individual having more than one stigmatising characteristic. In dementia, stigma is also heavily compounded by age-related fear and ageism (Birt et al., 2017).

When stigmatising characteristics or ‘marks’ are not always visible, conceptualising the essence of stigma becomes problematic. Although many parts of the world have moved on from burning or cutting marks into those who are of low *moral status*, the concept of stigma still exists in the absence of a physical mark. Concealability refers to the extent to which a stigmatising mark can be hidden, and this is important because the visibility of the mark can create nuances in the way stigma is experienced. The FINIS is the only framework thus far that acknowledges the varying visibility of stigmatising characteristics (e.g. symptoms akin to a diagnosis of depression), however, deterioration in dementia can be incremental and hidden to an extent but this is not accounted in the FINIS. As I outlined in Chapter 1, dementia is uniquely placed as being concealable to an extent, therefore, the stigma experience may transform as symptoms of dementia progress.

### ***2.3.4 Multidimensional Model of Perceived Stigma***

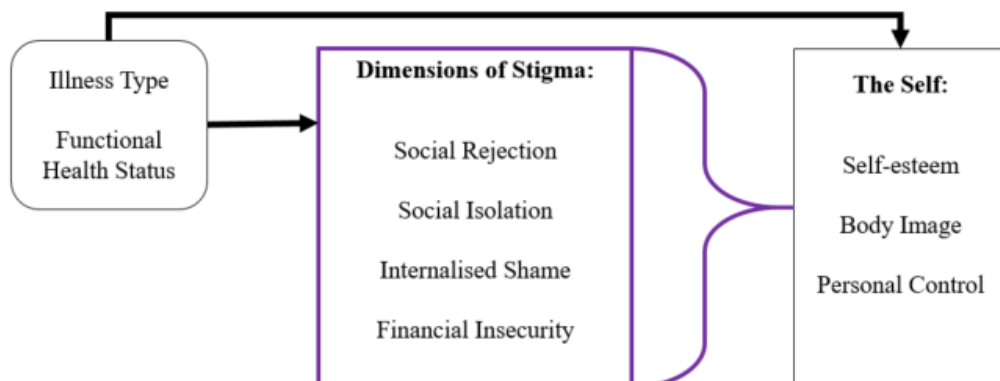
The multidimensional model was based on the aforementioned Modified Labelling Theory (Link & Phelan, 2001) explanation of stigma and the assumption that behaviour and the sense of self is based on social responses or social positioning of individuals, otherwise known as symbolic interactionism (Stryker, 1987, 2006). Fife and Wright, (2000) tested the multidimensional model to explain the impact of stigma on the self in people with HIV/AIDS (n =130) and cancer (n = 76) using the Social Impact Scale that consists of four stigma

dimensions: social rejection, internalised shame, social isolation and financial insecurity (see Figure 2.3).

Findings suggest that type of condition (function health status and symptom severity of HIV/AIDS or cancer) did not directly affect any dimension of the self (self-esteem, body image and personal control), but the effects of HIV/AIDS and cancer on the self, were primarily experienced through the dimensions of stigma. Fife and Wright (2000) noted that different mechanisms of stigma have differing consequences, where self-esteem was explained through social rejection and social isolation, body image was partially explained by social isolation, and personal control was explained by financial insecurity and social isolation. The latter was the only dimension that significantly affected all three dimensions of the self. This is consistent with previous work that suggests stigma functions to separate marked individuals from mainstream society (Goffman, 1963). The multidimensional model of stigma proposed by Fife and Wright (2000) provided an understanding of how dimensions of stigma can be harmful to the self-perceptions of those with chronic or terminal conditions.

*Figure 2.3.*

*Multidimensional Model of Stigma Impact (adapted from Fife and Wright, 2000)*

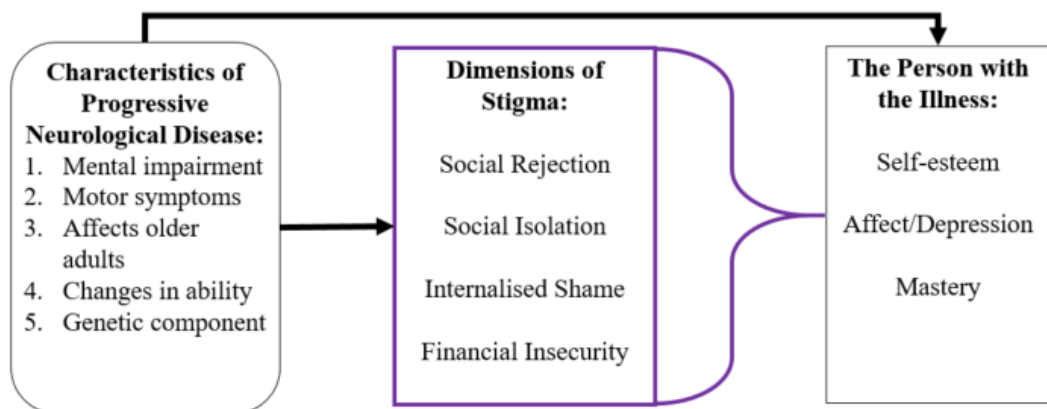


### 2.3.4.1 Adaptation of the Multidimensional Model for Alzheimer’s and Parkinson’s disease

Burgener and colleagues adapted the multidimensional model to explain the impact of stigma in chronic and long-term health conditions (see Figure 2.4) such as Alzheimer’s and Parkinson’s disease (Burgener & Berger, 2008). The adaptation of the multidimensional model was necessary to account for several nuances related to having a diagnosis of Alzheimer’s or Parkinson’s disease that differ from diagnoses of cancer and HIV/AIDS.

Figure 2.4.

*Multidimensional model of perceived stigma adapted by Burgener & Berger (2008)*



Self-awareness and insight are important prerequisites for stigma impact. Those who are aware of their stigmatised identities and have lengthy disease trajectories, as seen in Alzheimer’s and Parkinson’s disease (2 to 20 years), are particularly susceptible to the impact of stigma for prolonged periods. As I previously alluded to whilst outlining the selfhood explanation of dementia, for several years, it was suggested that people living with dementia, due to their neurological impairment, were unaware of the impact of their diagnosis, the changes that were to come, and the reactions of others, all of which are necessary aspects for self-stigmatisation (Burgener & Berger, 2008). An important addition

to the multidimensional model is the extent to which an individual experiences mental impairment.

Burgener and Burger (2008) acknowledged that, even though neurological impairment exists in both Alzheimer's and Parkinson's disease, there may be a variation in stigma experience based on the variation of physical symptoms. For example, the inclusion of motor symptoms in the illness-type component of the multidimensional model is because, in Parkinson's disease, individuals present with motor impairments whereas, in Alzheimer's disease, it is more likely individuals present with cognitive impairment.

Burgener and Colleagues tested the relevance of the multidimensional model of perceived stigma, which formed the theoretical origins of the Stigma Impact Scale (SIS; Burgener & Berger, 2008; Fife, & Wright, 2000). Preliminary psychometric testing of the SIS suggested poor to adequate internal consistency, with no test retest reliability reported (Burgener & Berger, 2008). Correlations used to test the validity of the SIS showed a significant negative relationship between the overall SIS score and self-esteem suggesting, as levels of self-stigma increase, levels of self-esteem decrease. Further, the SIS has a significant positive correlation with depression scores suggesting that, as self-stigma increases, so do symptoms of depression. No positive correlations were found between the SIS and mastery. Overall, the preliminary testing of the adapted multidimensional model suggests that self-stigma experiences are related to reduced self-esteem and depressive symptom but not to mastery (Burgener & Berger, 2008).

Only two of nine empirical studies in a recent systematic review included quantitative measures for self-stigma in dementia, both studies used the SIS and

were part of one longitudinal design, where the first publication summarised baseline data and the second analysed longitudinal findings (Burgener, Buckwalter, Perkhounkova, & Liu, 2015; Burgener et al., 2013; Nguyen & Li, 2018). In the longitudinal study, data was gathered from 50 people living with dementia in the United States, at six, 12 and 18 months using the SIS to measure self-stigma (social rejection, internalised shame, financial insecurity and social isolation) alongside various quality of life constructs (depression/anxiety, behavioural symptoms, mastery, physical health, self-esteem, and social support and activity participation). Financial insecurity was removed from the longitudinal analysis based on poor internal consistency and lack of conceptual relevance for retired older adults (Burgener & Berger, 2008; Burgener, Buckwalter, Perkhounkova, Liu, et al., 2015).

Social rejection was associated with anxiety and an increase in behavioural symptoms (Burgener, Buckwalter, Perkhounkova, Liu, et al., 2015). Internalised shame was associated with anxiety, mastery, health, self-esteem, social support understanding and assistance, and activity participation. Social isolation was associated with higher depression, higher anxiety, mastery, health self-esteem, social support understanding and activity participation (Burgener, Buckwalter, Perkhounkova, Liu, et al., 2015). For associations found with self-esteem and self-stigma, the interactions depended on gender (increased scores of internalised shame related to decreased scores of self-esteem for females not for males) and living situation (increase in social isolation related to decreased self-esteem for people with dementia who lived with someone, but not for those who lived alone).



Overall, at least one of three dimensions of the multidimensional model (social rejection, internalised shame, social isolation) were associated with quality of life outcomes (depression/anxiety, behavioural symptoms, mastery, physical health, self-esteem, and social support and activity participation) for people living with dementia.

### **2.3.4.2 The Multidimensional Model and Dementia**

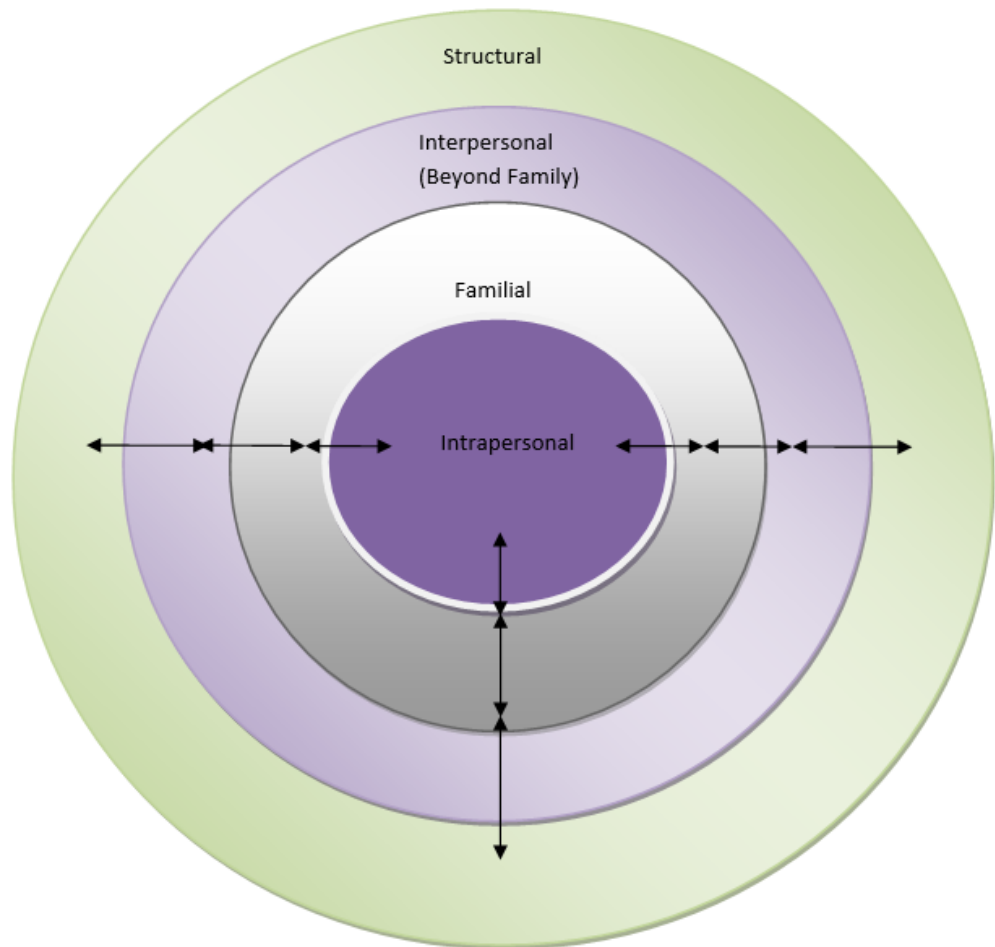
The Multidimensional Model is the only framework that has been previously tested in a population of people living with dementia. It should be noted that the testing was only carried out in people living with Alzheimer's disease and psychometric properties were not always reported. The Multidimensional Model only includes self-stigma concepts rather than the maintenance and initiation of public stigma. However, the results of previous testing suggest that the model can explain the influence of self-stigma on self-esteem, which is fruitful for further psychometric validation. This is the first model presented in this Chapter to explain the clinical relevance of self-stigma in people living with dementia.

## **2.4 Stigma Reduction Initiatives and Interventions**

Interventions for stigma change can be categorised across three levels in the multi-level model (Cook, Purdie-Vaughns, Meyer, & Busch, 2014), which was adapted to present ways in which intellectual disability stigma can be challenged (Scior & Werner, 2016; see Figure 2.5). I will now present stigma reduction initiatives and interventions that have been implemented in dementia utilising each level of the multi-level model for stigma change.

Figure 2.5.

*Multilevel Model of Stigma Change Interventions (adapted from Cook et al., 2014 by Scior & Werner 2016)*



#### ***2.4.1 Structural Level Interventions***

Structural level interventions reduce stigma by reaching a large audience to promote change where the aim is to implement societal level stigma reduction. Many of the interventions at a structural level are based on the assumption that raising awareness of dementia reduces stigma.

Two key structural level interventions were in the form of policy documents: the National Dementia Strategy and the Prime Minister's Challenge on Dementia (Department of Health, 2015; Department of Health, 2009). Although the National Strategy and Challenge on Dementia were not specifically designed to reduce the stigma of dementia, both called for the stigma surrounding dementia to be eradicated by raising awareness such that dementia would be better understood by everyone including the public, people living with dementia, carers and health professionals. The National Strategy and Challenge on Dementia placed a great deal of importance on early diagnosis, where lack of help seeking and reduced diagnostic rates were attributed to a lack of knowledge about dementia and the public stigma of dementia. As I will discuss below, the National Strategy and Challenge on Dementia laid the foundation for many interpersonal level interventions.

#### ***2.4.2 Interpersonal-Level Interventions***

Interpersonal interventions target social relationships between stigmatised and non-stigmatised individuals. There are two main types of interpersonal-level interventions. Firstly, there are education-based approaches that challenge negative stereotypes through raising awareness and providing information. Secondly, there are contact-based approaches that increase the contact between

the stigmatised and non-stigmatised individuals to reduce stigma through interaction.

### **2.4.2.1 ‘Worried About Your Memory?’ Campaign**

An output from the Challenge on Dementia has been the ‘Worried about your memory?’ campaign to encourage earlier diagnoses of dementia and earlier help-seeking behaviours that may otherwise have been delayed because of the stigma of dementia. The Department for Health invested £500,000 to fund the ‘Worried about your memory?’ campaign, creating materials (leaflets, posters, booklets) for GP practices in England to encourage people to seek medical advice if they were worried about their memory.

In an earlier report by the National Audit Office, approximately one third of GPs felt they had enough basic knowledge, information and training to diagnose and manage dementia (National Audit Office, 2007). Therefore, as part of the campaign, support for diagnosing dementia was provided to GPs in the form of a Computer Disk Read Only Memory (CD-ROM) that outlined how to make diagnostic decisions and positively support people living with dementia and their carers.

### **2.4.2.2 The ‘Living Well’ Campaign**

The National Dementia Strategy outlined the importance of raising awareness and understanding, both publicly and professionally (Department of Health, 2009). Based on consultations with a range of experts (e.g. people living with dementia and their carers, health and social workers), a consistent message emerged, which was the need to raise awareness and understanding about dementia.

This strategy identified key messages for the national ‘Living Well’ awareness raising campaign, which was launched shortly after the Strategy (Department of Health, 2009). The purpose of the campaign was to encourage help-seeking, earlier reporting of dementia symptoms, normalise dementia, send a message that a person living with dementia is no less a person and increase community understanding in order to create supportive networks. The ‘Living Well’ campaign was targeted at major employers and representative bodies whose organisations had regular interactions with the public (e.g. milkmen, transport staff). To address how institutional structures could support employees within the work force, human resources departments were also targeted to raise awareness of early symptoms of dementia and how dementia can affect carers.

Simulating the experience of living with dementia was another part of the ‘Living Well’ campaign as a way in which members of the public could increase their awareness and understanding of dementia. This part of the ‘Living Well’ campaign was called ‘I have dementia, I also have a life’, and took the form of [a series of videos](#) on television and social media featuring people living with dementia (Alzheimer’s Society, 2015). The videos aimed to normalise dementia, as stated previously as one of the overall aims of the larger ‘Living Well’ campaign, but also to dispel fears around developing dementia and engaging with people living with dementia.

### **2.4.2.3 Dementia Friendly Communities and Dementia Friends Initiative**

In the Prime Minister’s challenge on dementia (Chapter 1), there was a call for communities to sign up to become dementia-friendly, raise awareness of dementia and develop evidence for what a [dementia friendly community](#) would

look like in practice, thereby reducing stigma (Alzheimer's Disease International, n.d.).

The [Dementia Friends initiative](#) was one of the outputs from the Prime Minister's challenge to dispel the myths of dementia and inform the public of ways they could make a positive difference spearheaded by the (Alzheimer's Society, 2017). To become a Dementia Friend, individuals have to watch an online video or attend a one-hour workshop where they learn about dementia after which individuals pledge to raise awareness of dementia to make those living with dementia in their communities better understood by others. After becoming a Dementia Friend, some can choose to become a Dementia Friends Champion where they can run the workshop for others.

#### **2.4.2.4 Dementia Community Roadshow**

The Alzheimer's Society, in partnership with the supermarket Tesco, launched an outreach and awareness raising initiative called the [Dementia Community Roadshow](#) (Alzheimer's Society, 2011). The aim of the initiative was to travel around the UK to not only raise awareness of dementia but also encourage help seeking for those worried about their memory. Roadshows took place in Tesco supermarket car parks, and were hosted by Alzheimer's Society staff and volunteers who provided information and support to those who were worried about their memory. Staff and volunteers also signposted individuals to local services for further information and advice.

#### **2.4.2.5 The Early Dementia Users' Cooperative Aiming to Educate (EDUCATE) Project**

The [EDUCATE project](#) was an outreach initiative led by people living with early stage dementia (EDUCATE, n.d.). The project aimed to overcome

isolation, raise awareness about dementia, inspire others to live well, deliver training to professionals who diagnose dementia, and assess the accessibility of buildings and events for the inclusion of people living with dementia. As part of EDUCATE, people living with dementia interacted with various groups of people without a diagnosis (e.g. groups of schoolchildren) and share experiences of their dementia. The EDUCATE project enabled people living with dementia to gain confidence through sharing experiences and, at the same time, facilitated awareness raising and increased understanding of dementia.

### **2.4.2.6 Advocacy**

In Alzheimer's Europe's position paper that I have already outlined in Chapter 1, the definition of disability by the Disability Rights Movement was adapted to explain the experiences of people living with dementia. More specifically, how the disability associated with dementia went beyond the physical or biological condition but was a social construct which, if reversed, was capable of accommodating for people living with dementia rather than creating excess disability and stigmatisation (Mehta & Thornicroft, 2013; S. Sabat, 1994). The Disability Rights Movement is an advocacy model, where those whom are part of marginalised groups are encouraged to publicly voice views on equality and support others within the marginalised group to become empowered.

As the importance of patient and public involvement (PPI; INVOLVE, 2012b) in dementia research grew, so did the number of people diagnosed with dementia who became advocates to raise awareness of dementia, promote the PPI movement and engage the public in their own experiences (Ilfie, Mcgrath, & Mitchell, 2013). Over time, this created huge effects through social media outlets (e.g. Twitter) where people living with dementia were actively challenging

negative stereotypes of living with dementia, changing discourses from deficit driven to ability driven representations such as ‘living well with dementia’.

Advocacy occurred not just on an individual level but groups formed locally, nationally and internationally.

The presence of the advocacy model gave rise to groups such as Dementia Alliance International, Dementia Advocacy and Support Network International and the European Working Group of People with Dementia (EWGPWD). Many members of the EWGPWD, for example, actively advise on UK research projects. In addition, the EWGPWD have worked internationally to co-produce the position paper reframing dementia as a disability (Gilliard et al., 2005; Gove et al., 2019).

[Dementia Engagement and Empowerment Project \(DEEP\)](#) groups were set up across the UK consisting of people living with dementia who sought to influence local services, policies and attitudes that affect their lives (DEEP, 2011). DEEP groups play an active role in reducing stigma from raising awareness of dementia through outreach materials but they also have links to local community organisations to share their experiences with those without dementia. DEEP have produced guides and resources for community organisations to encourage safe and accommodating environments for people living with dementia. Topics covered include guidance on involving people living with dementia in conferences and events, and choosing dementia friendly meeting spaces.

### **2.4.2.7 Language Initiatives**



In Chapter 1, I presented how the media have exacerbated fear and negative stereotypes of dementia. To minimise stigmatising language used by media outlets, language guidelines were created by voluntary sector organisations with input from people living with dementia (reviewed in Swaffer, 2014).

An example of such language guidelines came from DEEP, namely, [‘Dementia words matter: Guidelines on language about dementia’](#) (DEEP, 2014). The guidelines targeted the use of language by the media, organisations and communication departments around dementia. The rationale behind the guidelines was that language about dementia influences the way people living with dementia are seen by others but also how they see themselves. The guidelines described words that should be avoided such as “sufferer” or “demented” as they formed the basis of negative stereotypes, which people living with dementia are negatively affected by.

### ***2.4.3 Intrapersonal and Familial-Level Interventions***

Interventions at the intrapersonal and familial levels focus on supporting people affected by stigma, such as those living with dementia or their carers. Intrapersonal and familial interventions seek to promote coping behaviours to deal with the negative effects self-stigma.

Although approaches such as cognitive behavioural therapy (CBT) have been used with people living with dementia and carers (Spector et al., 2015), there is no evidence to suggest that these approaches have utility in self-stigma reduction. However, it is plausible that people living with dementia and carers who undergo CBT may actively challenge harmful self-beliefs, such as

stereotypes and prejudices associated with dementia that may interrupt the process of self-stigmatisation.

The Meeting Centre Support Program was based on the Adaptation Coping model, set up with the aim of promoting the independence of community dwelling people living with dementia integrating education, social activities and discussion groups for carers of people living with dementia (Dröes, Breebaart, Ettema, van Tilburg, & Mellenbergh, 2000; Dröes et al., 2017). According to the Adaptation Coping Model, people living with dementia and carers are required to adapt to dementia-related changes and therefore this adaptation can be seen as a means of maintaining a positive self-image (Droes et al., 2000). The Meeting Centre model, originating in the Netherlands, has been extended to Italy, Poland and Britain where the multidimensional model of stigma was used to evaluate the self-stigma experienced by attendees living with dementia. Results indicated that British people living with dementia had significantly higher levels of self-stigma, felt more socially rejected, socially isolated and internalised shame, according to the SIS (Lion et al., 2019). Although no pre and post measures were taken, cross sectional results suggest that self-stigma is associated with social relationships where those who felt more stigmatised rated decreased levels of satisfaction in their social relationships (Lion et al., 2019). As I mentioned in Chapter 1, social support is a tractable factor when considering the mechanisms of action for psychosocial interventions (Spector & Orrell, 2010). In the Meeting Centres Program, the promotion of social relationships was related to the way people living with dementia experienced self-stigma.

#### **2.4.4 *Summary of Stigma Reduction Interventions in Dementia***

Most structural and interpersonal level interventions cited above are based on the rationale that raising awareness and understanding reduces the stigma associated with dementia. This includes raising awareness to dispel myths or negative stereotypes of dementia, changing misconceptions of what is it to live with dementia and removing the use of negative language to describe dementia. The rationale behind structural and interpersonal level interventions is problematic as the evidence for stigma reduction through education and contact is conflicted as presented in section 3 of this Chapter, where the results of numerous studies suggest that knowledge of dementia and proximity to people living with dementia did not lead to a reduction in stigmatising beliefs. There is also a lack of evaluative evidence on the impact and value of structural and interpersonal level interventions on stigma in dementia. To the author's knowledge, there are no intrapersonal or familial interventions that actively seek to reduce self-stigma in people living with dementia, nor interventions that seek to reduce courtesy and affiliate stigma in carers. The absence of such interventions is part of the rationale for the development of the intervention described in Chapters 6 and 7 of this thesis.

#### **2.5 Conclusion**

In this Chapter, I painted a picture of dementia-related stigma, considering stereotypes, prejudice and discrimination. A common stereotype of dementia is of cognitive incompetence. Whilst a deterioration in cognitive abilities is, by definition, a central feature of dementia, this does not necessarily preclude the individual with dementia from decision-making. In contrast, others' prejudicial responses and discriminatory behaviours may act as a barrier to the decisional

involvement of a person living with dementia. In the next Chapter, I review literature on decision-making and dementia.

### **3 The Nature of Decision-Making in People Living with Dementia: A Systematic Review**

A version of this Chapter has been published:

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The nature of decision-making in people living with dementia: A systematic review. *Aging & Mental Health*, 24(3), 363-373.

<https://doi.org/10.1080/13607863.2018.1544212>

#### **3.1 Introduction**

Investigating the influence of stigma on disclosure decision-making requires a robust understanding of how decision-making takes place in dementia, given the unique challenges of the condition. As I explored in the previous Chapters, people living with dementia are considered incompetent and unable to make decisions for themselves due to negative stereotypes, therefore stigma can manifest in decisional opportunities being taken away. The incompetence in dementia is typically associated with cognitive impairment, an unchangeable symptomatic characteristic of dementia, however it is important to consider whether decision-making by people living with dementia is effected by other factors rather than cognitive impairment alone. In this Chapter, I review the nature of decision-making in dementia after which I will discuss disclosure decision-making models. Together, factors influencing decision-making in dementia, and how disclosure decision-making has taken place in other populations, will inform the development of an intervention to support people living with dementia who are fearful of disclosing their diagnosis (Chapter 6).

### ***3.1.1 Conceptualising Decision-Making***

Understanding Kitwood's notion of personhood beyond that of one's personal capacity or relationships paved the way to thinking about personhood in terms of denial of a person's citizenship rights, where conceptualisations of dementia began to include that of citizenship. More specifically, narratives of deficit were countered by an ability-driven approach to highlight the agency people with dementia have to shape their social experiences (Birt et al., 2017; Gilmour & Brannelly, 2010; O'Connor et al., 2018). The work of this thesis is grounded in the stance that people living with dementia can shape their social experiences, moving away from the medical model to psychosocial conceptualisations of dementia gives rise to explore how people living with dementia are meaningful participants, beyond their diagnostic labels or pathological difficulties. Exploring an ability-driven approach can be achieved through understanding how people living with dementia play an active role in decision-making.

The ability to make decisions is an important exercise of a person's independence, control and autonomy. Decision-making allows the application of personal, social, professional and legal control over one's life. The consequences of impaired decision-making have been investigated in populations of Parkinson's disease (Poletti et al., 2009; Witt, 2007), stroke and brain injury (Foster, Tilse, & Fleming, 2004; Iaquina, 2007; Kelly, McDonald, & Kellett, 2014; Wood & McHugh, 2013) and dementia (Dahan & Eth, 2009; Davis, Ziolkowski, & Veltkamp, 2017; Whitlatch & Menne, 2009).

The ability to make decisions is critical for maintaining autonomy, well-being and the identity of people with dementia and their carers (Davis et al., 2017; Menne, Tucke, Whitlatch, & Feinberg, 2008; Whitlatch & Menne, 2009).

Decision-making is also an important aspect of ‘recovery’ in dementia, which is defined here as the ability to live an independent life in the presence of dementia symptoms (Hammond & Debney, 2017; Martin, 2009).

### ***3.1.2 Cognitive Impairment and Decision-Making***

The experiences of people living with dementia during decision-making have been typically attributed to a decline in and ultimately a loss of cognitive functioning (Derse, 1999; Jimenez et al., 2013). Several facets of decision-making have been empirically explored in dementia research, such as advanced care planning (Elliott et al., 2009; Mitchell, 2015), medical treatment (Appel, 2012) and everyday decision-making (Davis et al., 2017). However, the decisional involvement of people living with dementia may not always be attributable to disease-related factors such as cognitive impairment. Despite having the capacity to make decisions (Appel, 2012; Dahan & Eth, 2010; Derse, 1999), people living with dementia may still be excluded (Taghizadeh Larsson & Österholm, 2014) or overridden by others such as their carers (Livingston & Boyd, 2010; Piffaretti, 2012) due to the stereotype that people living with dementia are incompetent.

### ***3.1.3 Involvement of People Living with Dementia in Decision-Making***

The emphasis in previous research has been on shared decision-making between the person living with dementia and their carer (usually spousal). This is a collective or systems approach where carers (e.g. spouses, family members) and the person living with dementia, are informed about the available options and

contribute to an overall decisional outcome (Mariani, Vernooij-Dassen, Koopmans, Engels, & Chattat, 2017; Miller, Whitlatch, & Lyons, 2016; Whitlatch & Menne, 2009). There is typically a distinction between the extent to which people living with dementia prefer to be involved and how much involvement actually takes place (Whitlatch & Menne, 2009).

As I explained in Chapter 1, there has been a shift in attitudes to dementia, away from the medical model where an individual is a diagnostic label, toward a psychosocial approach, where the experience of the individual is central (Kitwood, 1997; Pratt & Wilkinson, 2003). However, there are no person-centred models of how decision-making takes place in dementia. Medical decision-making models for joint clinician-patient dyads range from clinician-led decisions to clinicians facilitating patient involvement (Murray, Charles, & Gafni, 2006; Whitney, 2003). A recent review by Davis, Ziomkowski and Velkamp (2017) focussed on the ability of individuals living with Alzheimer's disease to perform everyday decision-making. This review concluded that decision-making in dementia is complex and multi-faceted but that people living with Alzheimer's disease are able to contribute meaningfully to the decisional process in everyday decision-making.

### **3.1.4 Rationale**

To the author's knowledge, there is no review of decision-making across dementias, decisional types (individual and shared decision-making) and domains (diagnosis, daily living, respite, residential, financial decisions) nor any systematic review of factors that influence decision-making in dementia or the involvement of people living with dementia through decisions they may make



with their carers. The unique complexity of capacity in dementia gives rise to a series of decision-making challenges that current models of generic decision-making do not cover.

### **3.1.5 Aims**

The aim of this review was to understand the nature of decision-making in people living with dementia through the following objectives to:

1. Understand how people living with dementia are involved in decisions.
2. Explore the different decisional styles and domains of decision-making people living with dementia experience.
3. Identify what influences the level of decisional involvement of people living with dementia.

## **3.2 Methods**

### **3.2.1 Development of Systematic Review Protocol**

PRISMA-P guidance was used to develop a protocol for this systematic review (Moher et al., 2015) with the following eligibility criteria:

- *Study design*: studies reporting qualitative or quantitative findings with observational designs
- *Publication language*: studies published in the English language
- *Publication year*: peer reviewed studies published in academic journals between 1997-2017
- *Types of participants*: people living with dementia or other conditions where decision-making capacity is affected (e.g.

acquired cognitive impairment, Parkinson's disease, stroke or brain injury)

- *Review focus:* studies reporting how decision making is conducted by people living with dementia or other conditions where decision-making capacity is affected and can be compared to dementia

### **3.2.2 Search Strategy**

Two platforms were used to conduct a database search. Ovid (Medline, PsycINFO, Health And Psychological Interventions; HAPI) and EBSCOHost (CINAHL) were searched using the medical subject heading (MeSH) term “dementia” in combination with “decision-making” and “decision-making support”. Database filters were set such that only peer-reviewed full text articles in English, published between 1997 to 2017 in human populations appeared. Further MeSH terms were used to incorporate cross-disciplinary findings from conditions related to dementia such as “acquired cognitive impairment”, “Parkinson's”, “stroke” and “brain injury”. Additional articles were identified from an updated database search, recommendations by experts, reference lists of reviews, included full texts and articles that had cited these.

### **3.2.3 Identification of Articles**

For all articles, three screening stages were carried out. Firstly, article titles were screened. Titles that did not reflect the focus of this review were excluded. Secondly, the author and a post-doctoral student with experience of systematic reviews (CS) screened abstracts of included articles independently. Finally, all remaining full texts were independently screened for eligibility by the

author and an experienced reviewer (GC). Any disagreements over eligibility were discussed until an agreement was reached.

### **3.2.4 Quality Assessment**

A tool kit established by Mukadam, Copper and Livingston (2011) was used, which comprises of shortened versions of both qualitative (Critical Appraisal Skills Programme, 2006) and quantitative (Boyle, 1998) checklists. The author assessed the quality of articles independently from a second quality appraiser (HW; a PhD student with previous experience of carrying out quality appraisals). Articles were assigned a score of 0 (criterion not met) or 1 (criterion met) for each item, resulting in a quality score out of six. Discrepancies were discussed and consensus was reached. Quality of studies were categorised as low quality (0-2), moderate quality (3-4) or high quality (5-6).

### **3.2.5 Narrative Synthesis Methodology**

A narrative approach allowed both qualitative and quantitative evidence to be synthesised into a model of decision-making in dementia (Dixon-Woods et al., 2005). In line with guidance from Popay et al (2006), the narrative approach outlined four stages within the general framework of conducting a narrative synthesis: (1) developing a theory, (2) developing a preliminary synthesis, (3) exploring relationships and (4) assessing the robustness of the synthesis. The author conducted all narrative synthesis analysis.

#### **3.2.5.1 Stage 1: Developing a Theory**

The aims of this review and eligibility criteria were constructed through scoping existing literature and consulting a researcher leading on Public and Patient Involvement (PPI) and qualitative methodology in the Promoting

Independence in Dementia (PRIDE) study (Yates et al., 2019). This suggested the factors influencing decisional involvement of people living with dementia may include: kinship of carers (Miller et al., 2016), history of decision-making within a dyad (Harrison-Dening, King, Jones & Sampson 2017), familial restrictions (Groen-van de Ven et al., 2016) and cognitive ability (Mariani et al., 2017; Mitchell, 2015). In this review, the term involvement refers to the extent to which a person contributes to the outcome of the decision through participation in the decision-making process.

### **3.2.5.2 Stage 2: Developing a Preliminary Synthesis**

I developed a preliminary synthesis with eligible full text articles, which was the starting point for exploring patterns across included studies in line with the review question. Initial descriptions for included studies were tabulated into the following categories: author, year, peer reviewed journal, country, study aim/research question, decision-making type, decision-making domain, design, participant, measures and analysis and summary of study findings. Clustering of studies in this stage was based on the nature of results that were reported.

### **3.2.5.3 Stage 3: Exploring Relationships**

A visual diagram of the synthesis was then developed by conceptualising and exploring connections within clusters. To understand how decision-making may take place in dementia, the heterogeneity of the methods used in the included articles was explored. From stage two, the patterns across studies were clustered and these relationships were then developed into a synthesis. Concept mapping was used to link pieces of qualitative and quantitative evidence across individual studies to construct a model (Mulrow, Langhorne & Grimshaw, 1997). Articles

that identified frameworks of decisional styles were used as a skeleton to map the concepts of cross sectional articles. A synthesis model was then developed.

#### **3.2.5.4 Stage 4: Assessing the Robustness of the Synthesis**

In addition to the quality assessment of individual studies, a critical reflection on the synthesis process took place. This involved exploring the strengths and limitations of the process as implemented, assumptions made and the evidence used, in line with guidance outlined by Popay et al (2006).

### **3.3 Results**

#### **3.3.1 Study Identification**

Five-hundred and fifty-eight articles were identified (Figure 3.1). After duplicate removal (n=282), 237 articles were excluded by screening the title (n=194) and abstract (n = 43). The reference list of the remaining 39 articles was checked for relevant references (n = 16) and forward citations (n = 5), articles were also added from an updated database search (n = 6), references from relevant reviews n = 2, expert recommendations n = 1). Of the remaining 69 references, 54 were excluded. Studies that did not focus on how decision making was conducted by the person living with dementia (or other conditions where decision making is affected) were excluded (n = 30), as were studies that reported findings that did not relate to a decision-making situation that people living with dementia would be in (n = 6). Studies that did not report qualitative and quantitative findings in observational designs were excluded (n = 7). Studies that were review articles were also excluded (n = 11).

### **3.3.2 *Study Characteristics***

Fifteen studies fully met the eligibility criteria for this review of which 13 used qualitative, and two quantitative, methods. The majority of qualitative studies were cross-sectional (n= 9) whilst some were longitudinal (n=4); both quantitative studies were of a cross-sectional design. Qualitative designs comprised of structured/semi-structured-open ended interviews (n= 8), interviews and observations (n= 4) and focus group interviews (n =1). Qualitative studies were analysed through grounded theory (n= 4), thematic analysis (n = 4), interpretative or interpretative phenomenological analysis (n= 2), phenomenological analysis (n= 1) and mixed qualitative methods (n= 2). The two quantitative studies used correlations (both), hierarchical multiple regression (n=1) and multilevel modelling to analyse data (n=1). Studies were from the United States (n =5), United Kingdom (n =4), Australia (n =3), with one each from Norway, France and China.

### **3.3.3 *Participant Characteristics***

Participants were predominantly people with dementia, Parkinson's disease (n=1) and stroke (n=1). Within the included studies, some only collected data from those living with dementia or a related condition (n=2) whilst others included carers (n=13). Of the studies that included carers (n=13), carers were spouses, a mixture of family carers and friends (n=6), and a mixture of family and paid carers (e.g. nurses, physiotherapists, acupuncturists, n = 2). Sample sizes for qualitative and quantitative studies varied from 6 – 85 and 84 - 430 participants respectively. The mean age of participants was 68.38 years (n=10) whilst the other studies did not report this data (n= 5).

### **3.3.4 *Decision-Making Domains***

A decision-making domain refers to the category of a decision. Decision-making domains were everyday (n= 4), general (n = 4), health and social care planning (n= 3), driving, financial management, research participation, and exercise

### **3.3.5 *Quality Assessment***

Quality appraisal scores were not used to exclude studies but to assess the robustness of the synthesis. Ten qualitative studies were rated as moderate quality and three as high quality (a score of five). Both quantitative studies were of high quality (a score of five, see Table 3.1)

Figure 3.1.

PRISMA diagram of study screening and selection

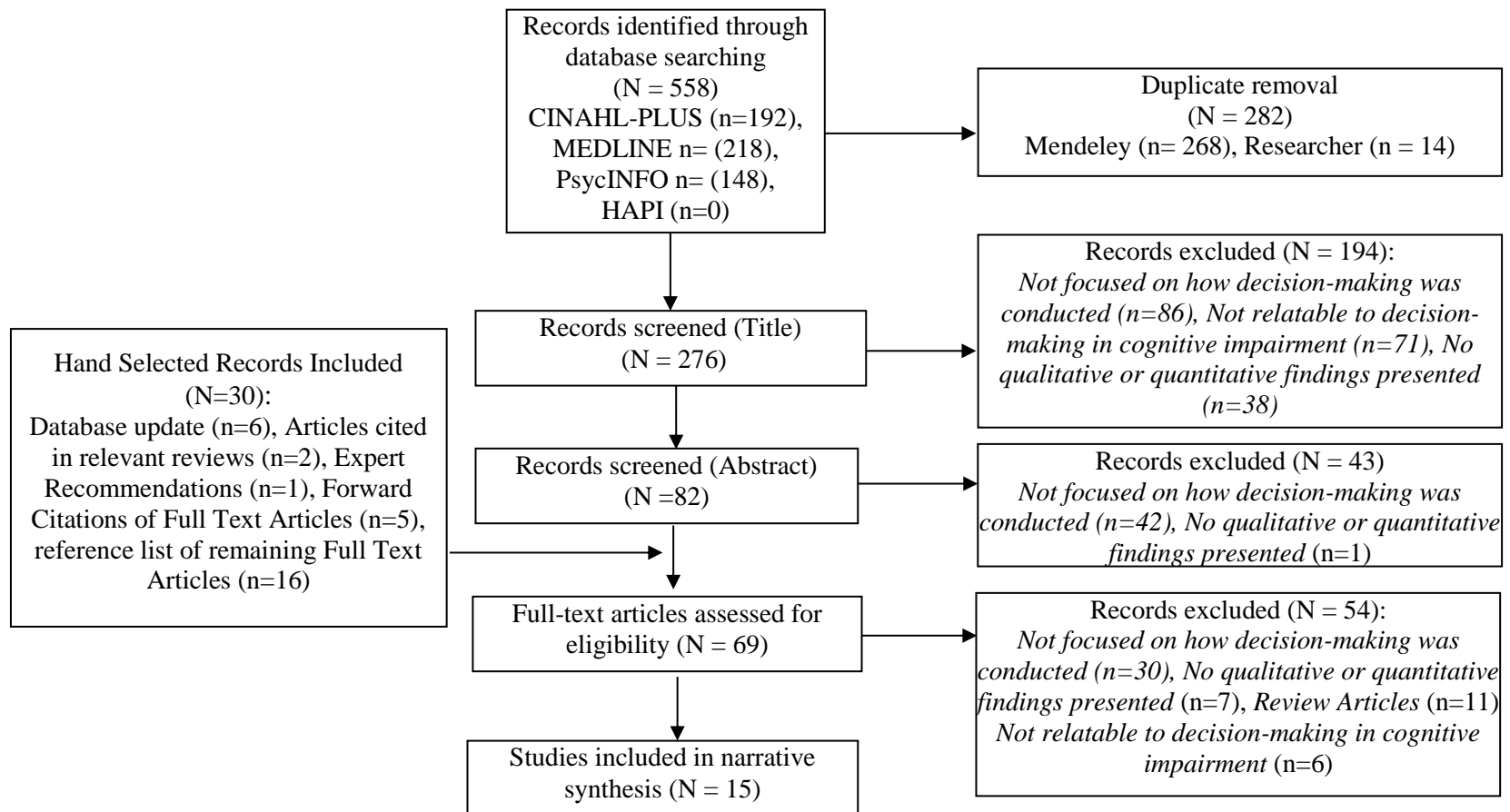




Table 3.1.

*Description of included studies*

Qualitative Studies							
Author	Year/ Country	Decision-making type/domain	Participants	Data collection	Analysis	Main Findings	Quality Score
Adler	2010/US	Shared/Driving	Plwd with licenses (n=20, male = 75%, Age range = 53-83, M=69.9 SD= 8.9) Spouses of current drivers (n=20, Female = 75%, Age range = 49- 82, M=68.0, SD= 9.5) Spouses of former drivers (n=25, Female = 92%, Age range = 54- 85, M=70.6, SD=7.7)	Early stage support group meetings 13 Focus Groups of 2 - 8	Thematic analysis	Driving decisions are a responsibility shared between families and professionals, and showed that diagnostic delays hamper families in making long-term plans.	4

Black, Wechsler, Fogarty	2013/US	Shared/ Research Participation	Plwd (N=39, Female = 51.3%, Age M= 74.2, SD=8.8) Surrogates (defined as the study partner or proxy decision maker, N=46, Female = 73.9%, Age M= 63.1, SD= 12.6, Spousal = 60.9%)	Semi-structured interviews	Grounded Theory	Ultimate decision-making involvement of plwd depends on cognitive impairment. 'Best interest' decision-making was the ethical standard for future proxy research decision-making	3
Boyle	2013/UK	Shared/ Everyday	21 married dyads Plwd (n = 21, Female=12, Range= 40-80)	Interview and observation ( <i>longitudinal</i> )	Thematic analysis	Spouses assist the autonomy of plwd facilitating everyday decisions (e.g. communication) so that they have a say. Assisted autonomy however is mediated by gender for <i>minor</i> decision-making where females are more facilitative spouses	5
Boyle	2013a/UK	Shared/ Financial	21 married dyads Plwd (n = 21, Female=12, Range= 40-80)	Interview and observation ( <i>longitudinal</i> )	Thematic and comparative analysis	Individual roles in decision-making are habituated through a marriage. Spousal carers undertook decision-making when plwd had limited capacity but in some cases plwd were marginalised and unable	5

						to exercise their capacity when they were able.	
Fetherstonhaugh, Rayner, Tarzia	2016/Australia	Shared/Everyday	7 married dyads and 2 spousal carers Plwd (n =7, Age Range = 56-79, Median =75, Time since diagnosis Median = 2 years, Range (2-6 years) Spousal carers (n=9, Age Range=57-80, Median =72.5)	Semi-structured interviews	Interpretive phenomenological approach	The caregiving relationship was the essence of decision-making where carers supporting and facilitating decision-making for plwd through understanding the importance of their autonomy, facilitating their autonomy but knowing when to override beliefs should decisions carry major consequences	3
Fetherstonhaugh, Tarzia, Nay	2013/Australia	Shared-individual /Everyday	Plwd (n=6, Age Range= 54-78), Time since diagnosis 1.5 - 16 years	Interviews	Phenomenological Analysis	The essence of decision-making for plwd is a feeling that “I am still here” facilitated through support, pragmatism and feeling central. These three domains however, can be disrupted having the opposite impact on decisional involvement of plwd	3
Harrison Dening, King, Jones,	2017/UK	Shared/Healthcare planning	6 married dyads and 1 additional carer (adult child)	Semi-structured interview	Content thematic analysis	Level of cognitive impairment and characteristics of the	4

Sampson			Plwd (n=6, Female = 3, Age Range = 70-88, M=77.6) Carers (n=7, Female = 3, Age Range= 49-85, M=73.4)			relationship between the plwd and carers impact decisional involvement	
Horton-Deutsch, Twigg, Evans	2007/USA	Shared/Healthcare	20 dyads Plwd (n=20, Age Range = 55 - 85 Females = 11, M= 72.6 SD = 9.1) Carers, (n=20, Age Range = 44 - 83, M= 69.6 SD = 11.4, 2 were non-spousal: <i>son/daughter</i> )	Semi-structured interview	Constant comparative method	A plwd's symptoms, resources, function and normality affects their health care decision-making	4
O'Brien, Clemson, Canning	2016/Australia	Individual /Exercise	8 individuals with Parkinson's disease (N=8, Females =2, Age Range 64 - 82, M= 71.38). Disease duration 3-11 years	Interview	Grounded Theory	Adapting to loss and change, the influence of others and making sense of the exercise experience influence decisions regarding exercise participation in Parkinson's disease.	4
Samsi & Manthorpe	2013/UK	Shared/Everyday	12 dyads Plwd (n=12, Female = 6, Age M= 81.5, Range 72- 92), Time since diagnosis = 3 – 11 months Carers (n=12, Female = 8, Age Range 49-88,	Topic guided interviews ( <i>longitudinal</i> )	Thematic analysis	A continuum representing decision-making discourse, where the carer gradually makes a transition from "supported decision-making" to "substitute decision-making" in	5

			M= 70.08), 7 spousal, 4 adult children/relative, 1 friend			their engagement of the plwd	
Smebye, Kirkevold, Engedal	2012/Norway	Shared /General	10 triads Plwd (n=10) Carers (n=10): spouse, adult children (in-law), sibling, Professionals (n=10): registered, enrolled or aid nurse.	Semi-structured interviews	Framework analysis and interpretive approach	Five types of decision-making outlined, autonomous, pseudo-autonomous, delegating, shared and non-involvement where decision-making involvement of the plwd and carer differs from each type	4
Tyrrell, Genin, Myslinski	2006/France	Shared/ Health and social care	21 dyads Plwd (n=21, Female=16, Age Range 74-91, M= 84) Carer (n=21, Age Range 45-85, M= 62) Carers were 14 daughters, 6 sons 1 husband	Semi-structured interviews	Framework Analysis	Highlight conditions of decision-making to for the involvement of plwd: being informed, listened to, expression of opinion, time for reflection and reversibility of choice. That contribute to involvement in care related decisions	3
Wang & Nolan	2016/China	Shared/General	People with stroke (n=19, Female = 5, Age Range 60-80) Family members (n=28, female=17, Age Range 33-77,)	Interviews and observations ( <i>longitudinal</i> )	Constant comparative analysis	Decision-making behaviours occurred in line with cultural ideals, hiding behaviours were employed to preclude the person who had had a stroke from full and	4

Quantitative Studies							
Author	Year/Country	Decision-making type/domain	Participants	Data collection	Analysis	Main Findings	Quality Assessment
			7-sons, 12- daughters, 3-husband, 5-wife, 1 son-in-law			active decisional involvement	
			Professionals (n=25, Age Range 24-46, 19 female) 15-doctors, 7-nurses, 2-physio, 1-accupuncturist				
Menne & Whitlatch	2007/US	Individual-Shared/General	215 dyads Plwd (n = 215, Female = 50% Age M= 75.89, SD = 9.26) Time since diagnosis M=33.63 (39.93) months 116 carers (approx.) were spousal	Psychometric scales: Decision making involvement scale, Memory and behavioural problem checklist, mini-mental state examination, dyadic relationship strain, values and	Bivariate correlations, Hierarchical multiple regression	Plwd who report more decision-making involvement are younger, female, had more education, have non-spousal carers, have fewer months since diagnosis, have fewer depressive symptoms, exhibit fewer activity of daily living problems and place more importance on autonomy and self-identity.	5

				preferences scale			
Miller, Lee, Whitlatch & Lyons	2017/US	Individual-Shared/General	42 dyads Plwd inpatients (n=21, Female = 45.24%, Age Range 72-88, M= 79.81 SD= 7.76) Carers (n=21, Female = 75%, Age Range = 48-74, M= 61, SD=12.95) 70% adult children/in-law, 30% spousal	Psychometric scales: Decision making involvement scale, mini mental state examination, role overload scale, dyadic strain subscale of the dyadic relationship scale, care values scale	Correlations and multilevel modelling (HLM)	Cognitive impairment, care related strain, relationship strain and value of autonomy were identified as being significantly affected the decision-making involvement of plwd	5
Plwd = person living with dementia							

### ***3.3.6 How do People Living with Dementia Make Decisions?***

Five studies referred to the term ‘shared decision making’ (SDM) across driving, every day, healthcare and general decisions. In some studies, SDM referred generally to the joint involvement of a person living with dementia and carer (Fetherstonhaugh, Tarzia, Bauer, Nay, & Beattie, 2016; Harrison Dening et al., 2017). However the term was also used to refer to the decisions made by carers and professionals (e.g. healthcare workers) for or with the person living with dementia without their active participation (Adler, 2010; Horton-Deutsch, Twigg, & Evans, 2007). In one study, SDM also referred to reminding a person living with dementia of past joint decision-making on a particular topic, such that a repetition of the process was not necessary (Smebye, Kirkevold, & Engedal, 2012). Across these examples, ‘SDM’ lacked operational consistency, with the term describing an array of decision-makers outside the typical carer-person living with dementia dyad. In some instances, SDM was used as a term of reference when the person living-with dementia was not involved in making the decision.

The extent to which a person living with dementia was involved, if at all, is unclear from the term SDM. Some studies emphasised the decline in decision-making ability due to dementia however still made use of the term SDM. The results of this systematic review have avoided SDM as a decisional style, as the actual amount of involvement from the person living with dementia or in fact the parties whom are involved in the process is unclear from previous research. More specific terminology was developed in this review in order to reduce ambiguity and clarify who is involved in the decision-making processes and how.



Decision-making led by the person with dementia was defined as autonomous typically when decisions had no serious consequences and were seen as minor decisions (Smebye et al., 2012). This was the least common form of decision-making as only a few studies reported the person with dementia being the ultimate decision-maker (Black, Wechsler, & Fogarty, 2013; Horton-Deutsch et al., 2007; Smebye et al., 2012).

### **3.3.6.1 Managed Autonomy**

Managed autonomy was decision-making with support from both formal and informal carers (Smebye et al., 2012). Spousal carers implemented support strategies (discussion around choices, dialogue about consequences, understanding the person, negotiation and listening) to facilitate the person with dementia's autonomy in everyday decision-making (Boyle, 2013b; Fetherstonhaugh et al., 2016). The strategies employed by carers included: reinforcing the person with dementia's opinions, exchanging information through consultation and dialogue, encouraging questioning, and supporting reasoning and understanding (Boyle, 2013b; Fetherstonhaugh et al., 2016; Smebye et al., 2012).

### **3.3.6.2 Mutual**

In mutual decision-making, carers had increased responsibility for contributing to the overall outcome (Harrison-Dening et al., 2016). For this approach, carers were theorised to be compensating for the loss of abilities of the person with dementia whilst respecting boundaries by acknowledging the importance of autonomy to the person with dementia (Samsi & Manthorpe, 2013; Smebye et al., 2012).

### **3.3.6.3 Reductive**

This was defined by carers taking on a larger share of decisional responsibility due to the increasing impact of dementia symptoms (Samsi & Manthorpe, 2013). The strategy employed by carers, therefore, was to uphold and facilitate the remaining capacity of the person with dementia irrespective of the loss of abilities (Boyle, 2013a). Evidence supporting this form of decision-making in dementia suggests that the person living with dementia appreciated even trivial involvement in decision-making (Fetherstonghaugh et al., 2016).

### **3.3.6.4 *Delegated***

Delegated decision-making was the conscious act by the person with dementia of placing decision-making responsibility in the hands of others (Smebye et al., 2012). This decisional style was common in situations where consequences were major and of high risk. The carer is chosen to take on responsibility for making decisions was based on accumulated family bonds and social capital over a period of time (Smebye et al., 2012). As a consequence, decision-making responsibility was often deferred to the spousal carer and depended on the previous decision-making history and roles within the dyad (Horton-Deutsch et al 2007).

### **3.3.7 *What Factors Influence the Involvement of People Living with Dementia in Decision-Making?***

#### **3.3.7.1 Background Factors**

Background factors are those that should be present regardless of context and should run in the background for meaningful decision-making involvement. Tyrrell et al. (2006) suggest that people living with dementia are capable of expressing meaningful decisions but are often unheard in the decisional process. According to Tyrrell and colleagues' (2006) Freedom of Choice framework, a

person with dementia is in a better position to contribute to the decisional process if the following dimensions are in place: being informed, being listened to, ability to express opinion, time for reflection and reversibility of choice.

The components of the framework were implemented over various decision styles in the literature identified in this review. Carers managed the autonomy and expression of the person living with dementia in decision-making by upholding the necessary background factors (Boyle, 2013b; Fetherstonhaugh et al., 2016; Smebye et al., 2012). The framework was upheld by carers through supervision, guidance, emotional support and facilitating communication where carers played a resourceful role (Boyle, 2013b; Fetherstonhaugh et al., 2016; Horton- Deutsch et al 2006). Background factors created a ‘space’ in which a person living with dementia’s voice could be meaningfully heard. This concept of having space to decide, led people living with dementia to feel central to decisions. This was seen as a way of combatting dementia symptoms and conquering challenges such as negotiating support from carers whilst still remaining involved in the decision –making process (Fetherstonhaugh, Tarzia, & Nay, 2013).

The freedom of choice framework therefore can be seen as way of adapting in the face of symptomatic changes in chronic conditions, where decisional involvement contributed to an overall sense of empowerment (Fetherstonhaugh et al., 2016; Menne & Whitlatch, 2007; Miller et al., 2017; O’Brien, Clemson & Canning, 2016). When these background factors were not in place, there was lack of opportunity, marginalisation and exclusion of people living with dementia due to others (Boyle 2013a; Fetherstonhaugh et al., 2016;

Smebye et al., 2012). There were examples of decisional styles that violated the freedom of choice framework, suppressing involvement sometimes irrespective of decisional capacity. These decisional styles fell outside the freedom of choice framework and were not included in the final synthesis model as the person living with dementia was not involved in the process hence did not contribute to the outcome. These were styles such as pseudo-autonomous (“people talk about me, around me but not to me”, Fetherstonhaugh et al., 2013) and non-involvement (the product of either loss of decision-making ability or lack of opportunity, Smebye et al., 2012; Boyle, 2013a). Along with other carer-led styles such as retrospective (carers make decisions about a person based on accumulated knowledge; Samsi & Manthorpe, 2013) and best interest or substitute (completely carer-led decision-making regardless of consent from the person living with dementia; Samsi & Manthorpe, 2013).

### **3.3.7.2 Contextual Factors: Risk, Relationships and Resources**

Contextual factors are transient and unique to certain types of decisions within particular domains. The freedom of choice made up background factors that created the figurative space for people living with dementia to be involved in decision-making, however the contextual factors influences this involvement.

**Risk.** Authors of included papers illustrated the tensions experienced by carers of people living with dementia between supporting autonomy and maximising safety. In the presence of risk, some carers were able to facilitate activities such as driving in the face of deteriorating ability, upholding the freedom of choice framework (“[wife] we’ve discussed this issue about him losing his license eventually because his brother had a stroke and he eventually had to give up his license. So . . . one of these days it will come to that . . . and I think if we keep

educating him and keep telling him [it will help]”, Adler, 2010). However, sometimes the factor of risk led to decision-making occurring outside the freedom of choice framework and synthesis model as the person living with dementia was excluded from contributing to the outcome (“[carer speaking to a professional] I want you to tell him to stop driving”, Adler, 2010). High risk lowered levels of decisional involvement from the person living with dementia, and where a particular conclusion was deemed necessary (e.g. for the person living with dementia to discontinue driving), it became difficult for a carer to stay in a supportive role (Adler 2010; Fetherstonhaugh et al. 2016; Smebye 2012). To maintain risk aversion, spousal carers made decisions based on their own beliefs, overriding those of the person living with dementia, justifying their involvement as for the person’s “own good” (Fetherstonhaugh et al., 2016).

***Relationships.*** Research in healthcare decision-making suggested that people with dementia did not feel well informed, listened to, able to express their opinions, or reflect on decisions enough when supported by adult children compared to spousal carers (Tyrrell et al., 2006). For minor decisions, female compared to male spouses were better at ensuring background factors were in place, as highlighted by the freedom of choice framework (Boyle, 2013; Tyrrell et al., 2006). However, this gender difference was not apparent for major decisions, where background factors were not incorporated into the decision-making process irrespective of gender. Domineering behaviours left the person with dementia feeling marginalised and excluded from decisions, even in the presence of decisional capacity (Boyle, 2013; Fetherstonhaugh et al., 2013). This behaviour from the carer was often viewed negatively by the person with dementia, causing

them frustration and reducing their sense of control and opportunity (Fetherstonhaugh et al., 2013).

Married dyads had habituated roles (e.g. financial management), which had been established over time and provided an infrastructure for decision-making. In the face of dementia symptoms, men were more likely to resist financial management by their female spouses (Boyle, 2013a). In contrast, evidence from advanced health care planning suggests that, regardless of prior history, dyads did not initiate decision-making until a crisis occurred (Harrison-Dening et al., 2017). This suggests that the relationship history within a dyad may contribute to the domain-specific decisional involvement of a person living with dementia.

***Recourses.*** A carer's ability to perform a supportive role within the decisional process (employ support strategies) influenced the decisional-style used. For example, carers who dominated the conversation diminished the opportunity for the person with dementia to express their views (Boyle 2013b). Wang and Nolan (2016) outlined 'hiding' behaviours (failing to disclose negative information or tailoring the truth) performed by a sample of Chinese carers (formal and informal) that served the purpose of upholding cultural values but precluded individuals with stroke from difficult decisions, all together reducing their decisional-involvement. On the other hand, when carers provided guidance, emotional support and dialogue around choices they were seen as a resource to help the person living with dementia negotiate decisions (Boyle 2013; Fetherstonhaugh et al., 2016; Horton-Deutsch et al., 2006).

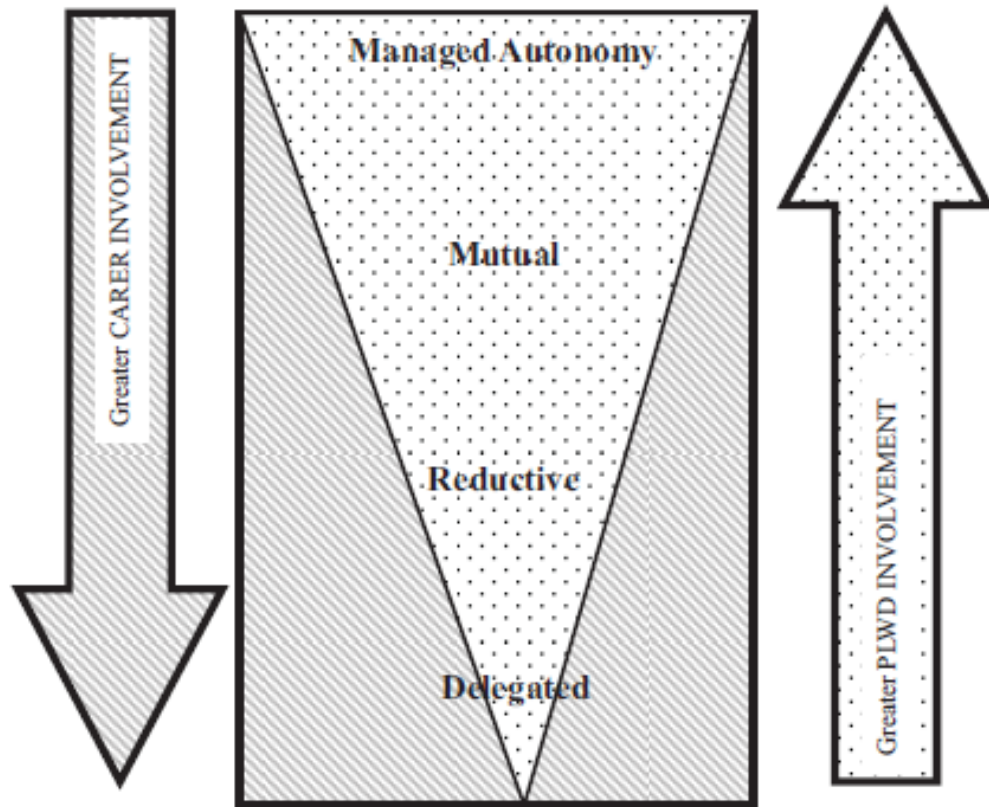
The presence of cognitive impairment was seen, by some, as a precluding factor for decision-making and could lead to the conclusion that the person living with dementia was unable to contribute to the decision-making process (Boyle 2013a; Fetherstonhaugh et al., 2013). However, when a carer performed a supportive role implemented the aforementioned support strategies it was still possible for the person living with dementia to meaningfully engage in the decision-making process (Tyrrell et al 2006).

### **3.3.8 *The Synthesis Model***

The synthesis model (Figure 3.2) is a representation of two dynamic transitions; the lesser involvement from the person living with dementia across decisional styles and the greater involvement from the carer. Involvement is defined as the extent to which a person contributes to a decisional outcome. This model is a reflection of evidence from research studies where the majority of participants were able to give written informed consent and had mild or moderate dementia. A key message arising from the model is that the involvement of a person living with dementia in decision-making is not always dictated by cognitive impairment or capacity. Other factors that contribute were explored through two lenses. Firstly, background factors (being informed, listened to, expression of opinion, time for reflection and reversibility of choice) placed a person living with dementia in a better position to participate in active and meaningful decision-making. Secondly, three domains (contextual factors) influenced the decisional style implemented. The involvement of a carer in the decision-making process, according to such contextual factors, gave rise to a spectrum whereby carers were placed as having a supportive to suppressive role.

Figure 3.2.

*Narrative synthesis model representing the decision-making involvement of a person living with dementia and carer.*



Background factors make the space for these decisional styles (Freedom of Choice Framework<sup>1</sup>) which can be influenced by contextual factors such as risk, relationships and resources.<sup>1</sup>Tyrrell et al., (2006): being informed, being listened to, expression of opinion, reflection and reversibility of choice



### **3.4 Discussion**

The studies in this systematic review cover decision-making by people with dementia on everyday-life, driving, health and social care, financial planning, research participation and exercise. No studies considered decision-making about diagnostic disclosure. The synthesis draws together four styles of decision-making that people living with dementia use with varying levels of involvement from carers. The term ‘shared decision-making’ lacks definitional specificity, as it refers to ambiguous and undefined levels of involvement from a person living with dementia and a carer (usually spousal). For this reason, other terms are used such as managed autonomy, mutual, reductive and delegated decision-making. Findings suggest that factors other than cognitive impairment contribute to the way in which people living with dementia make decisions. Factors that influence decisional involvement include background (freedom of choice framework) and contextual factors (risk, relationships and resources).

#### ***3.4.1 Summary of Model***

Narrative synthesis methodology allowed the findings of both qualitative and quantitative studies to be brought together in a synthesis model. The model represents how people living with dementia make decisions based on their level of involvement across decisional styles, rather than over cognitive decline or time.

The synthesis model encompasses four decisional styles (managed autonomy, mutual, reductive and delegated) that are implemented based on the presence or absence of background and contextual factors. Findings suggest that cognitive impairment is not always the key dimension through which the

decisional involvement of a person living with dementia is determined. A plethora of factors such as background factors and contextual factors also contribute.

This review provides support for previous research on the importance of decision-making to the ongoing autonomy of people living with dementia (Davis et al., 2017; Menne, Tucke, Whitlatch & Feinberg, 2008; Whitlatch & Menne, 2009). The findings suggest that preservation of autonomy and decisional involvement are related objectives (Fetherstonhaugh et al 2013; Miller, Lee, Whitlatch & Lyons, 2017; Samsi & Manthorpe, 2013). This review has successfully linked these objectives through the presence of background and contextual factors.

### ***3.4.2 Critical Reflection of Robustness of Synthesis***

The review had well-defined inclusion and exclusion criteria that were developed in a protocol with the aim of capturing as many relevant studies in line with the research question. Further, the identification and selection process was conducted over a number of pre-specified stages with two independent reviewers during two critical stages, namely, abstract screening and quality appraisal of studies, greatly reducing the impact of bias.

A narrative approach allowed for the synthesis of both qualitative and quantitative literature to construct a model of decision-making in dementia. Although suitable for the evidence base in this review, a narrative synthesis does pose methodological limitations. The range of techniques that can be implemented in a narrative synthesis may cause the same evidence to synthesise in different ways. In addition, there is limited guidance on the synthesis of both qualitative and quantitative research designs (Dixon-Woods et al., 2005).

Regardless of these limitations, this review was conducted in line with guidance from Popay et al., (2006) for methodological consistency. The final synthesis model was discussed with a small group of carers who validated the decisional styles and factors through personal experiences with their spouses living with dementia. Further, the qualitative and quantitative quality appraisal tools used were standardised and comparable between study designs. The latter suited the nature of this review as the evidence reviewed was of both a qualitative and quantitative nature.

### **3.4.3 Limitations**

The chosen databases were based on the author's previous knowledge, recommendations from experts and published reviews. Only peer-reviewed, published full text studies in the English language were eligible for inclusion. Therefore, some relevant material may not have been included, for example non-academic literature. This review also contained a small number of studies from predominantly Western parts of the world, restricting the generalisability of findings to other cultural backgrounds.

### **3.5 Implications**

The above systematic review did not find any papers that covered disclosure decision-making in dementia, despite the importance of disclosure for accessing support from others (Chapter 1) and the challenge of disclosure due to societal- and self-stigma (Chapter 2). Therefore, disclosure decision-making models will now be discussed, in light of the findings of the systematic review presented in this Chapter to inform the development of an intervention to support

people living with dementia who are fearful of disclosing their diagnosis (Chapter 6).

### ***3.5.1 Stigma, Secrecy and Disclosure Decision-Making***

Receiving a diagnosis of dementia presents individuals with both social and psychological challenges where stigma is a pivotal and powerful negative force shaping people's experiences (Harper et al., 2018; O'Connor et al., 2018). Henceforth, the term 'diagnostic disclosure' in this thesis is used specifically to refer to disclosures made by individuals living with dementia who decide to tell others their diagnosis or difficulties they are experiencing related to dementia (e.g. memory problems, diagnosis of Alzheimer's), differing from diagnostic disclosures made by clinicians, for example, which were discussed in Chapter 1. It is important to note that carers may also make disclosure decisions and this will be explored in Chapters 6 and 7.

Stigma literature has approached concealability through the lens of disclosure where individuals may conceal their 'mark' to avoid negative ramifications. There is an important dichotomy relating back to the work of (Goffman, 1963) on concealability; where the way in which an individual experiences stigma depends on the extent to how concealable the mark is. This is because 'marks' vary in visibility, for example someone who is in a wheelchair cannot conceal this whereas someone with depression may be able conceal their diagnostic label. The *private hell* of cognitive preoccupations that result of concealing stigma can have three main impacts: (1) double distress associated with the consequences of possessing a stigma compounded by the fear that the stigma may be discovered; (2) forfeiting the benefits that come from identifying

with other members of a stigmatised group and (3) never fully being able to internalise feedback from others and feedback of one's true self (Pachankis, 2007).

There is a significant body of evidence supporting stigma as a barrier to disclosure in mental health and other populations (Benoit et al., 2018; Corrigan et al., 2016, 2015; Oexle et al., 2017; Thornicroft et al., 2016). Several authors have sought to understand disclosure in populations such as bisexual people (Pachankis, 2007), children and adults with mental health difficulties (Corrigan, Larson, & Rüsche, 2009; Corrigan et al., 2016) and sex workers (Benoit et al., 2018). These authors posit that the need to be secretive about one's concealable stigmatising characteristic (e.g. mental health diagnosis) is one of the consequences of experiencing self-stigma.

Self-stigma can stop a person disclosing their stigmatised identity (e.g. secrecy or concealment) to protect against social avoidance and rejection (Corrigan et al., 2009), experiencing judgement and conflict with others (McLean, 2007) and being labelled and stigmatised in the form of discrimination by others (Buchholz, Aylward, McKenzie, & Corrigan, 2015).

Secrecy or concealment as a result of self-stigma has also been considered to be a "torturous burden" (Paxton, 2002; p564), with consequences such as low self-esteem (Corrigan, Kosyluk, & Rüsche, 2013), delayed help-seeking from family and friends (Gronholm, Thornicroft, Laurens, & Evans-Lacko, 2016) negative consequences of suppression such as intrusive thoughts and paranoia (Pachankis, 2007)

Experiencing self-stigma creates difficulties in the disclosure decision-making process. People with stigmatised identities have to consider not only coping with negative internalised stereotypes but also the immediate reactions of others and the potential for long-term consequences such as public stigma. Disclosure decision-making is therefore, charged with fear and anxieties about the reactions of others, whether there will be a potential loss of love and support and lack of acceptance (McLean, 2007). In HIV/AIDS the concept of disclosure has been described as a paradox because, although disclosing a diagnosis may lead to opportunities for support, disclosure can make an individual vulnerable to the perceived stigma of others, where a choice may be made to sustain a ‘double life’ if concealability is possible (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003; Paxton, 2002). Diagnostic disclosure led individuals to feel an improvement in stress and health even though disclosing to others was difficult and frightening (Paxton, 2002). In one study, young people with mental health problems conceptualised disclosure as an act of undermining self- and public stigma and therefore promoted empowerment and courage through telling others about their mental health difficulties (Buchholz et al., 2015)

### ***3.5.2 Models of Disclosure Decision-Making***

To the author’s knowledge, there are no models of disclosure decision-making in dementia. This section will describe disclosure models in other populations coupled with the findings of the systematic review presented previously in this Chapter to develop an understanding of how stigma may influence the disclosure process for people living with dementia.

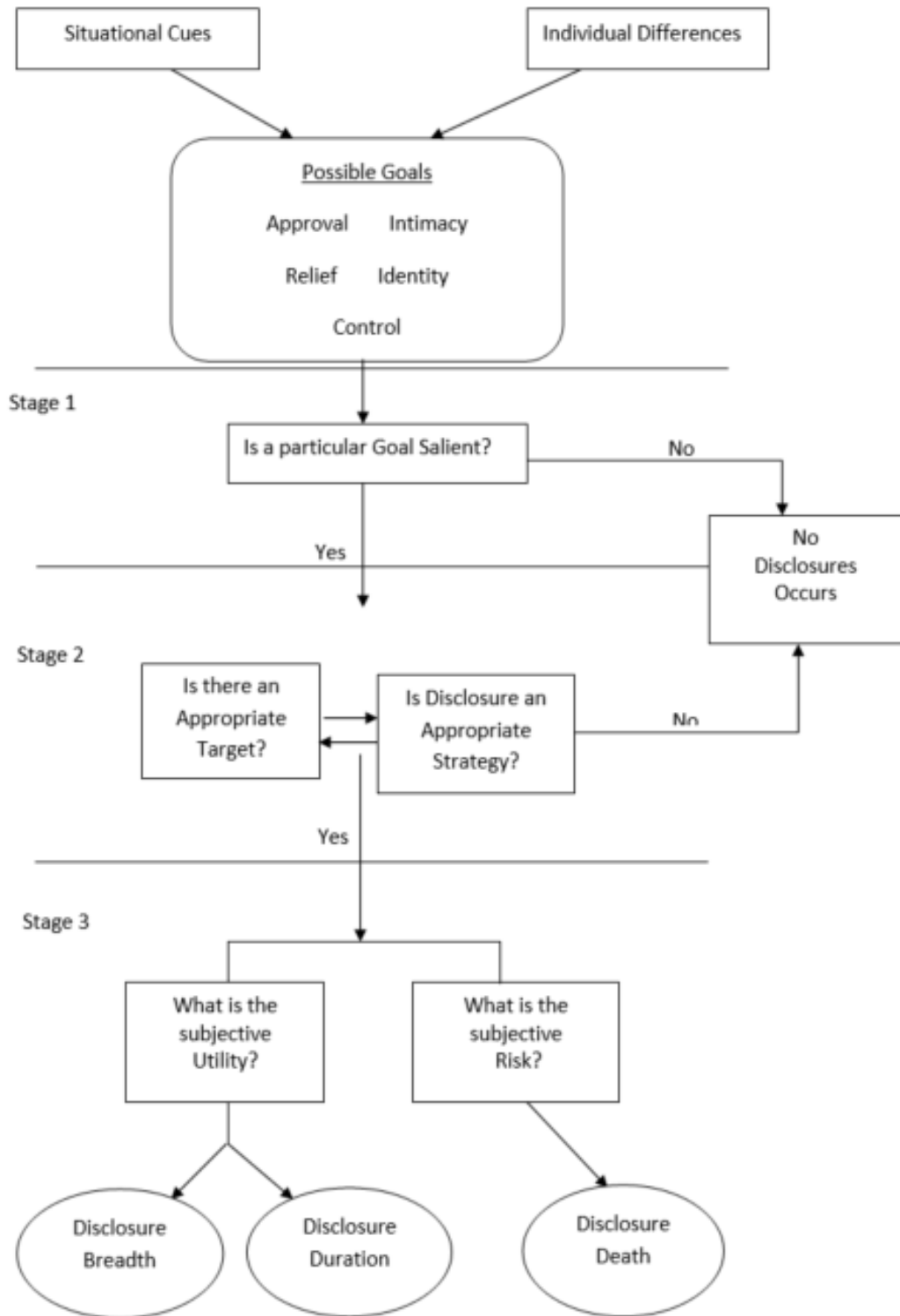
#### **3.5.2.1 The Disclosure Decision Model (Omarzu, 2000)**

The Disclosure Decision Model is not population-specific and includes three stages that aim to explain how a disclosure event takes place across various different social situations, based on the assumption that disclosure decisions (what, how and who) are the product of careful consideration of risks and rewards (Figure 3.3; Omarzu, 2000).

Before stage one begins, in order to analyse whether disclosure is the most efficacious means of reaching one of five potential goals (social approval, intimacy, relief from distress, clarification of identity, social control), social cues and individual differences are evaluated. The evaluation of social cues and individual differences predicts the breadth (number of topics), length (time or number of words) and depth (level of details) of the disclosure (Omarzu, 2000).

*Figure 3.3.*

*The Disclosure Decision Model (Omarzu, 2000)*





***Stage 1: Entering the Situation and Pursuit of Social Goal.*** In order for disclosure to occur, individuals must enter into a situation where disclosure is made accessible and the goal of doing so be clearly defined and justifiable (Omarzu, 2000). Sometimes in complex situations, the accessibility and goal is not always clear and at times there may be conflict, for example, disclosure may achieve relief from distress whilst simultaneously compromising approval from others. More specifically to dementia, accessibility of a situation could be understood through the background factors (being informed, being listened to, ability to express opinion, time for reflection and reversibility of choice) presented earlier in this the systematic review (Tyrrell, Genin, & Myslinski, 2006). Background factors may create accessible environments in which people living with dementia may meaningfully engage in the disclosure decision-making process.

***Stage 2: Strategy Selection and Target Search.*** When both a situation and goal become accessible, an individual then evaluates whether disclosure is an appropriate strategy to exercise and if so, then with whom. Alternatives to disclosure are goal dependent; intimacy, for example, can be achieved through behaviours representing affection rather than the sharing of personal information. It is possible for a target to be selected before the goal pursuit strategy, or vice versa. In the context of dementia, it is likely that the target may be predetermined (children, neighbours or friends) and disclosure may happen in many different ways (email, telephone, letter) however, the Disclosure Decision Model only includes verbal disclosure.

**Stage 3: Subjective Utility versus Subjective Risk.** Once disclosure has been nominated as the appropriate strategy and a target has been selected, the last stage involves decisions of the features of disclosure (breadth, length and depth). Subjective utility refers to the perceived value placed upon the social goal and subjective risk refers to any adverse effects of disclosure such as social rejection, discomfort or betrayal.

### **3.5.2.2 An Integrated Model of Health Disclosure Decision-Making (HDDM; Greene, 2009)**

The HDDM outlines the disclosure decision-making process (see Figure 3.4), that takes place face to face between people rather than disclosure in public situations (Greene, 2009). The basic assumption of the HDDM is that disclosing a diagnosis can be planned and mindful however, this does not dissipate the unpredictability of the process as it can be interrupted at any point.

**Assessing Information.** Initially the discloser (person with a diagnosis) makes sense of the information available about their diagnosis through five components: the stigma associated with the diagnostic label, the prognosis of a diagnosis, symptoms, preparation and the relevance of the diagnosis to others.

**Assessing the Receiver.** The discloser considers the quality of the relationship between themselves and the receiver (person potentially being told the diagnosis) and then begins to make judgements on the way in which the receiver will react.

**Disclosure Efficacy.** The disclosure efficacy is the relationship between a discloser's ability to share the diagnosis and whether a desirable outcome will be produced. Disclosure efficacy may also be framed within the contextual factors outlined in the systematic review previously presented. For example, for people living with dementia disclosure efficacy may depend upon the resources

available, which included a carer's ability to play a support role and the cognitive impairment of the person living with dementia.

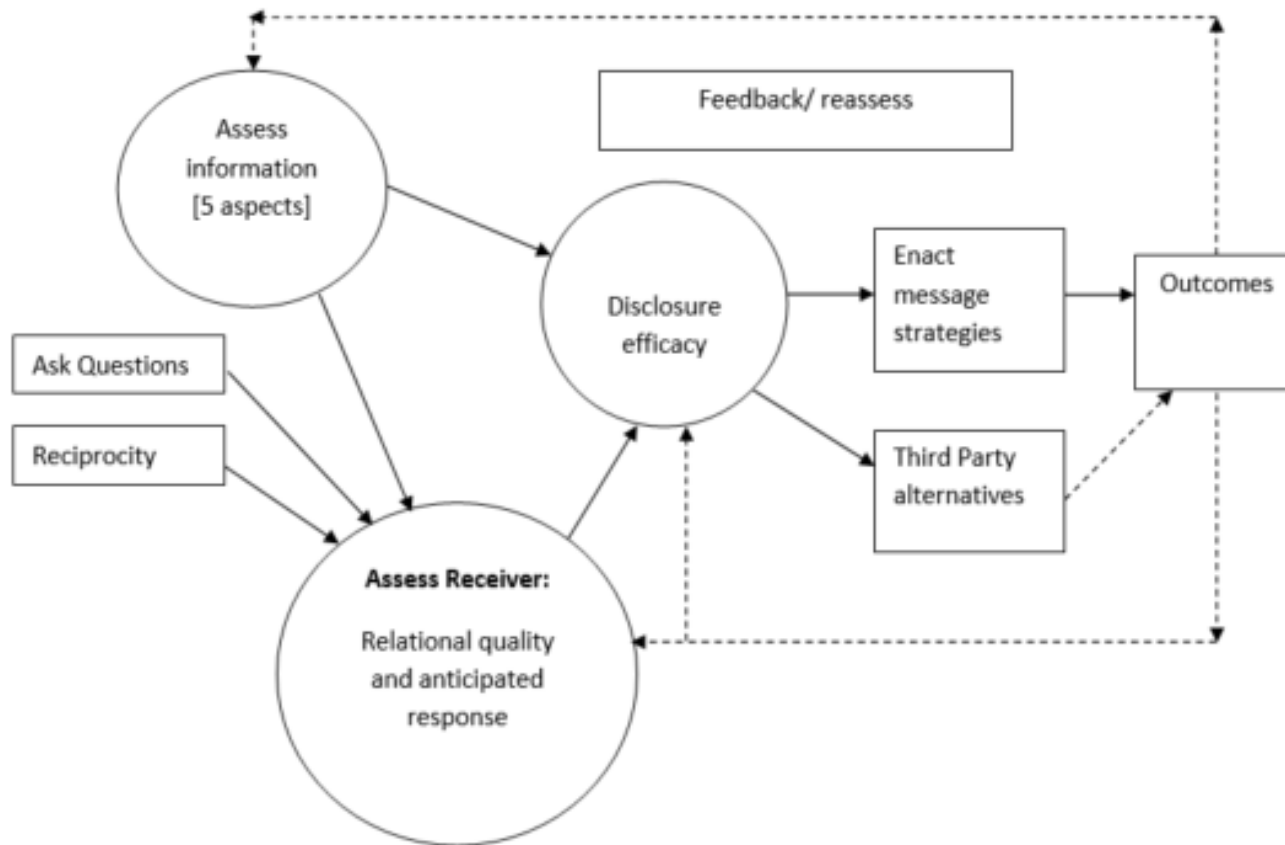
***Third party disclosure.*** This element of the HDDM refers to the potential for people other than the discloser to do the sharing. This can be through intentional or unintentional reasons. This is particularly relevant for people living with dementia as demonstrated in the systematic review where certain styles of decision-making require greater involvement from carers. In the reductive style of decision-making defined by carers took on a larger share of decisional responsibility due to the increasing impact of dementia symptoms (Samsi & Manthorpe, 2013) and in the delegated decisional style, carers took on the responsibility for making decisions on behalf of people living with dementia (Smebye et al., 2012). Where third party disclosure is concerned, the strategy employed by carers was to uphold and facilitate the remaining capacity of the person with dementia irrespective of the loss of abilities (Boyle, 2013a).

***Interruptions in the Model.*** As the disclosure process is nonlinear, there are instances or circumstances that can change a discloser's intention to share the diagnosis. Interruptions can be the result of questions or reciprocity. For example, there are instances where questions from others can initiate disclosure but also create a situation where the discloser cannot escape the act of disclosing, especially if that person has information such as knowing the discloser had a hospital appointment or is waiting on test results. Reciprocity in the HDDM is seen as a potential reason for disclosure, as people who share generally receive an equivalent amount of information as disclosure is reciprocated.

When adequate disclosure efficacy is perceived, and all other components of the model are assessed and point towards following through with disclosure, the enactment of disclosing occurs which may be through planning (how and when) and rehearsal. The outcome can become difficult to quantify as it can go beyond the act of disclosing, for example, even with firm intentions of sharing a diagnosis a discloser may not do so because there can be a separation between goals and behaviour.

Figure 3.4.

An integrated model of health disclosure decision-making (Greene, 2009)



### 3.5.2.3 The Disclosure Process Model (Chaudoir & Fisher, 2010)

The Disclosure Process Model (Figure 3.5) is based on the assumption that disclosing a concealable stigmatised diagnosis is a complex process that can result in benefits and harm (Chaudoir & Fisher, 2010; Chaudoir, Fisher, & Simoni, 2011). The DPM is designed to help understand when and why disclosing a stigmatising characteristic is beneficial to an individual. It is important to note that Chaudoir and Colleagues (2010) did not describe disclosure as a single event; in fact, disclosure is an ongoing process that has implications across several domains.

***Antecedent Goals.*** Individuals predict the outcomes of disclosure based on antecedent goals that are based on an approach (e.g. attainment of reward) or avoidance (e.g. avoiding punishment) motivational system.

***Disclosure Event.*** The disclosure event is the situation in which information about one's identity is disclosed (e.g. stigmatised diagnosis) in a verbal exchange between a discloser and confidant.

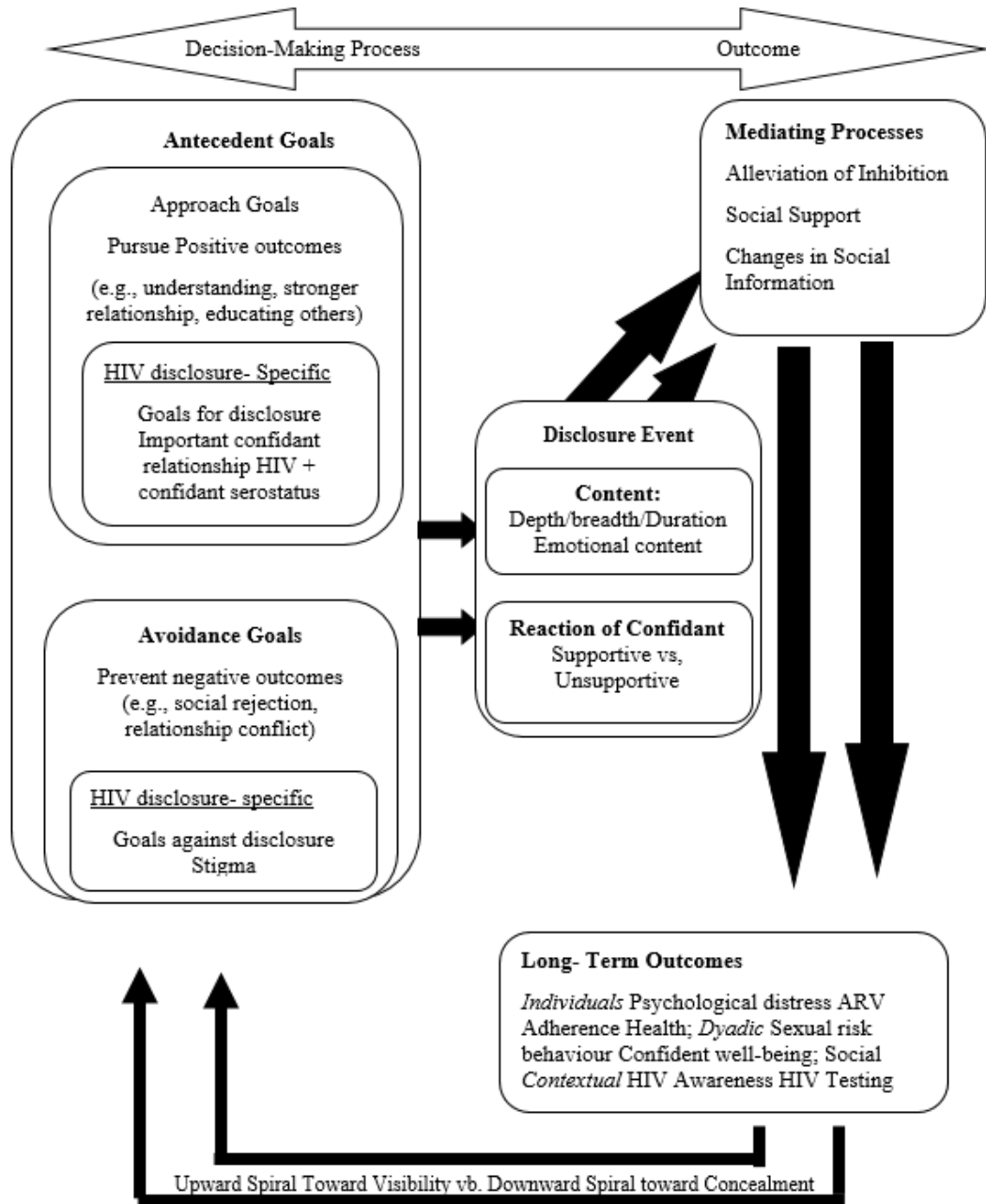
***Mediating Processes and Disclosure Outcomes.*** Chaudoir and Fisher (2010) outlined that that a disclosure event can effect individual (e.g. psychological stress), dyadic (e.g. quality and intimacy between discloser and confidant) and social contextual (e.g. HIV awareness) outcomes. The impact of disclosure on these three outcomes is mediated by three potential process. Firstly, the alleviation of inhibition, the social support that is available and the changes in social information. Applying this to dementia would be mean that disclosing a diagnosis of dementia may alleviate negative psychosocial and physiological

consequences of suppression, nurture social relationships through and introduce new information about what it is like to live with dementia to shape the perceptions of others in both the context of the disclosure event but also beyond this time.

***Feedback Loop.*** Single disclosure events influence the ways in which future disclosure takes place, this element of the DPM is called the feedback loop.

Figure 3.5.

The Disclosure Process Model (Chaudoir & Fisher, 2010)





#### **3.5.2.4 Appraisal of Disclosure Decision-Making Models for People living with Dementia**

The component of interpersonal risk is addressed in all three disclosure decision-making models (Chaudoir & Fisher, 2010; Greene, 2009; Omarzu, 2000) as well as the systematic review presented previously in this Chapter 3 (Adler, 2010; Fetherstonhaugh et al., 2016; Smebye et al., 2012). All three disclosure decision-making models presented above omit the role of a carer which has been highlighted to influence the decision-making process for people living with dementia (Boyle, 2013a; Tyrrell et al., 2006). There was however, mention of third party decision-making which may be how carers of people living with dementia influence disclosure decision-making for people living with dementia (Omarzu, 2000). Together, it is plausible to suggest that risk can add important context to disclosure decisions for people living with dementia that may have implications for the roles carers play in supporting or hindering the decisional process.

The literature reviewed in Chapter 2 and the importance placed upon the role of stigma in two of the disclosure decision-making models (Chaudoir & Fisher, 2010; Greene, 2009) highlights an understudied phenomenon in the nature of decision-making in dementia that was not identified in the previously presented systematic review.

#### **3.5.3 *Disclosure Decision-Making Literature in Dementia***

Secrecy or dilemmas around disclosing can lead to harmful psychological and social consequences for those living with a stigmatised identity; however, secrecy can also provide protection from further stigmatisation (Corrigan et al., 2009). Not knowing who, how or when to tell others about a diagnosis of

dementia and associated difficulties can be disempowering, leading some people living with dementia, and their close family, to cut themselves off from social activities and pastimes (O'Connor et al., 2018). It is important to acknowledge the complexities of disclosure that are grounded in various contexts that may be dynamic and highly individualised (Chaudoir et al., 2011). Disclosure by people living with dementia to others in their social networks has been understudied with only two empirical papers to date, by O'Connor, Mann, and Wiersma, (2018) and Weaks, Wilkinson, & McLeod, (2015).

In the study by Weaks et al., (2015), qualitative interviews with five people living with dementia and their carers were conducted within 6 months of receiving the diagnosis to explore the experiences of sharing the diagnosis with others, using a grounded theory approach. Participants of the study noted that disclosure decision-making was challenging and complex with factors that needed to be carefully considered such as whether or not to disclose and the implications of not disclosing versus disclosing, who should be told and when and dealing with the reactions of others.

Participants' reasons for not wanting to disclose included being a private person, loss of information control once others had been told and not wanting to be subject to stigmatisation. Weaks and Colleagues (2015) noted that stigma was a barrier to participants disclosing a diagnosis of dementia and associated with this was fear of the reactions of others. The stigma associated with dementia perpetuated the negative consequences of disclosure where one participant noted 'well if I told a lot more people I would think that relationships would change, but I haven't told that many people... it's a stigma' (Weaks et al., 2015; p772). The

main reason noted by participants to disclose a diagnosis was in order to provide an explanation for behaviour changes, another reason included the worry of dementia being genetic and therefore participants felt a responsibility to alter other family members. Collectively, Weaks et al (2015) found that there were more reasons for participants to remain secretive about their diagnosis. Choosing whom to tell about a diagnosis of dementia was based on personal feeling towards members of a participant's social network (respect or liking for an individual) but was also a strategic attempt to inform those who could make necessary accommodations for participants (e.g. disclosing to a church pastor because the participant felt they may be unable to volunteer as often). The process of deciding who to tell generated both feelings of unity within families but also a great deal of stress and concern (Weaks et al., 2015).

Implications for disclosing a diagnosis of dementia included obtaining more support that was also seen as a loss of autonomy. Implications for secrecy were mostly negative, such as isolation from others and potential services who could provide support, however secrecy was heavily support as a means of protection against the negative reactions of others. Participants noted mixed reactions to disclosing a diagnosis of dementia. Some were met with sadness and denial by those they told but also understanding and support, whereas in other cases the topic of the diagnosis was not brought up again. When the latter occurred, participants felt unable to have meaningful discussions and express how they were feeling, participants felt it was important 'to be able to talk about it' (Weaks et al., 2015; p778).

Weaks and Colleagues (2015) found that disclosing a diagnosis of dementia depended upon the pre-existing relationships and resources (e.g. support from the carer) and personality traits (e.g. greater emotional resilience led participants to more easily disclose). These findings are similar to that of the systematic review presented earlier within this Chapter, where meaningful decision-making by people living with dementia depended on contextual factors such as support from carers and the quality of existing relationships. (Boyle, 2013b; Fetherstonhaugh et al., 2016; Horton-Deutsch et al., 2007; Wang & Nolan, 2016).

O'Connor and Colleagues (2018) used participatory action research methodology to explore what people living with dementia need to know to live well, by doing so the connection between experiencing stigma and disclosure decision-making spontaneously emerged (O'Connor et al., 2018). Eight people living with dementia who met monthly were interviewed over 16 months (O'Connor et al., 2018). People living with dementia discussed the topic of disclosure with fear and trepidation but framed the exercise as a protective measure to increase tolerance through understanding and to explain or justify behaviours that may be unusual to others clearing the space for help. Disclosure was also spoken about by people living with dementia in terms of risk, specifically the risk of being discriminated and stigmatised by others once others knew about a diagnosis: '*Stigma can hurt. It can hurt your feelings*' (p44, O'Connor et al., 2018). Some participants found that disclosure led to a loss of opportunity, active participation and meaningful activity (O'Connor et al., 2018).

The link between stigmatisation and disclosure as evidenced by O'Connor and colleagues is consistent with previous work (Burgener, Buckwalter, Perkhounkova, & Liu, 2015). However, participants interviewed by O'Connor et al. (2018) also framed disclosure as a mechanism to combat stigma (e.g. an act of resistance) to empower the person doing the disclosing but also others around them living with dementia. The promotion of empowerment and benefits of disclosing as an act of stigma resistance has also been found in other populations as mentioned previously (Buchholz et al., 2015; Kalichman et al., 2003; Paxton, 2002). Together, O'Connor and colleagues highlight the integral role of stigma in the experiences of people living with dementia, identifying stigma as a barrier to disclosure and paradoxically disclosure as an act of stigma resistance.

### ***3.5.4 Disclosure Decision-Making Support Interventions***

One of the most prominent interventions to support disclosure decision-making in social networks is the Honest Open Proud (HOP) programme. It was based on an early intervention for homosexual women with the aim of promoting disclosure and reducing the negative impact of secrecy (Morrow, 1996). Non-experimental results of this work showed higher disclosure rates corresponded with identity development and enhanced personal empowerment. Major and O'Brien (2005) argue from the perspective of social psychology that identifying with a stigmatised group (once membership is possible e.g. diagnosis of a mental health condition) resolves self-stigma by less stress arising from prejudice. Corrigan, Larson and Rusch (2009) outlined the way in which personal reactions to stereotypes can become internalised causing harmful influences on health and achievement of personal goals, in adults with mental health conditions. A diagnostic label or related difficulties can therefore cause withdrawal from

participation in services and avoidance of situations where one feels the stigma attached to their diagnostic label will cause them harm (Corrigan et al 2010; Corrigan et al 2013; Link et al 1989). Stigma as a barrier to disclosure and identity adoption, however, is not just a concern for individuals with a mental health; compelling evidence already presented in this thesis from other populations suggest that secrecy is a method to avoid stigmatisation both externally and internally (Chaudior, Fisher & Simoni 2011; Paxton 2002; Schrimshaw, Downing & Cohan 2016).

Corrigan et al. (2013) used the work of Marrow (1996) to address mental health disclosure and self-stigma through HOP, a peer-group programme with the aim of supporting people with mental health problems make empowered disclosure decisions. The manual for HOP is [freely available online](#) and includes useful sections, which will be presented in Chapter 6. HOP is based on the rationale that self-stigma is a barrier to disclosing a mental health diagnosis. The intervention seeks to reduce levels of self-stigma which has been defined as the process of internalising the stigma experience leading to diminishing self-esteem and self-efficacy (Corrigan & Watson, 2002).

HOP is organised into three lessons with an additional booster lesson that serves the purpose of helping participants revisit disclosure decision over time (Scior, Rüscher, White, & Corrigan, 2019). As suggested previously, disclosure is not just a single event but occurs over a period of time and is dynamic depending on the context and situation (Chaudoir & Fisher, 2010). HOP is facilitated (or co-facilitated) with people who have lived experience of mental health problems and have themselves completed the HOP programme along with the master training.

### **3.6 Conclusion**

The systematic review I presented in the first part of this Chapter and the disclosure decision-making literature presented in the latter part, together, can help to form an understanding of the influence of stigma on disclosure decision-making in dementia. The systematic review established background and contextual factors that influence decision-making practices that were defined across four styles of decision-making. The disclosure decision-making models add the nuanced role of stigma and how it may exacerbate both the interpersonal and social risk associated with the decisional process for people living with dementia. Previous literature cited in Chapter 2 and earlier within the current Chapter, speak to the notion that stigma is a barrier to disclosure decision-making and therefore, influences disclosure through adding the complexities associated with the consequences of stigma (social isolation, withdrawal, rejection, low self-esteem, fear of negative reactions, loss of relationships). To make way for further empirical study, it is now necessary to develop and evaluate psychometric instruments of self-stigma for use in people living with dementia that will be the focus of Chapter 4.

#### **4 Adaptation and preliminary psychometric properties of three self-stigma outcome measures for people living with dementia**

A version of this chapter has been submitted for publication and is available on Research Square as a preprint:

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##### **4.1 Introduction**

Chapter 2 outlined a field of dementia related-stigma research, which has mostly consisted of public stigma rather than self-stigma measurement. Chapter 3 shed light on the influence of stigma on disclosure decision-making in other populations where self-stigma has been found to be a barrier to people disclosing their stigmatised identities. The aim of this Chapter is to describe the development and evaluation of psychometric instruments of self-stigma for use in people living with dementia.

As covered in Chapter 2, self-stigma has lasting negative consequences for people living with dementia such as withdrawing from everyday activities or interactions, delays in help-seeking, loss of confidence and feeling inferior (Devlin et al., 2006; Morgan et al., 2002; O’Sullivan et al., 2014; Walmsley & McCormack, 2016; Werner et al., 2010). Furthermore, recent systematic reviews found self-stigma to be associated with increased anxiety and depression, and lower levels of mastery, self-esteem, social support and activity participation



(Burgener, Buckwalter, Perkhounkova, & Liu, 2015; Burgener, Buckwalter, Perkhounkova, Liu, et al., 2015; Nguyen & Li, 2018).

#### ***4.1.1 Quantifying Self-Stigma***

The measurement of self-stigma is complex with no widely recognised ‘gold standard’ approach. For example, a review of 57 empirical papers documented five self-stigma outcome measures for people with a mental health diagnosis (Brohan, Slade, Clement, & Thornicroft, 2010). Authors of the five self-stigma measures reported content validity, however no or little detail was given on other important psychometric properties such as internal consistency and convergent validity. A further systematic review examining the efficacy of psychosocial self-stigma interventions for people with schizophrenia-spectrum diagnoses identified six self-stigma measures from 12 studies (Wood, Byrne, Enache, & Morrison, 2018). Again, these measures were psychometrically limited with no of sensitivity to change in seven randomised controlled trials (RCTs). Collectively, both systematic reviews conclude that further refinement of self-stigma measures in line with reliability and validity criteria, careful cultural considerations and condition-specific adaptation with those who have lived experience of the condition are necessary avenues for future research (Brohan et al., 2010; Terwee et al., 2007; Wood, Byrne, Varese, & Morrison, 2016).

#### ***4.1.2 The Stigma Impact Scale***

As stated in Chapter 2, the Stigma Impact Scale (SIS) was based on the adapted Multidimensional Model of Perceived Stigma, which was used to explain self-stigma experienced by people living with Alzheimer’s and Parkinson’s disease (Burgener & Berger, 2008). The adaptation process included making the

instructions relevant specifically for persons with a progressive neurological disease, referring to these disease specific effects rather than other conditions. Further item modification was necessary to change HIV/AIDS references to those with neurological impairments. For example, 'Friends and family have avoided me since my diagnosis of HIV' was changed to 'Friends and family have avoided me since my diagnosis of neurological impairment'. All items are rated from 1 ('strongly disagree') to 4 ('strongly agree') with the addition of 0 for 'not applicable' items. The scale has four subscales: social rejection (9 items, e.g. "I feel others avoid me because of my impairment"); financial insecurity (3 items e.g. "My job security has been affected by my impairment"); internalised shame (5 items, e.g. "I feel others think I am to blame for my impairment"); and social isolation (7 items e.g. "I feel set apart from others who are well"). In a population of people with Alzheimer's disease, internal consistency for the subscales was 0.82, 0.56, 0.72 and 0.60 respectively (Burgener & Berger, 2008).

The JPND-MEETINGDEM project in people living with dementia used the SIS to evaluate the psychosocial programme, with 3 items relating to financial insecurity removed due to lack of relevance (Mangiaracina et al., 2017; Szcześniak et al., 2017). The JPND-MEETINGDEM study used the most updated version of the SIS, with the financial subscale removed, that has already been tested in people living with dementia in the UK, Poland and Italy (Lion et al., 2019; Szcześniak et al., 2017). The reported internal consistencies for the subscales of the SIS across all three countries ranged from 0.65-0.82, 0.69-0.80, and 0.67-0.84 respectively for social rejection, internalised shame and social isolation (Lion et al., 2019). In the UK sample only, the SIS overall had an

internal consistency of 0.85, with 0.65 for social rejection, 0.69 for internalised shame and 0.67 for social isolation (Lion et al., 2019).

Recent testing of the SIS in people living with dementia suggests an association between decreased levels of self-esteem and increased levels of internalised shame and social isolation, speaking to the inverse relationship between self-esteem and stigma concepts which has been found in other mental health conditions (Burgener, Buckwalter, Perkhounkova, Liu, et al., 2015; Corrigan et al., 2013).

The SIS is the only self-stigma scale that had been previously tested in populations living with dementia (Nguyen & Li, 2018). However, it now requires further testing as previous studies have underreported psychometric properties (internal consistency, convergent validity with self-esteem) and have not considered experts in adapting or modifying the instrument for people living with dementia in the UK (Burgener & Berger, 2008). In addition to this, there has not been any attention paid to disclosure-related distress or the stress appraisal of stigma, and how this may be associated with self-stigma concepts in people living with dementia.

### ***4.1.3 Aim and Objectives***

The aim of this Chapter is to describe the development and evaluation of psychometric instruments of self-stigma for use in people living with dementia.

The objectives were to:

- 1) Extract relevant psychometric outcome measures from the HOP evidence base (Corrigan et al., 2013);
- 2) Appraise identified measures for psychometric quality;

- 3) Modify measures for culture (UK) and condition (dementia) using stakeholder consultations;
- 4) Pilot the modified measures in a small sample of people living with dementia to test acceptability, and preliminary psychometric properties (internal consistency, test-retest, concurrent and convergent validity).

## **4.2 Methods**

### ***4.2.1 Stage 1: Review of Honest, Open, Proud (HOP) Outcome Measures***

As described in Chapter 3, Honest, Open, Proud (HOP) is a group-based psychosocial intervention delivered over three sessions to help people with mental health difficulties consider disclosing stigmatised identities (Corrigan et al., 2013; Scior et al., 2019). A review of the HOP intervention studies was conducted to identify stigma-related outcome measures that had been previously used in peer reviewed journal articles up until December 2018. Instruments were only included if: the focus of the measure was self-stigma as defined by Corrigan, Kerr, & Knudsen, (2005); the instrument had been used as an outcome measure in the evaluation of a HOP intervention; and intervention studies were published in peer reviewed academic journals. Instruments were excluded if the focus of the measure was on constructs not applicable to dementia, for example symptomatic recovery.

### ***4.2.2 Stage 2: Measure Selection***

Measures were selected using a combination of psychometric quality and research team appraisal.

#### **4.2.2.1 Psychometric Quality Appraisal**

The instruments identified were appraised for psychometric quality using guidance by Terwee, et al., (2007), which has been used in previous research to establish the quality of psychometric instruments (Stansfeld et al., 2017; Stoner, Orrell, & Spector, 2015; Windle, Bennett, & Noyes, 2011). A focussed search for journal articles describing the development of each identified measure was conducted and each was appraised across seven domains: 1) content validity; 2) internal consistency; 3) construct validity; 4) reproducibility (in two parts: agreement and reliability); 5) responsiveness; 6) floor and ceiling effects; and 7) interpretability.

Instruments were scored from 0 to 2 on each domain. Further details of scoring procedures are described in Stansfeld et al., (2017) and a summary can be found in Table 4.1. Overall quality appraisal scores were calculated by summing the scores for each domain, with a potential score range between 0 and 18. Labels were assigned to interpret the quality of the instruments based on Stansfeld et al., (2017), where instruments that scored 0-4 were categorised as ‘poor’ quality, 5-9 as ‘moderate’ quality, 10-14 as ‘good’ quality, and 15-18 as ‘very good’ quality

Table 4.1.

*Quality criteria for psychometric instruments (adapted from Terwee et al., 2007 and Stansfeld et al., 2017)*

Property	Definition	Quality Criteria
1. Content Validity	The extent to which the domain of interest is comprehensively sampled by the items in the questionnaire (the extent to which the measure represents all facets of the construct under question)	<p>2 A clear description of measurement aim, target population, concept(s) that are being measured, and the item selection AND target population (investigators OR experts) were involved in item selection.</p> <hr/> <p>1 A clear description of the above-mentioned only target population involved OR doubtful design</p> <hr/> <p>0 No target population involvement No information found on target population involvement</p>
2. Internal Consistency	The extent to which items in a (sub)scale are inter-correlated, thus measuring the same construct	<p>2 Factor analyses performed on adequate sample size (<math>7 \times \# \text{items}</math> and <math>\geq 100</math>) AND Cronbach's alpha(s) calculated per dimension AND Cronbach's alpha(s) between 0.70 and 0.95</p> <hr/> <p>1 No factor analysis OR doubtful design or method</p> <hr/> <p>0 Cronbach's alpha(s) <math>&lt; 0.70</math> or <math>&gt; 0.95</math>, despite adequate design and method/No information found on internal consistency</p>
3. Criterion Validity	The extent to which scores on a particular questionnaire relate to a gold standard	<p>2 Convincing arguments that gold standard is "gold" AND correlation with gold standard <math>\geq 0.70</math></p> <hr/> <p>1 No convincing arguments that gold standard is "gold" OR doubtful design or method</p>

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Property	Definition	Quality Criteria
		0 Correlation with gold standard <0.70, despite adequate design and method/No information found on criterion validity
4.	Construct Validity	The extent to which scores on a particular questionnaire relate to other measures in a manner that is consistent with theoretically derived hypotheses concerning the concepts that are being measured
		2 Specific hypotheses were formulated AND at least 75% of the results are in accordance with these hypotheses
		1 Doubtful design or method (e.g.) no hypotheses)
		0 Less than 75% of hypotheses were confirmed, despite adequate design and methods/No information found on construct validity
5. Reproducibility		
5.1	Agreement	The extent to which the scores on repeated measures are close to each other (absolute measurement error)
		2 SDC < MIC OR MIC outside the LOA OR convincing arguments that agreement is acceptable
		1 Doubtful design or method OR (MIC not defined AND no convincing arguments that agreement is acceptable)
		0 MIC <= SDC OR MIC equals or inside LOA despite adequate design and method/No information found on agreement
5.2	Reliability	The extent to which patients can be distinguished from each other, despite measurement errors
		2 ICC or weighted Kappa >=0.70
		1 Doubtful design or method
		0 ICC or weighted Kappa <0.70, despite adequate design and method/No information found on reliability

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Property	Definition	Quality Criteria
	(relative measurement error)	
6	Responsive ness	The ability of a questionnaire to detect clinically important changes over time
		2 SDC or SDC < MIC OR MIC outside the LOA OR RR > 1.96 OR AUC > = 0.70
		1 Doubtful design or method
		0 SDC or SDC > = MIC OR MIC equals or inside LOA OR RR < = 1.96 or AUC < 0.70, despite adequate design and methods/ No information found on responsiveness
7	Floor and ceiling effects	The number of respondents who achieved the lowest or highest possible score
		2 =<15% of the respondents achieved the highest or lowest possible scores
		1 Doubtful design or method
		0 >15% of the respondents achieved the highest or lowest possible scores, despite adequate design and methods/No information found on interpretation
8	Interpretability	The degree to which one can assign qualitative meaning to quantitative scores
		2 Mean and SD scores presented of at least four relevant subgroups of patients and MIC defined
		1 Doubtful design or method OR less than four subgroups OR no MIC defined
		0 No information found on interpretation

MIC= minimal important change; SDC= smallest detectable change; LOA= limits of agreement; ICC= Intraclass correlation; SD = standard deviation; RR = responsiveness ratio; AUC = area under the curve



#### **4.2.2.2 Research Team Appraisal**

In addition to the quality appraisal criteria, two experts also appraised instruments: one an expert in stigma and disability (KS) and the other an old age psychology expert with specialist knowledge in the measurement of psychological constructs (GC). Collectively, decisions were made to include instruments that satisfied all three of the following criteria:

1. Instrument did not require significant changes to language that might invalidate previous psychometric findings (e.g. stereotypes and language used would be similar for a UK population);
2. The instrument was deemed acceptable and relevant for a person living with dementia;
3. The instrument could serve as a feasible outcome measure for a ‘disclosure decision-making’ intervention to support people living with dementia to share the diagnosis within their social networks.

#### **4.2.3 Stage 3: Adaptation and Modification**

##### **4.2.3.1 Consultation with Research Experts**

Five expert researchers in the field of dementia research (1- dementia prevention assessment and intervention, 2- behaviour change and intervention fidelity, 3 - positive psychological outcomes and psychometrics, 4 - mixed methods research understanding the impact of chronic health conditions, 5- psychological support for people living with dementia and family carers) were asked to review the instruments on an item by item basis. The items were sent to each expert in a word document with instructions to indicate which items were relevant to people living with dementia based on their suitability and acceptability.

##### **4.2.3.2 Consultation with Lived Experience Experts**

A second expert group was made up of lived experience experts (people living with dementia and carers) involved in a patient and public involvement (PPI) capacity. PPI members were split into three sub-groups of approximately 2-3, with each group supported by one researcher. The instructions were to perform a card-sorting task where all items of the selected instruments were presented on strips of paper in no particular order and had to be sorted into two envelopes labelled “acceptable” and “not acceptable”. PPI members were informed that, in order for an item to be deemed acceptable, they must feel that it is understandable, relevant and that a person living with dementia would be able to answer the question. A round-robin technique was used to elicit thoughts and discussions on items from each member of the sub-groups. This methodology outlined by Delbecq & VandeVen, (1971) allows for all group members to communicate a position rather than the acceptability of items being determined by a dominant personality. The card-sorting task was designed so that each item was reviewed at least twice, by two different groups.

### **4.2.3.3 Measure Modification Framework**

A measure modification framework (Stewart, Thrasher, Goldberg, & Shea, 2012) was used to incorporate modifications from consultation with two expert groups (Delbecq & VandeVen, 1971; Denning, Jones, & Sampson, 2012). In the event that expert groups had conflicting feedback about the instruments, discussions between authors were used to resolve this until a conclusion was reached. The Modification Framework described by Stewart et al., (2012) increased the likelihood that adaptations to the psychometric measures would lead to items with comparable meanings, reliability and validity to that of the original measures. Three types of modifications were used based on the above expert

consultations: (1) drop dimension (a dimension (subscale) is omitted); (2) drop items (items are removed from an existing scale; and, (3) modify items (substituting a term or modifying wording without changing meaning).

#### **4.2.4 Stage 4: Pilot Testing**

##### **4.2.4.1 Participants and Sample Size**

Participants were recruited via three avenues. Firstly, researchers contacted participants who had declared an interest or who matched the study criteria on the Joint Dementia Research (JDR) database. Secondly, participants who had heard about the research (e.g. via social media and advertisements placed in local community buildings and shops) self-identified for participation. Thirdly, outreach activities were carried out by the researchers such as attending dementia groups (e.g. Alzheimer's Society localities).

Participants were included if they were an adult over the age of 18, and (2) had a primary progressive diagnosis of dementia. Participants were excluded if they had a chronic, terminal medical condition of which they were in the later stages, had a significant sensory impairment that could not be compensated for and precluded participation or lacked capacity to consent to the study.

Ethical approval for this research was granted by the University College London Research Ethics Committee (Project: 11501/002; Appendix 10.1.1).

The nature of the current study falls under feasibility testing and therefore no sample calculations were conducted. Previous research has suggested that a sample size of 30 participants is a reasonable minimum for a study where preliminary psychometric properties and scale feasibility are being tested (Johanson & Brooks, 2010).

#### 4.2.4.2 Measures

In addition to the measures selected and adapted through stages 1 to 3, the following two measures were employed for concurrent and convergent validity, respectively.

***Stigma Impact Scale (Burgener & Berger, 2008)***. All 21 items were rated from 1 ('strongly disagree') to 4 ('strongly agree') with the addition of 0 for 'not applicable' items across four subscales, namely, social rejection (9 items, e.g. "I feel others avoid me because of my impairment"), internalised shame (5 items, e.g. "I feel others think I am to blame for my impairment") and social isolation (7 items e.g. "I feel set apart from others who are well"). As per previous research, the financial insecurity subscale was excluded (Lion et al., 2019; Mangiaracina et al., 2017; Szcześniak et al., 2017).

***Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1979)***. The RSES consists of 10 items rated from 1 ('strongly disagree') to 4 ('strongly agree') measuring an individual's beliefs and attitudes toward themselves (e.g. "On the whole, I am satisfied with myself").

#### 4.2.4.3 Procedure

Potential participants were given a study information sheet and at least 24 hours to consider participating before consent was sought. Data were collected either independently online or face-to-face data with the author or one of three masters-level students. Qualtrics (Qualtrics, Provo, UT) was used for online data collection, where a participant accessed the participant information sheet, screening questions, consent form and study measures through a survey link. During face-to-face data collection, these documents were presented in paper to participants. All participants were invited to complete the study instruments one

to two weeks later (T2) in the same format in which they had completed them initially (T1).

#### **4.2.4.4 Data Analysis**

The author conducted all analyses. The Statistical Package for Social Sciences (SPSS, Version 26) was used for data input and analysis. Acceptability and suitability were ascertained using completion rates, time taken to complete T1 and floor and ceiling effects on the premise that a more acceptable and suitable instrument would yield high completion rates, have similar times of completion across measures and no floor or ceiling effects. Floor and ceiling effects were considered to be present where 15% of participants achieved the highest or lowest possible scores. Researchers who conducted home visits took field notes on their experience of completing the instruments to understand the acceptability and suitability of the instruments.

**Internal consistency.** The internal consistency for each scale and subscales was assessed using Cronbach's Alpha. A value for alpha  $\geq 0.7$  was considered acceptable (George & Mallery, 2003).

**Test Retest Reliability.** Stability was assessed through an Intraclass Correlation Coefficient (ICC) analysis using a two-way random effect model. ICC figures  $\geq .70$  or above indicated stability (Souza et al., 2017; Terwee et al., 2007).

**Concurrent Validity.** A Pearson Product-Moment Correlation Coefficient (Person's  $r$ ) was used to assess concurrent validity against the SIS. A correlation of  $\geq .70$  was considered an indication of good concurrent validity (Terwee et al., 2007).

***Convergent Validity.*** The RSES was used to assess convergent validity as self-esteem has been previously negatively correlated with stigma experience (e.g. application of self-stigma and secrecy). It was hypothesised that a low to moderate positive correlation between self-stigma and self-esteem would be found as per previous research (Burgener & Berger, 2008). Adequate convergent validity was considered if at least 75% or the results were in accordance with this hypothesis (Terwee et al., 2007).

***Relationships between Stigma and Disclosure Related Distress (DRD).*** A preliminary analysis was conducted to understand the relationship between stigma variables and DRD. In the first instance, Pearson's R correlations were used to understand the strength and direction of relationships between variables.

### **4.3 Results**

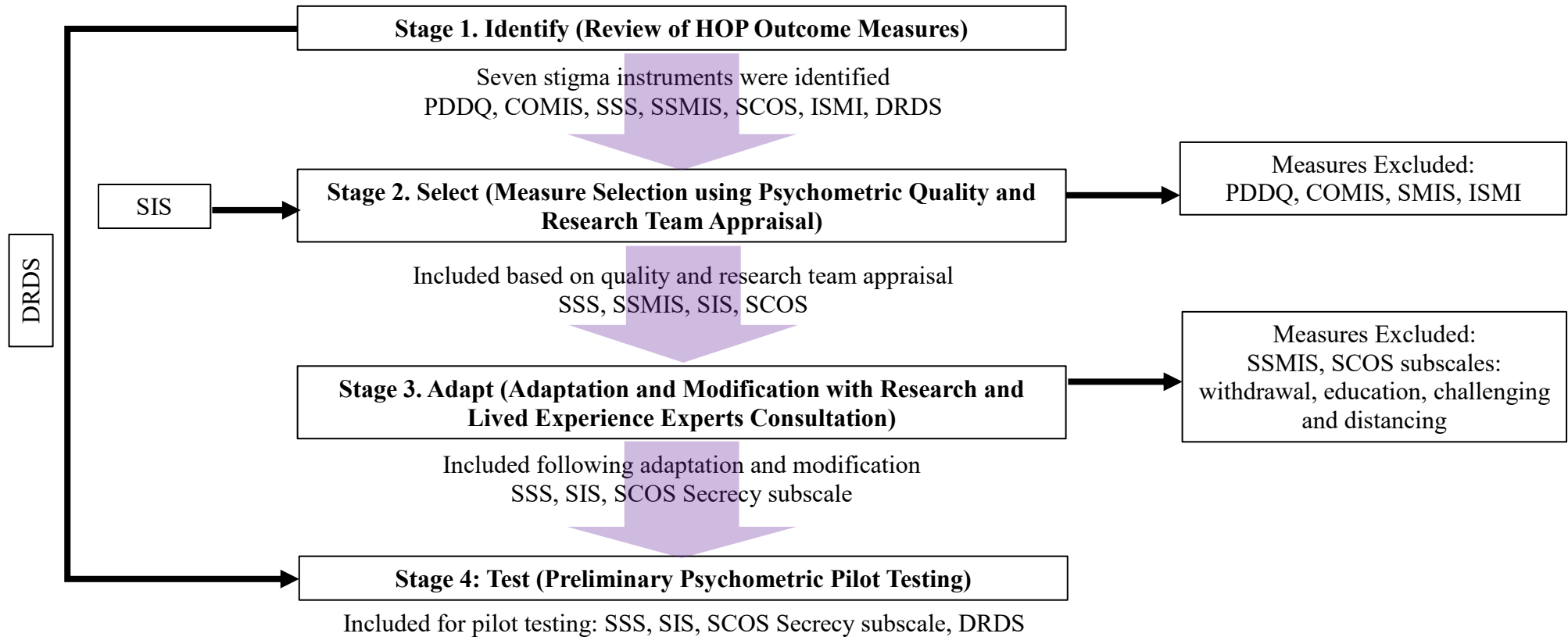
A diagrammatic representation of the methodology described in the previous section and results described in the below section can be found in Figure 4.1.

#### ***4.3.1 Stage 1: Review of HOP Outcome Measures***

Seven stigma instruments were identified from three HOP intervention studies: Perceived Devaluation Discrimination Questionnaire (PDDQ; Link, 1987); Coming Out with Mental Illness Scale (COMIS; Corrigan et al., 2010); Stigma Stress Scale (SSS; Rüscher et al., 2009); Self-Stigma Of Mental Illness Scale (SSoMIS; Corrigan, Watson, & Barr, 2006); Stigma Coping Orientation Scale (SCOS; Link, Struening, Neese-todd, Asmussen, & Phelan, 2002); Internalised Stigma Of Mental Illness (ISMI; Ritsher, Otilingam, & Grajales,

2003); Disclosure Related Distress Scale (Mulfinger et al., 2018; Rüsçh et al., 2014).

Figure 4.1. Diagrammatic representation of four stages used to identify, select, adapt and test psychometric measures of self-stigma



PDDQ = Perceived Devaluation Discrimination Questionnaire; COMIS = Coming Out with Mental Illness Scale; SSS = Stigma Stress Scale;

SSoMIS = Self-Stigma Of Mental Illness Scale; SCOS = Stigma Coping Orientation Scale; ISMI = Internalised Stigma Of Mental Illness;

DRDS = Disclosure Related Distress Scale; SIS = Stigma Impact Scale.



### **4.3.2 Stage 2: Measure Selection**

#### **4.3.2.1 Quality Appraisal**

None of the identified measures reported information on reproducibility-agreement or responsiveness (see Table 4.2). Internal consistency findings using Cronbach's alpha (between  $>0.70$  or  $< 0.95$ ) in the absence of a factor analysis were reported for all measures apart from the SCOS. Criterion validity and floor and ceiling effects were only reported for the ISMIS (Ritsher et al., 2003). Content validity was adequately reported only for the COMIS, SSMIS, ISMI and SIS, with a clear description of the measurement aim, target population, concepts being measured and item selection. Target population involvement in item selection was not reported for the SCOS. Construct validity was adequately reported for the ISMI but not for the SSMIS and all other measures only partially met the criterion (as less than 75% of hypotheses were confirmed despite adequate design and method).

Table 4.2.

*Quality appraisal of stigma instruments*

Scale	Reference	Content Validity	Internal Consistency	Criterion Validity	Construct Validity	Reproducibility		Responsiveness	Floor/Ceiling Effects	Interpretability	Total
						Agreement	Reliability				
PDDQ	Link, (1987)	0	1	0	1	0	0	0	0	2	4
COMIS	Corrigan et al. (2010)	2	1	0	1	0	0	0	0	1	5
SSS	Kaiser et al. (2004)	0	1	0	1	0	0	0	0	1	3
	Rüsch et al. (2009)	0	1	0	1	0	0	0	0	1	7
SSMIS	Corrigan et al. (2006)	2	1	0	0	0	2	0	0	0	5

Scale	Reference	Content Validity	Internal Consistency	Criterion Validity	Construct Validity	Reproducibility		Responsiveness	Floor/Ceiling Effects	Interpretability	Total
						Agreement	Reliability				
SCOS	Link et al., (1989)	0	0	0	1	0	0	0	0	1	2
	Link et al. (2002)	2	0	0	0	0	0	0	0	2	4
ISMI	Ritsher et al. (2003)	2	1	1	2	0	2	0	1	1	9
SIS	Fife & Wright, (2000)	2	1	0	1	0	0	0	0	1	5
	Burgener & Berger, (2008)	1	1	0	1	0	0	0	0	1	4

Quality appraisal modified from Terwee et al (2007), for scoring see Stansfeld et al. (2017)

PDDQ = Perceived Devaluation Discrimination Questionnaire; COMIS = Coming Out with Mental Illness Scale; SSS = Stigma Stress Scale; SSoMIS = Self-Stigma Of Mental Illness Scale; SCOS = Stigma Coping Orientation Scale; ISMI = Internalised Stigma Of Mental Illness; SIS = Stigma Impact Scale

Information on reproducibility reliability was adequately reported for only the SSMIS and ISMI. Interpretability was adequately reported for the PDDQ and SCOS however, only partially reported for COMIS, SSS, ISMI and SIS (no definition of minimal important change or absence of at least four subgroups). No interpretability findings were reported for SCOS. It was not possible to appraise the psychometric quality of the Disclosure Related Distress Scale (DRDS, Mulfinger et al., 2018; Rüscher et al., 2014) as the scale is an unvalidated measure previously used as a screening tool for HOP (Mulfinger et al., 2018). The DRDS dichotomised into a family variable (1 item; DRDS\_Family) and friends variable (1 item; DRDS\_Friend) which were included for pilot testing to ascertain suitability and acceptability for people living with dementia and understand the relationship between stigma and disclosure. No psychometric analyses were conducted on either DRDS variable.

### **4.3.2.2 Research Team Appraisal**

The SSS, SSMIS and SIS met all expert appraisal criteria (Table 4.3). The PDDQ, ISMI, COMIS, SCOS would have required significant changes that would invalidate previous psychometric findings, such as mentions of symptomatic recovery throughout ('going back to work after recovery') and item stems across subscales that were not deemed relevant or acceptable for a UK population of people living with dementia ("I came out of the closet"; "I stayed in the closet"; "I will come out of the closet"; "I stay in the closet") and the lack of transference of stereotypes from mental health to dementia. The COMIS was appraised as being the only measure that would not be accessible and relevant for people living with dementia. The COMIS, SCOS and ISMI were deemed unsuitable to serve as feasible outcome measures for a disclosure decision-making intervention for

people living with dementia. This was because the COMIS dichotomised disclosure between ‘coming out’ and ‘staying in’ the closet rather than acknowledging the stages in-between (e.g. selective disclosure). The SCOS had only one subscale containing relevant concepts to disclosure, whilst the others were psychiatric treatment based.

Table 4.3.

*Expert appraisal of stigma instruments*

Scale	Reference	Criterion 1 <sup>a</sup>	Criterion 2 <sup>b</sup>	Criterion 3 <sup>c</sup>	Decision
PDDQ	Link, (1987)	No	Yes	Yes	Excluded
COMIS	Corrigan et al. (2010)	No	No	No	Excluded
SSS	Kaiser et al. (2004)	Yes	Yes	Yes	Included
	Rüsch et al. (2009)				
SSMIS	Corrigan et al. (2006)	Yes	Yes	Yes	Included
SCOS	Link et al., (1989)	No	Yes	No	Excluded
	Link et al. (2002)				
ISMI	Ritsher et al. (2003)	No	Yes	No	Excluded
SIS	Fife & Wright, (2000)	Yes	Yes	Yes	Included
	Burgener & Berger, (2008)				

<sup>a</sup>Measure would not require significant changes to language that would invalidate previous psychometric findings

<sup>b</sup>Measure is acceptable and relevant for people living with dementia

<sup>c</sup>Measure serves as a feasible outcome measure for a disclosure decision-making intervention to support people living with dementia to share the diagnosis within their social network

### **4.3.3 Stage 3: Results of Adaptation and Modification**

Lack of appropriate or relevant language for people living with dementia, cognitive burden of completion and the inclusion of items around recovery were the main issues with the identified measures (see Table 4.4). It was necessary to drop all dimensions on the SSMIS and four subscales on the SCOS to leave only the secrecy subscale of the SCOS. All dimensions on the SIS and SSS were retained. Item removal was necessary for the Secrecy scale where two items were not relevant for people living with dementia: “In order to get a job a former mental patient will have to hide his or her history of hospitalisation”; and “you believe that a person who has recovered from mental illness earlier in life should not tell other people about it”. Item removal was necessary for the DRDS where the second item of the scale referring to employer/teacher disclosure was deemed irrelevant for a disclosure decision-making intervention to support people living with dementia to share a diagnosis of dementia to their social networks. Consequently, the first item was divided in two, where the first item asked about disclosure to friends and the second to family. The DRDS items thus read as follows: “In general how comfortable would you feel talking to [item one: a friend; item two: a family member] about dementia, for example, telling them you have a dementia diagnosis and how it affects you?”. Item modifications were made on the SSS, Secrecy scale and DRDS to change references to “mental illness” to “dementia”. In the SSS, the term “prejudice” was replaced with “stigma” on the premise that stigma is the most colloquially appropriate. For the SIS, the term “dementia” was inserted into the instructions to be used interchangeably with “impairment”.

Table 4.4.

*Summary of modifications and adaptation to stigma instruments*

	Stigma Stress Scale	Self-stigma of Mental Illness Scale	Secrecy Scale	Stigma Impact Scale
Scale	8 item Likert scale from 1	4 subscales answered on a 9-point	9 items are answered on a 4-point	21 items are rated from 1
Description	(strongly disagree) to 7 (strongly agree). Four items are design to measure perceived harm caused by stigma and four focus on the impact of stigma on one's resources to cope with such harm.	likert scale representing: <b>awareness</b> of stereotypes, <b>agreement</b> with stereotypes, <b>applying</b> stereotypes to self and suffer <b>harm</b> from self-applied stereotypes. Each subscale has five items	Likert scale from 1 (strongly disagree) to 4 (strongly agree). Assess the extent to which an individual endorses concealment as a means of avoiding stigma related rejection.	('strongly disagree') to 4 ('strongly agree') with the addition of 0 for those items participants found 'not applicable'. The scale has four subscales, namely, social rejection (9 items), internalised shame (5 items) and social isolation (7 items).



Comments from lived experience experts	“Just call it stigma rather than prejudice”—in an UK population the term ‘stigma’ was considered more colloquially appropriate than the word ‘prejudice’	The term “less confidence” should be used rather than “less respect”	No comments	No comments
Comments from research experts	Define prejudice in the instructions Item 6 wording is complicated Items 7 & 8 similar Supplement challenges for the word demands	Using “most people” and “the public” to describe the same thing is confusing. The perspective change between subscales was problematic in the past. This scale relies on stereotypes of mental health, therefore these also need to be relevant to dementia	Removal of recovery and employability item. Issues with the term impairment – maybe use “diagnosis”	Change the use of the word “impairment”, for example replace with “dementia”
Drop dimension	None	All dimension dropped	Dropped four of five dimensions from the original Stigma Coping Orientation Scale to leave only the secrecy subscale	None

Items Removed	None	None	Items 6 and 8 removed	None
Item Modification	<p>“people with mental illness” changed to “people living with dementia” .</p> <p>“prejudice” changed to “stigma” .</p>	None	<p>“mental illness” changed to “dementia” for the purposes client group adaptation</p>	None
Other Modification	<p>“Prejudice” was replaced with “stigma” in the instructions, on the premise that “stigma” is the more colloquially appropriate</p>	None	None	<p>The term “dementia” was inserted into the instructions to be used interchangeably with “impairment”. The instructions read “dementia or neurological impairment...”</p>

#### **4.3.4 Stage 4: Pilot Testing**

##### **4.3.4.1 Sample Characteristics**

Forty-one people living with dementia met the eligibility criteria and provided informed consent to take part in this study. One participant who took part online was excluded due to large amounts of incomplete data. Eighteen participants took part online and 22 participants completed the study during face-to-face visits (see Table 4.5 for sample characteristics).

##### **4.3.4.2 Acceptability and Suitability**

The reported scores on the SSS, SIS and Secrecy scale were normally distributed, with low levels of missing data. A Little's Missing Completely At Random (MCAR) was non-significant for each measure ( $p = 1.00$ ) indicating data were missing completely at random and therefore mean imputation at an item level was appropriate to deal with missing data (Eekhout, 2015; Graham, 2009).

Time taken was recorded for a small sample of face-to-face participants who took a mean of 43 minutes ( $n = 7$ ) to complete the measures at T1. The time taken for completion ranged from 15- 60 minutes. No floor or ceiling effects were identified as the percentage of participants scoring the lowest or highest possible scores on each instrument was lower than 15%. Field notes were collected during 14 of the 22 home visits carried out for face-to-face data collection. Three participants found the response categories of the Secrecy scale challenging for items that were a double negative (item 1 and 4), and also those for which the response was dependent on who the participant had in mind (e.g. item 7 of Secrecy scale).

Table 4.5.

*Participant characteristics and demographic information*

<b>Participant Characteristic</b>		<b>M (SD) or N</b>
Age, years		72.40 (10.61)
range		56 - 95
Months since diagnosis		45.20 (33.10)
range		2 - 120
Gender (M/F/ND)		20/20
Type of dementia	Alzheimer's Disease	21
	Vascular Dementia	7
	FTD (behavioural variant)	1
	Lewy Body	1
	Mixed	6
	ND/Unknown	4
Ethnicity	White	36
	Other Ethnic Group	3
	ND	1
Living alone	Yes	13
	No	27
Employment status	Employed	5
	Retired	30
	Other	4
	ND	1
English as first language	Yes	37
	No	3
ND=Not disclosed		

For items that required more thought, participants read aloud items as questions for themselves with each response category (e.g. Do I agree that [item wording]) or included the item in a sentence with response categories (e.g. I agree that [item wording]), to establish a level of agreement and disagreement. The scales were presented in tables with items on each row and response categories on each column. One participant found it difficult to align the column and rows to tick the appropriate response box.

Two participants found the phrase ‘stigma against people living with dementia’ (SSS) confusing due to being unsure whether the item was referring to themselves as a person living with dementia, to others with dementia but not themselves, or to people living with dementia more generally. One participant found item 21 of the SIS (“changes in my appearance have affected my social life”) difficult to relate to dementia.

### **4.3.4.3 Reliability**

The SIS ( $\alpha = .906$ ) and Secrecy scale ( $\alpha = .864$ ) had acceptable internal consistency but the SSS ( $\alpha = .643$ ) did not (Table 4.6). The Cronbach’s alpha values for all subscales were acceptable with the exception of the SIS subscale of internalised shame ( $\alpha = .614$ ), which fell below the cut-off for acceptability and was not improved through item removal. ICC<sub>agreement</sub> estimates and their 95% confidence intervals were calculated using data from 25 participants who completed both T1 and T2. Reliability of all measures between T1 and T2 was moderate.

Table 4.6.

Summary of descriptive, reliability and validity statistics

	M(SD)	Min-Max		Skewn ess	Kurtosis	Floor and Ceiling		Reliability		Validity (Pearson's R)						
						Lowest Score (%)	Highest Score (%)	Internal consistency (α)	Test - Retest			Concurrent			Convergent	
									ICC	CI <sup>a</sup>		SIS Total	SR	IS		SI
						Lower	Upper									
SSS	-7.73 (10.37)	-24	16	.304	.812	5	0	.643	.721	.467	.866	.525*	.441*	.160	.590**	-.475*
SSS Harm	15.73 (8.16)	4	28	-.009	-1.28	15	12.5	.938	.864	.717	.937	.587*	.499*	.177	.654**	-.295*
SSS Cope	23.47 (4.02)	12	28	-1.23	1.81	5	22.5	.866	-.199	-.507	.294	-.259 <sup>^</sup>	-.256 <sup>^</sup>	-.160 <sup>^</sup>	-.234 <sup>^</sup>	.278 <sup>^</sup>
Secrecy scale	1.83 (0.64)	1	3	.378	-1.07	10	0	.864	.746	.503	.880	-.001	-.175	.488*	-.015	-.320
SIS Total	42.54 (12.88)	21	79	.531	.606	0	0	.906	.774	.550	.894					-.587**
SR	17.24 (6.90)	7	36	.755	.221	0	2.5	.868	.707	.435	.860					-.416*
IS	8.60 (2.84)	5	16	.763	.132	0	0	.614	.518	.158	.759					-.483*
SI	16.07 (5.53)	7	28	.006	-.794	0	2.5	.869	.841	.674	.927					-.600**
DRDS_Family	5.87(1.56)	1	1	-1.45	1.63	2.5	52.5									
DRDS_Friend	5.55(1.83)	7	7	-1.34	1.03	7.5	45.0									

\*p <.05 \*\*p<.001; <sup>^</sup>non parametric tests; SR = social rejection; IS = internalised shame; SI = social isolation

#### 4.3.4.4 Validity

The SSS total was positively correlated with the SIS, however, the correlation coefficient was below the necessary cut-off to demonstrate satisfactory concurrent validity SIS ( $r = .525, p < .001$ ). The perceived harm subscale of the SSS and the SIS total were positively correlated but the ability to cope subscale of the SSS did not correlate with the SIS total. This may be because they quantify conceptually different components (ability to cope vs social and psychological impact of stigma). The perceived harm subscale of the SSS was positively correlated with the social rejection and social isolation subscales of the SIS but not the internalised shame subscale. The ability to cope subscale of the SSS was not significantly correlated with the SIS subscales of social rejection, internalised shame or social isolation. The Secrecy and the SIS total ( $r = -.001, p > .05$ ), social rejection and social isolation subscales were not significantly correlated. The Secrecy subscale was positively correlated with the internalised shame subscale of the SIS. In line with predictions, the overall SSS ( $r = -.475, p < .05$ ) and SIS ( $r = -.587, p < .001$ ), including all subscales with the exception of ability to cope subscale, were negatively correlated with the RSES. Correlations were within the predicted range of low to moderate with the exception of the perceived harm subscale. The Secrecy subscale ( $r = -.032, p > .05$ ) did not correlate with the Rosenberg self-esteem, which was not in line with predictions or previous research.

#### 4.3.4.5 Relationships between Stigma and Disclosure Related Distress

DRDS\_Family and DRDS\_Friends were both negatively skewed and therefore nonparametric correlations were used (see Table 4.7). There was a negative moderate significant correlation between DRDS\_Family and

DRDS\_Friends, and Secrecy suggesting that as levels of secrecy related to stigma increase, disclosure-related stress similarly increases (lower DRDS scores are indicative of higher distress). There was a moderate but significant negative correlation between DRDS\_Family and DRDS\_Friends, and internalised shame, suggesting that as levels of internalised shame increase, disclosure-related distress increases. No other significant relationships were found between stigma variables and disclosure related distress.

Table 4.7.

*Relationship between stigma and disclosure related distress*

Spearman's rho correlation coefficients ( $r_s$ )				
DRDS Variable				
	Family		Friends	
Stigma Variables	$r_s$	$p$ value	$r_s$	$p$ value
SSS Harm	-.196	.225	-.288	.071
SSS Cope	.206	.203	.178	.273
Secrecy scale	-.481	.000	-.579	.000
SR	.028	.826	.058	.721
IS	-.419	.007	-.371	.019
SI	-.148	.361	-.096	.556

SR = social rejection; IS = internalised shame; SI = social isolation



## **4.4 Discussion**

### ***4.4.1 Summary of Findings***

The results of the small-scale pilot suggest that the subscales of the SSS, Secrecy scale, and SIS are acceptable for use in a UK population of people living with dementia. All measures had moderate test-retest reliability, suggesting they may be suitable for use as longitudinal outcomes measures (baseline versus follow-up), and all measures except the SSS total, and the internalised shame subscale, had good internal consistency. Concurrent and convergent validity for measure totals was found for the SSS but not the Secrecy scale. The latter finding was not as predicted, however, as the Secrecy scale was positively correlated with internalised shame. Findings from the current study suggest a relationship between disclosure-related distress and stigma, where secrecy as a result of stigma and the experience of internalised shame were related to how comfortable people living with dementia felt about telling family and friends about their diagnosis or related difficulties.

### ***4.4.2 Findings in the Context of Existing Research***

The hypothesised link between the appraisal of stigma as harmful (perceived harm subscale of the SSS) and social rejection and isolation was supported in the current study. However, the absence of a correlation between perceived harm and internalised shame was not predicted, given that previous mental health literature suggests that internalised shame plays an integral role in shaping stigma experiences (Rüsch et al., 2009; Wood, Byrne, Burke, Enache, & Morrison, 2017). In addition, the SSS total and the SSS ability to cope subscale did not correlate significantly with internalised shame. This may be an artefact of the SSS scoring protocol where the ability to cope subscale (mean of items 5-8) is

subtracted from the stigma harm subscale (mean of items 1 to 4) and a positive score indicates greater harm than ability to cope with stigma. Contrary to findings from mental health which have identified a linear relationship between harm and coping (Rüsch et al., 2009), this may not be the case in the current sample of people living with dementia. Therefore, the SSS may not adequately measure the stigma stress appraisal process for people living with dementia in the same way as in mental health. Further, the internal consistency of the SSS was improved when the subscales were treated separately rather than as one overall score. As the two subscales aim to operationalise conceptually opposite phenomena and no items were identified as improving the overall internal consistency if removed, treating the subscales separately in future psychometric research may be more useful.

The Secrecy scale only correlated with the internalised shame subscale of the SIS, which was not as predicted but may indicate that an individual does not have to have had overt experiences of stigma to experience negative consequences. To be more specific, secrecy may be associated more with cognitive components of self-stigmatisation than the more social and overt aspects, such as social rejection and isolation. Measuring levels of secrecy, therefore, may be a way of operationalising internalised shame rather than measuring the appraisal of stigma (SSS).

Significant negative correlations were found between the SIS total, all three SIS subscales and self-esteem, whereas previous work was only able to find this for the internalised shame subscale (Burgener & Berger, 2008). The relationship between self-stigma and self-esteem is well documented in mental health stigma research, but less so in dementia. The current study, therefore,

provides important preliminary evidence of the similarly important role of self-esteem in self-stigma for people living with dementia.

The relationship between disclosure-distress and stigma was also explored for the first time in the current study. Initial findings suggest that secrecy about a diagnosis of dementia is related to experiencing increased disclosure-related distress, thus addressing a key gap in stigma and decision-making literature. This is the first study to give evidence of the potential relationship between secrecy as a component of stigma and its influence on disclosure; specifically, increased levels of stigma-related secrecy were related to increased levels of disclosure related distress. In addition, there was a significant relationship between internalised shame as a component of self-stigma and disclosure-related distress. While this finding is preliminary, given the sample size and novelty of testing the SIS and DRDS in dementia, it suggests that stigma may influence the way in which people living with dementia disclose to family and friends. Although requiring replication, the findings from the current study suggest that there is now a rationale to understand disclosure decision-making through stigma, particularly through the lens of internalised shame. There were no other significant relationships between stigma variables and disclosure suggesting that internalised shame may be key, over and above other concepts. Speaking to the influence of stigma on disclosure decision-making, internalised shame may therefore be a barrier to disclosing a diagnosis of dementia.

The internalised stigma of mental illness scale (ISMI) was excluded at the stakeholder consultation stage of the current study, however it has been a popular measure for use in stigma reduction interventions for other mental health

conditions (for a review, see Wood et al., 2016). Although the ISMI had the highest quality rating of all identified measures, the content would have required significant changes for use in a population of people living with dementia. This speaks to the importance of acknowledging the nuances in the experience of self-stigma between clinical populations. With this in mind, the current study has begun to clarify the potential use of stigma measures in dementia, but efforts to establish specific frameworks (e.g. stress appraisal process in dementia) and theories should underpin the modification process as some measures may perform well in certain clinical populations and not others.

In line with recent guidance, the effectiveness of complex interventions such as stigma reduction for people living with dementia relies on robust design and development, along with feasible outcome measures to observe mechanisms of change (Craig et al., 2008; Wight, Wimbush, Jepson, & Doi, 2015). Self-stigma in dementia has been under-defined and poorly operationalised (Nguyen & Li, 2018), with a lack of suitable outcome measures. The present study directly addresses this by developing outcome measures that can be used in self-stigma research to evaluate interventions aimed at reducing stigma.

### ***4.4.3 Methodological Considerations***

The current study has established preliminary acceptability, suitability and psychometric measures however it is important to note that the small sample size limits the interpretation of results. Although previous research has suggested 25 to 40 participants are adequate for preliminary development and piloting measures (Johanson & Brooks, 2010) further large-scale, quantitative studies are needed to confirm the psychometric properties of the self-stigma measures.

The format of participation (online versus face-to-face) may have affected the results as participants may have been more likely to answer in a socially desirable manner if participation took place in person rather than online. In addition to this, four different researchers were involved in administering the instruments during face-to-face participation, potentially affecting inter-rater reliability. However, all researchers were trained in consistent administration of the outcome measures and all had prior experience of working with people with dementia. Due to the small sample size, comparison between online and face-to-face participants and inter-rater reliability would not have led to meaningful agreement scores.

Although overall acceptability was satisfied, some participants felt that response categories were too absolute, where the answer would depend on whom the participant was thinking about at the time. For example, “how comfortable do you feel when talking to a friend about dementia?” depended on the “friend” in question, with some participants noting they had told some but not all of their “friends”. The idea that disclosing a dementia diagnosis may be dependent on the friend in question speaks to the notion of disclosure being an on-going process as covered in the Disclosure Process Model (Chaudoir & Fisher, 2010) in Chapter 3. Disclosure to some friends and not others may be a product of assessing subjective utility versus subjective risk (Omarzu, 2000) or disclosure efficacy (Greene, 2009) within a particular friendship, which mediates the disclosure process by forecasting the social impact of disclosure (Chaudoir & Fisher, 2010). The levels of interpersonal risk can therefore explain why people living with dementia felt comfortable telling some friends but not others. Thus, whom the participant chose as the referent may have influenced the responses given.

However, this feedback can be used to improve item wording and response categories for this measure in the future.

The SIS was the only instrument available that had an existing evidence base for people living with dementia, and was therefore used as the ‘gold standard’ measure to assess concurrent validity. However, the SIS may not truly offer a ‘gold standard’ measure as defined by Terwee et al., (2007). For this reason, concurrent validity of the SSS and Secrecy scale with the SIS should be interpreted with caution.

The current study is the first to evidence the relationship between stigma-related secrecy and internalised shame in people living with dementia, however, results should be treated as preliminary due to the small number of participants. In addition, the DRDS specifically asked participants how “comfortable” they would feel disclosing to a family member or friend, and comfort could be seen as conceptually separate from distress. Therefore, perhaps, the DRDS should be framed as a measure of disclosure-related comfort rather than distress in the literal sense. There is no evidence to suggest that those who do not feel comfortable also experience levels of distress or vice versa. Furthermore, as mentioned, field notes collected in the current study highlighted that many participants had varying relationships with family members and friends and sometimes the answer “depends” on the person, therefore the DRDS may be difficult to interpret as the subjective relationship quality between whom the participant was envisaging when answering the DRDS was not recorded. For example, comfort levels may be different when telling a close friend of many years versus someone whom is considered a friend but more recently acquired. Lastly, the DRDS assumes that a

person has friends and family whom they can envisage when answering. This may not always be the case, given the evidence that people living with dementia are one of the most isolated populations in the UK (Windle, Francis, & Coomber, 2011). It is therefore the responsibility of researchers to sensitively manage conversations around a participant's social network and to enrich future data collection; information about social networks and quality of relationships may be useful.

Lastly, the nuances that exist within the stigma experiences of different types of dementia were beyond the scope of the current study however are important to consider. It is plausible that within the labels of dementia, nuances exist in stigmatization, for example, those whom have dementias with more overt behavioural symptoms at earlier stages may experience increased levels of social rejection or isolation in comparison to those with Alzheimer's disease where symptoms can be masked more easily. There is no literature for this in the dementia field. However, the work of Wood, Birtel, Alsawy, Pyle, & Morrison, (2014) suggests that there are nuances in stigma experiences of various mental health labels where schizophrenia is more stigmatised than anxiety and depression. It is therefore plausible that akin to the umbrella term of 'mental health', nuances exist between different dementias that should be considered further.

#### **4.4.4 Conclusion**

The current study has begun to address the criticisms of previous work, namely the lack of reporting on psychometric properties. Three self-stigma measures were identified and adapted using a robust four-stage process. The

Secrecy scale, SIS and SSS were acceptable for use in a UK population of people living with dementia. However, the psychometric properties were established on a small sample and further psychometric analysis is required before such measures can be implemented in psychosocial research.



## **5 Experiences of courtesy and affiliate stigma in carers of people living with dementia**

### **5.1 Introduction**

As noted in Chapter 3, carers play an active role in decision-making and therefore carers may share the psychological and social challenges that a diagnosis of dementia presents the person living with dementia. One of these challenges includes the influence of stigma in disclosure decision-making. For this reason, measuring stigma as a psychosocial construct in carers of people living with dementia is a necessary addition to the work within the thesis. In the recent ADI report on attitudes to dementia, a third of carers reported they have hidden the diagnosis of the person they care for from friends and family (Alzheimer's Disease International, 2019). Furthermore, over half of family carers reported that their physical well-being, work and social life has been negatively affected as a consequence of caring for someone living with dementia (Alzheimer's Disease International, 2019).

#### ***5.1.1 Carer Stress and Burden***

##### **5.1.1.1 A Conceptual Model of Carers Stress**

Pearlin, Mullan, Semple and Skaff (1990) introduced a model outlining the components of carer stress, which consisted of four domains. Firstly, background and context speaking to the history of the dyadic relationship, characteristics of the carer such as status, ethnicity, education, age and gender and resources available to the carer which may include transportation services (Pearlin et al., 1990). Secondly, primary stressors include the cognitive status or problematic behaviours of the person living with dementia, and secondary stressors that include the capacity of the carer when meeting the demands of the

caring role. This may cause two types of strain: role (familial conflict, economic strain); and intrapsychic strain (role captivity, loss of self, self-esteem). Thirdly, the mediators of stressors such as coping (self-management of situations) and social support that explain why carers may be affected by stress differentially. Finally, the manifestations and outcomes of stress are the impact of stressors on the well-being, mental and physical health of carers (Pearlin et al., 1990). The burden placed upon carers is therefore the consequence of background and context, primary and secondary stressors, coping and social support and the impact of stressors on carer well-being.

### **5.1.1.2 Factors Affecting Carer Burden**

A body of literature has established how caregiver burden relates to objective variables such as characteristics of both the carer and the person living with dementia. In a regression model removing characteristics of the person living with dementia such as behavioural or psychological symptoms of the person living with dementia (BPSD), it was shown the experiences of role captivity (unwillingness towards the caring role), carer overload, adverse life events and relationship quality strongly predicted the burden experienced by carers (Campbell et al., 2008). As such, rather than the objective load placed upon a carer due to characteristics of the person living with dementia, carer burden may be more likely a consequence of individual factors related to one's sense of self and ability to carry out caring responsibilities (Campbell et al., 2008).

For instance, levels of self-efficacy may influence the way in which carers appraise and handle stressors (positive – personal accomplishment, negative – emotional vulnerability) and therefore experience the burden of caregiving (Crellin, Orrell, McDermott, & Charlesworth, 2014). Behavioural and

psychological symptoms of dementia (BPSD) have been associated with increased levels of distress in carers (Feast, Moniz-Cook, Stoner, Charlesworth, & Orrell, 2016). The appraisal of BPSD by carers as challenging has been associated with the extent to which symptoms transgress from established social norms, where a lack of understanding around the causality of such transgressional behaviours built the foundations for misunderstandings within the dyadic relationship and experiences of embarrassment and shame in carers (Feast, Orrell, et al., 2016).

The burden of stigmatisation is not considered in the caregiver stress and burden literature. As suggested by Pearlin and Colleagues (1990), social support mediates the impact of carer well-being, physical and mental health. However, the impact of stigma as a barrier to social support has not yet been acknowledged. In a recent systematic review of caregiver burden in dementia, none of the included studies measured the effect of stigmatisation in carers (Xiong et al., 2020). The burden placed on family carers due to courtesy and affiliate stigma has been understudied, yet has been evidenced in other populations to have significant repercussions for the wellbeing of carers (Mitter et al., 2018; Östman & Kjellin, 2002). Therefore, robust and evidenced measures of these concepts are needed in carers of people living with dementia.

### ***5.1.2 Stigma Impact in Carers***

The concept of ‘courtesy stigma’ was developed initially in mental health literature, and is defined as stigma experienced due to being associated with a stigmatised individual, also referred to as ‘stigma by association’ or ‘family stigma’ (Ostman & Kjellin, 2002). Although individuals do not have the

stigmatising characteristic or ‘mark’, they may care for, live with, work with or share proximity with someone who possesses a stigmatised identity (Pescosolido & Martin, 2015). Association with an individual who is stigmatised may lead to devaluation by others around them through the belief that they may somehow be responsible for the stigmatising characteristic, or may not have done enough to prevent it. Courtesy stigma has been associated with low levels of self-esteem, shame, distrust, anger, hopelessness and increased burden for family members (Östman & Kjellin, 2002).

Affiliate stigma is the internalisation (cognitive, affective and behavioural consequence) of courtesy stigma, as seen in carers of people with intellectual disabilities (Mitter et al., 2018). Affiliate stigma has cognitive (sense of shame, inferiority), affective (unhappiness), and behavioural (social withdrawal, concealment of carer status) consequences for carers and is related to decreased positivity towards caring for someone with intellectual disability (Mak & Cheung, 2008).

### ***5.1.3 Quantifying Courtesy and Affiliate Stigma***

Three scales have been previously used to quantify affiliate stigma, namely the Family Stigma in Alzheimer’s Disease Scale (Werner et al., 2010), the Affiliate Stigma Scale (Chang et al., 2016; Mak & Cheung, 2008) and the Family Stigma Instrument (FAMSI; Mitter et al., 2018). Of these, two also encompass items or scales to measure courtesy stigma. All three scales have incorporated a cognitive-behavioural explanation of affiliate stigma outlined by the stereotypes-prejudice-discrimination framework (see Chapter 2; Corrigan & Watson, 2002; Corrigan et al., 2006):

- *Stereotypes*: carers become aware of the negative thoughts and attitudes towards them from others which are internalised and translate to negative beliefs about oneself.
- *Prejudice*: agreement with negative beliefs generates negative emotional reactions towards oneself.
- *Discrimination*: the behavioural manifestation of prejudice may be seen in avoidance behaviours performed by oneself.

### **5.1.3.1 The Family Stigma in Alzheimer's disease Scale (FS-ADS; Werner et al., 2010)**

The FS-ADS was developed from qualitative interviews with adult children of those living with Alzheimer's disease (Werner et al., 2010), and findings were analysed in line with the aforementioned SPD framework proposed by Corrigan and colleagues. To create the FS-ADS, a 100-item pool was reduced to 62 items measuring the cognitive, affective and behavioural aspects of the three dimensions of the stereotypes- prejudice-discrimination framework. The three dimensions in the FS-ADS were: caregiver stigma (affiliate stigma), lay persons' stigma (perceived family stigma) and structural stigma (the injustices in social structures and political decisions; Werner, Goldstein, & Heinik, 2011). The FS-ADS demonstrated acceptable reliability, and construct validity.

### **5.1.3.2 The Affiliate Stigma Scale (Chang et al., 2016; Mak & Cheung, 2008)**

The Affiliate Stigma Scale comprises of 22-items with three subscales (cognitive, affective and behavioural) and has been used to quantify the affiliate stigma in family carers of those with learning disabilities (LD; Mak & Cheung, 2008). The Affiliate Stigma Scale has also been used to understand the

experiences of carers of people living with dementia, showing good reliability and concurrent validity (Chang, Su, & Lin, 2016). Findings from a study with carers of people living with dementia suggest that affiliate stigma has a three-factor structure: cognitive; affective; and behavioural; which respectively map on to the stereotype –prejudice-discrimination framework (Chang et al., 2016; Mak & Cheung, 2008).

### **5.1.3.3 The Family Stigma Instrument (FAMSI; Mitter et al., 2018))**

More recently, in a cross-sectional study to quantify the courtesy and affiliate stigma in family carers of people with LD, the items of the Affiliate Stigma Scale and ten other scales (56 items in total) were pooled to develop a new measure, namely, the FAMSI (Mitter et al., 2018). Through stakeholder involvement with psychiatrists, clinical psychologists and carers of people with LD, a version of the FAMSI with 28 items was tested in 407 family carers of people with LD. Three domains were tested by using the FAMSI: courtesy stigma (one subscale), affiliate stigma (three subscales: cognitive, affective and behavioural) and positive aspects of caregiving (one subscale). Following a principal component analysis, 26 items were retained with factor loadings  $>.50$ . Endorsement ratings were created based on carers who had answered ‘agree’ or ‘strongly agree’ to items and these were converted into percentages to represent the endorsement of each FAMSI domain. More than half of carers endorsed affiliate stigma constructs (65.9%), positive aspects of caregiving (60%) and courtesy stigma (59.3%; Mitter et al., 2018).

### **5.1.4 Limitations of Previous Measures**

Previous measures such as the FS-ADS and the Affiliate Stigma Scale have neglected to acknowledge positive narratives around caring that may be a

potentially protective factor against the experience of affiliate stigma constructs (Farran, 1997; Kramer, 1997). Although stigma narratives are usually negatively charged, the FS-ADS consists only of negatively worded items (e.g. to what extent do you feel your relative looks [filthy, neglected, unkempt, not aesthetic; disgusting]) which may lead to demand characteristics and therefore biased responses that may be avoided with the presence of positively worded items. Further, research from healthcare decision-making literature that I described in Chapter 3 indicates that people living with dementia did not feel informed, listened to or able to express their opinions when supported by adult children compared to those supported by spousal carers. The FS-ADS was developed based on qualitative feedback from children of people living with dementia. However, if spousal carers were also involved, the feedback may have differed. Concerning the Affective Stigma Scale, Chang and colleagues (2016) only included carers of people with Alzheimer's disease and vascular dementia, whereas recruiting participants who care for people with varying forms of dementia may provide a better representation of the population and capture experiences beyond those felt by carers of people with Alzheimer's disease and vascular dementia.

### **5.1.5 FAMSIS Domains**

As suggested in the FAMSIS development paper, there may be a two-step process involved in the stigma experienced by carers (Mitter et al., 2018). Firstly, carers become aware of the negative evaluations of the stigmatised individuals and those family members associated to them ('perceived family stigma'). Secondly, first hand experiences of perceived family stigma may occur (cognitive affiliate stigma), where carers may feel negatively about their caregiving role

(affective affiliate stigma) and may engage in behaviours to avoid social interactions (behavioural affiliate stigma; Mitter et al., 2018). The proposed two-step process suggests two separate factors, one related to courtesy stigma quantified by the ‘perceived family stigma’ subscale, and the other to affiliate stigma quantified by three cognitive-behavioural subscales (cognitive, affective and behavioural). These two factors should be treated separately rather than within one overall score, given that they are measuring different areas of family stigma. In addition, positive aspects of caregiving do not conceptually map onto courtesy or affiliate stigma, but rather is a factor within itself that may be related to how family stigma is experienced. Although Mitter and colleagues (2018) suggest including the positive aspects of caregiving scale when calculating the total score of the FAMSI, they also noted that experiencing positivity within ones caring role is negatively related to the experiences of affiliate stigma. On this basis, the FAMSI was hypothesised to comprise of three conceptually-related domains that were treated separately in the current study rather within an all-encompassing total score: (1) perceived family stigma; (2) affiliate stigma; and (3) positive aspects of caregiving. Item scoring for the FAMSI remained as per the development paper with responses ranging from ‘strongly disagree’ (1) to ‘strongly agree’ (5) with a midpoint of ‘neither agree nor disagree’ (3).

### **5.1.6 Rationale**

The FAMSI addresses some of the aforementioned limitations of the FS-ADS and the Affiliate Stigma Scale. Specifically, the FAMSI has a domain quantifying the ‘positive aspects of caregiving’ potentially reducing the response bias that may be caused from using the FS-ADS which consists only of negatively worded items. Unlike the Affiliate Stigma Scale, the FAMSI also goes beyond



measuring affiliate stigma by including a courtesy stigma domain ('perceived family stigma' scale). The FAMSI domains were submitted for testing in the current study but were treated separately in the analysis for two reasons summarised in depth in the above section. Firstly, previous literature has noted a two-step process to explain stigma in family carers, where courtesy stigma and affiliate stigma are conceptually separate but associated domains. Secondly, positive aspects of caregiving has been associated with decreased courtesy and affiliate stigma therefore, creating an overall total score of the FAMSI would not be methodologically sound.

Although the FAMSI had not been used with carers of people with dementia the inclusion of positive aspects of caregiving and both affiliate and courtesy stigma built a rationale for first ever quantification of stigma concepts in carers of people living with dementia in the UK. Using the FAMSI allows for an exploration of both types of stigma and a focussed investigation of affiliate stigma (the self-stigma equivalent in carers). The FAMSI was the only measure covering stigma and positive aspects of caregiving, which had thus far, not been considered in parallel in the dementia literature.

### ***5.1.7 Aims and Research Questions***

The aim of the current study was to conduct an independent assessment of the psychometric properties of the three FAMSI domains when treated as three-**separate concepts** (courtesy stigma, affiliate stigma and positive aspects of caregiving), in a UK population of family carers of people living with dementia. This aim was addressed through the following research questions:

1. Are factors of the FAMSI acceptable, reliable and valid for carers of people living with dementia?
2. Do carers of people living with dementia endorse the domains of the FAMSI?
3. What are the relationships between the domains of the FAMSI?
4. Is the structure of self-stigma in carers (the FAMSI affiliate stigma domain; cognitive, affective and behavioural components) represented in the data from carers of people living with dementia in the UK?

## **5.2 Methods**

### **5.2.1 Design**

A quantitative cross-sectional design was used in which participants completed the FAMSI either online or face-to-face with a researcher.

### **5.2.2 Participants and Sample Size**

Participants were recruited via three avenues: (1) researchers contacted participants who declared an interest or were matched to the study criteria on Join Dementia Research (JDR) database, (2) self-identification where participants had heard about the research and expressed an interest in taking part (e.g. via social media and advertisements placed in local community buildings and shops) and, (3) through outreach activities carried out by the researchers such as attending groups (e.g. Alzheimer's Society localities).

Participants were included if they: (1) were an adult over the age of 18 and, (2) were a carer of someone with a diagnosis of dementia. Participants were excluded if they: (1), had a chronic, terminal medical condition of which they were in the later stages, (2), were a former carer and (3) they had a significant

sensory impairment that could not be compensated for and precluded participation. Ethical approval for this research was granted by the University College London Research Ethics Committee (UCL REC: 11501/002; Appendix 10.1.1).

The sample size calculation was based on the fourth aim of this study where seven multiplied by the number of items, is the sample size required for a confirmatory factor analysis (Terwee et al., 2007). As the affiliate stigma scale has 12 items, 84 participants were required.

### **5.2.3 Measures**

#### **5.2.3.1 Perceived Family Stigma**

The perceived family stigma scale consists of 8 items, with the same response options as the original FAMSI scale: ‘strongly disagree’ (1) to ‘strongly agree’ (5) with a midpoint of ‘neither agree nor disagree’ (3). Each item on the scale began with the phrase, ‘*some people might*’. For example, item 1 read as “some people might feel embarrassed about associating with them”. The original perceived family stigma scale had a Cronbach’s alpha value of 0.91 and an intraclass correlation coefficient (ICC) of 0.45, indicating that items in the scale measured the same factor but were not stable over time in carers of people with LD (Mitter et al., 2018).

In order to make items of the perceived family stigma scale relevant to carers of people living with dementia the instructions were changed in the following way “the questions are framed as such: some people might..., where “them” or “their” refers to the family of someone with learning disabilities (LD)” was replaced with “the questions are framed as such: some people might..., where

“them” or “their” refers to the family of someone living with dementia”. A total score for the scale was calculated by summing up the response options for each item.

### **5.2.3.2 Positive Aspects of Caregiving**

The positive aspects of caregiving scale consists of 6 items with the same response options as the original FAMSI scale. The original positive aspects of caregiving scale had a Cronbach’s alpha and ICC value of 0.78 indicating adequate internal consistency and stability overtime in carers of people with LD (Mitter et al., 2018).

In order to make the instructions relevant to carers of people living with dementia, “with LD” was replaced with “living with dementia”. The instructions were therefore changed from “to what extent do you agree that caring for your family member with LD has changed you in the following aspects?” and replaced with “To what extent do you agree that caring for your family member living with dementia has changed you in the following aspects?”. Each item began with the following phrase “*caring for my family member living with dementia has...*” For example, item 1 read as follows, “caring for my family member living with dementia has enabled me to develop a more positive attitude toward life”. A total score for the scale was calculated by summing up the response options for each item.

### **5.2.3.3 Affiliate Stigma**

The affiliate stigma scale comprised of three subscales, namely, behavioural affiliate stigma (4 items), affective affiliate stigma (4 items) and cognitive affiliate stigma (4 items). The behavioural, affective and cognitive affiliate stigma subscales had Cronbach’s alpha values of, 0.77, 0.82, 0.85 and

ICC values of 0.68, 0.77, and 0.68, respectively. All three subscales had adequate internal consistency however only the affective affiliate stigma subscale was stable over time in carers of people with LD (Mitter et al., 2018).

For the current study with family carers of people with dementia, the cognitive affiliate stigma subscale was renamed to perceived affiliate stigma, as items on this subscale were related more closely to the personal experiences of carers rather than thoughts.

The instructions “with LD” was replaced by “living with dementia” to ensure relevance to carers of the current study. All items within the behavioural, affective and perceived affiliate stigma subscales began with the following phrases respectively, “*I avoid* (e.g. introducing my friends to them)”, “*I feel* (e.g. embarrassed about them)”, “*I am* (e.g. treated differently by some people when I am with them)”. A total score for the subscale was calculated by summing up the response options for each item within the scale, the affiliate stigma total score is the sum of all three subscales.

#### **5.2.3.4 The Rosenberg Self-Esteem Scale (RSES)**

Previous literature has documented the inverse relationship between self-esteem and stigma concepts in dementia, HIV/AIDs and cancer (Burgener & Berger, 2008; Fife & Wright, 2000). Based on the literature there is evidence of a convergent relationship between stigma and self-esteem. Previous research has noted the negative impact of stressors on carer self-esteem using the RSES (Chappell, Dujela, & Smith, 2015; Pearlin et al., 1990). Positioning stigma as a stressor that has been previously understudied in relation to carer burden, the

current study hypothesised that stigma experienced by carers would contribute to lower levels of self-esteem.

#### **5.2.3.5 Demographic Questionnaire**

In addition to the aforementioned measures, the following demographic information was collected for carers of people living with dementia: gender, age, relationship to person living with dementia (e.g. spouse), ethnicity, whether the carer lives alone, employment status, whether English is their first language and the cared for person's details (age, time since diagnosis, type of dementia).

#### **5.2.4 Procedure**

Potential participants were given a study information sheet and were given at least 24 hours to consider participating before taking part. Participation methods were either independently online or face-to-face data collection with a researcher (the author or one of three master's students). Qualtrics (Qualtrics, Provo, UT) was used for online data collection, where a participant accessed the participant information sheet, screening questions, consent form and study measures through a survey link. The author or one of two MSc students carried out face-to-face data collection. All participants were asked to complete the measures one to two weeks later (T2) in the same format in which they had completed them initially (T1). Re-consent was not formally sought for this follow-up but was always verified, whether online ("Please only click "next" if you are happy to complete the questionnaires again. Please remember that participation is voluntary") or verbally.

#### **5.2.5 Data Analysis**

##### **5.2.5.1 Handling Missing Data**

The author conducted all the analysis. Participants who took part online were prompted when an item was left unanswered, however, they were able to continue to the next set of questions despite having unanswered items if they wished to. All data was subject to missing values analysis. Depending on the amount of data that were missing, and the significance of the Little's test, well-established guidelines were used to determine the best course of action (Eekhout, 2015; Graham, 2009). If the Little's MCAR test was non-significant and less than 10% of data were missing, mean imputation was used to replace missing data points with the mean of that particular scale (Eekhout, 2015; Graham, 2009).

### **5.2.5.2 Field Notes**

Field notes were taken during face-to-face home visits by researchers. The field notes were used to understand the participant experience of completing the psychometric instruments and to ascertain the acceptability and suitability of the measures.

### **5.2.5.3 Assessment of Psychometric Properties of FAMSI domains**

Data distributions of the measures (floor and ceiling effects and normality), internal consistency, test retest reliability and convergent validity were analysed using the same analysis and standards described in Chapter 4 section 2 using the Statistical Package for Social Sciences (SPSS, Version 26). The RSES was used to assess the convergent validity of the perceived family stigma, positive aspects of caregiving and affiliate stigma. It was hypothesised that the perceived family stigma and affiliate stigma would be negatively correlated and the positive aspects of caregiving positively correlated with the RSES.

### **5.2.5.4 Endorsement of FAMSI domains**

Percentages for each response option were compared for each FAMSI item to explore which FAMSI domains were endorsed over others as per the analysis conducted by Mitter et al. (2018).

### **5.2.5.5 Relationships between FAMSI domains**

As per the analysis conducted by Mitter et al. (2018), relationships between perceived family stigma, positive aspects of caregiving and affiliate stigma were assessed with Pearson's R correlations.

### **5.2.5.6 Factor Analysis**

A confirmatory factor analysis (CFA) was conducted in R software (RStudio Team, 2015) using the Lavaan package (version 0.6-5) for structural equation modelling. A CFA is used to explain relationships among observed variables by specifying the latent structure connecting them (Petscher, Schatschneider, & Compton, 2013). When there is a sufficient rationale for (1) certain factors to be present within data, and (2) which variables define each factor, it is appropriate to use a CFA rather than an exploratory factor analysis (EFA) (Henson & Roberts, 2006). Based on this, CFA can be used to examine the 'goodness of fit' of a measurement model that has been previously proposed between observed factors and the underlying latent structure. For the present study, a measurement model for the affiliate stigma experienced by family members of stigmatised people was used. More specifically, the fit of the hypothesised factor structure in the measurement model (affiliate stigma = behavioural + affective + perceived) proposed by Mitter, Ali and Scior (2018) was determined by conducting a CFA.

The most widely reported test statistic for evaluating model fit is Chi-square, however it is often influenced by myriad factors that may result in type I



or type II errors and therefore best practice is to use alternative indicators alongside the Chi-square test value (Petscher et al., 2013). More specifically, in small samples, the power of the Chi-square test is low such that it can become difficult to reject a false model whilst in large samples statistically significant results may occur in the presence of model-data discrepancies (Petscher et al., 2013). Therefore, to minimise the risk of type I and type II errors, the following global fit indices were computed: Comparative Fit Index (CFI) and Root mean square error of approximation (RMSEA). To indicate good model fit, values of the CFI and RMSEA should be close to 0 (Petscher et al., 2013). CFI values  $>.90$  are acceptable and  $>.95$  indicative of good model fit to the data whilst, values of RMSEA below  $<.08$  are considered acceptable and  $<.06$  indicative of good model fit (Hu & Bentler, 1999).

### **5.3 Results**

#### **5.3.1 *Sample Characteristics of Carers***

Seventy-four carers of people living with dementia attempted to complete the study of which seventy carers of people living with dementia met the eligibility criteria and provided informed consent. Four participants took part face to face and 66 participants took part online (see Table 5.1). Three participants discontinued online data collection during screening and one online participant was excluded due to the level of incomplete data (omission of affiliate stigma and RSES scales, and all demographic items).

Data collected across all measures had low levels of missing data ( $<10\%$ ), indicative of high completion rates and acceptability and suitability of using the measures in this population. A Little's Missing Completely At Random (MCAR)

was non-significant for each measure ( $p=.623$ ) indicating data were missing completely at random and therefore mean imputation at an item level was performed to deal with the low levels of missing data (Eekhout, 2015; Graham, 2009).

Table 5.1.

*Participant characteristics and demographics (N=70)*

		M (SD) or N	
Sociodemographic variables of carers	Age, years/range	60.00(13.19)/27-	
	Gender (M/F/ND^)	16/53/1	
	Ethnicity	White	65
		Black/African/Caribbean	1
		Mixed Multiple	1
		Other Ethnic Group	2
		ND	1
	Relationship to person living with dementia	Spouse/partner	24
		Child/Child in Law	38
		Other	7
		ND	1
	Living alone	Yes	16
		No	53
		ND	1
Employment status	Employed	32	
	Retired	35	
	Other	2	
	ND	1	
English as first language	Yes	68	
	No	1	
	ND	1	
Sociodemographic variables of people living with dementia <sup>a</sup>	Age, years/range	80.61 (7.76)/63-	
	Months since diagnosis/range	69.04 (47.61)	
	Type of dementia	Alzheimer's Disease	26
		Vascular Dementia	13
		FTD (behavioural variant)	8
		Lewy Body	2
		Mixed	17
		Not disclosed/Unknown	4

### **5.3.2 Field Notes**

Field notes were collected from the four face-to-face visits carried out by researchers who were two master's students at University College London. All carers completed the questions independently and found them straightforward to understand and answer. One participant felt that some questions were broad and participants were left, wanting to answer, "it depends" rather than conform to the response categories.

One participant said they were worried about looking "boastful" if they answered 'strongly agree' to some of the positive items on the RSES (e.g. I feel that I have a number of good qualities). This participant also mentioned that some items in the RSES were very negative (e.g. all in all, I am inclined to think that I am a failure) and may upset others but did not have this effect on them.

### **5.3.3 Assessment of Psychometric Properties of FAMSI domains**

#### **5.3.3.1 Perceived Family Stigma**

The data from the perceived family stigma scale did not show any floor and ceiling effects and the kurtosis value was within range. However, data were negatively skewed and only 55.7% of participants scored above the mean (see Table 5.2). The perceived family stigma scale had an ICC value  $\geq .70$  indicating adequate test retest reliability (Terwee, et al., 2007) and a Cronbach's alpha value  $\geq .70$  indicating adequate internal consistency, and was not improved by deleting any items (Terwee, et al., 2007). There was no significant correlation between perceived family stigma and RSES, indicating a lack of convergent validity. On an item level, there was one significant correlation between RSES and perceived family stigma (item 2 "some people might feel uncomfortable going to the house of family of a person living with dementia",  $r_s = .237$   $p = .019$ ), however the

Person's correlation coefficient was below the threshold showing a weak relationships ( $r = .30$ )

### **5.3.3.2 Positive Aspects of Caregiving**

The data from the positive aspects of caregiving scale did not have any floor and ceiling effects and both skewness and kurtosis values for the scale were within range and close to 0, indicating a normal distribution. The positive aspects of caregiving had an ICC value  $\geq .70$  indicating adequate test retest reliability (Terwee, et al., 2007) and a Cronbach's alpha value  $\geq .70$  indicating adequate internal consistency where no items if deleted, would have improved value (Terwee, et al., 2007). There was no significant correlation between positive aspects of caregiving and RSES, indicating a lack of convergent validity. On an item level, there were no significant correlations between any of the positive aspects of caregiving items and RSES.

### **5.3.3.3 Affiliate Stigma**

Data from the overall affiliate stigma scale and the perceived affiliate stigma subscale had no floor or ceiling effects and were normally distributed with skewness and kurtosis values within range. Data from the behavioural and affective affiliate stigma subscales had floor effects however, both subscales had skewness and kurtosis values within the acceptable ranges and therefore were considered to not deviate from normality. The affiliate stigma total score and the three subscales (behavioural, perceived and affective affiliate stigma ) had an ICC value  $\geq .70$  indicating adequate test retest reliability (Terwee, et al., 2007) and had Cronbach's alpha values  $\geq .70$  indicating adequate internal consistency where no items if deleted, would have improved the value (Terwee, et al., 2007). There were no significant correlations between the total affiliate stigma scale and

subscales with the RSES indicating a lack of convergent validity between affiliate stigma and self-esteem. There was one significant correlation between item 3 on the affective affiliate stigma subscale (“I feel guilty about having my family member with dementia in the family”) and RSES ( $r = -.345$ ,  $p = .003$ ), indicating a weak negative relationship between feeling guilty about having a family member with dementia in the family and carers’ self-esteem.

Table 5.2.

*Reliability and validity statistics of the FAMSI*

FAMSI Domains	Distribution of data			Floor and Ceiling		Reliability			Convergent Validity			
	M(SD)	Skewness	Kurtosis	Min	Max	Lowest Score (%)	Highest Score (%)	Internal consistency ( $\alpha$ )	Test - Retest			Pearson's <i>r</i>
									ICC	Lower	Upper	
Perceived Family Stigma	27.37(6.96)	-1.255	1.630	8	38	5.7	0	0.917	0.822	0.699	0.894	0.098 <sup>^</sup>
Positive Aspects Of Caregiving	19.26(4.39)	-0.046	0.160	8	30	0	2.9	0.720	0.832	0.715	0.900	0.039
Affiliate Stigma (total)	25.76(7.51)	0.188	-0.223	12	44	5.7	0	0.858	0.728	0.544	0.840	-0.120
Affective	6.93(2.93)	0.694	-0.640	4	14	32.9	0	0.857	0.749	0.577	0.851	-0.183
Perceived	12.09(4.23)	-0.429	-0.625	4	20	7.1	2.9	0.875	0.818	0.696	0.893	0.023
Behavioural	6.74(2.56)	0.794	0.073	4	14	30.0	0	0.759	0.746	0.570	0.850	-0.181

<sup>a</sup>Confidence interval; \*p <.05 \*\*p <.001

### **5.3.4 Endorsement of FAMSI Domains**

#### **5.3.4.1 Perceived Family Stigma**

Response options endorsed by carers for each item of the FAMSI are represented in Table 5.3. Endorsement was calculated as a combination of the percentage of “somewhat agree” and “strongly agree” response options.

More than half of carers endorsed that some people may feel embarrassed about associating with (64.3%) or uncomfortable going to the house of someone with dementia (78.6%). More than half of carers endorsed that others may avoid making friends with someone with dementia (68.5%), people may not want to hear about their problems (71.4%) and they may be treated more negatively by others (71.4%). More than a third of carers endorsed experiences that others might behave negatively toward someone with dementia when they are in public (51.4%) and they may not invite the family of someone with dementia to social events (68.6%). The majority of carers were in agreement with the items on the perceived family stigma scale. However carers “somewhat disagreed” or “strongly disagreed” with one item in particular (some people might think that the family has done something wrong because of them [person living with dementia]; 58.6%).

#### **5.3.4.2 Positive Aspects of Caregiving**

Over half of carers agreed or strongly agreed that caring for someone with dementia had allowed them to form friendships with others in a similar situation (64.3%). Approximately half of carers agreed that caring for someone living with dementia made them feel needed (54.3%), feel that they have made positive contribution to society (47.2%) and strengthen relationships with family and friends (48.6%). Over a third of carers disagreed or strongly disagreed that caring



for someone with dementia had enabled them to develop a more positive attitude towards life (41.4%) or strengthened their spirituality and faith (45.7%).

#### **5.3.4.3 Affiliate Stigma**

Perceived affiliate stigma was the only affiliate stigma subscale in which carers chose the “strongly agree” option. Carers reported experiences of perceived affiliate stigma (46.1%) almost eight times more than affective affiliate stigma (6.4%) or behavioural affiliate stigma (6.4%).

Carers “somewhat disagreed” or “strongly disagreed” with all four items of the affective affiliate stigma subscale where the majority of carers did not feel embarrassed about the person living with dementia (72.9%), did not feel distressed about being associated with them (88.6%), did not report feeling guilty about having them in the family (92.9%), and did not report feeling uncomfortable around friends because of the person living with dementia (74.3%).

The majority of carers “somewhat disagreed” or “strongly disagreed” with items on the behavioural affiliate stigma subscale, suggesting that carers did not endorse avoidance behaviours: avoid introducing the person living with dementia to friends (72.9%); avoid telling people they were related (95.7%); avoid making new friends because of the person living with dementia (79.4%); and avoid being seen with them (92.8%).

For the perceived affiliate stigma subscale, carers endorsed (“somewhat agree” and “strongly agree”) experiencing being treated differently (57.2%), aware how others look at them (44.2%), being treated differently when in the company of the person living with dementia (50%). For item 2 of the perceived

affiliate stigma (I am excluded from activities when other people find out about their dementia), responses from carers were conflicted where some carers did not endorse this experiences (48.6%) whilst others did (32.8%).

Table 5.3.

*Endorsement ratings of the FAMSI domains*

FAMSI Domain		Item wording	Endorsement of each response option n (%)					
			Strongly Disagree	Somewhat disagree	Neither disagree/agree	Somewhat agree	Strongly agree	
Perceived Family Stigma	Some people might...	1	feel embarrassed about associating with them	6(8.6)	13(18.6)	6(8.6)	37(52.9)	8(11.4)
		2	feel uncomfortable about going to their house	4(5.7)	5(7.1)	6(8.6)	41(58.6)	14(20.0)
		3	treat them more negatively	4(5.7)	6(8.6)	10(14.3)	40(57.1)	10(14.3)
		4	think that the family has done something wrong because of them	14(20.0)	27(38.6)	20(28.6)	5(7.1)	4(5.7)
		5	behave negatively towards them when they are with the person living with dementia in public	7(10.0)	11(15.7)	16(22.9)	28(40.0)	8(11.4)
		6	avoid making friends with them	5(7.1)	6(8.6)	11(15.7)	40(57.1)	8(11.4)
		7	not want to hear about any of their problems	5(7.1)	8(11.4)	7(10.0)	40(57.1)	10(14.3)
		8	not invite the family to social events	5(7.1)	7(10.0)	10(14.3)	32(45.7)	16(22.9)

			Endorsement of each response option n (%)					
Positive Aspects of Caregiving	Caring for my family member living with dementia has...	9	enabled me to develop a more positive attitude toward life	5 (7.1)	24 (34.3)	16 (22.9)	17 (24.3)	8 (11.4)
		10	has made me feel needed	-	11(15.7)	21(30.0)	25(35.7)	13(18.6)
		11	has strengthened my spirituality and faith	15(21.4)	17(24.3)	23(32.9)	8(11.4)	7(10.0)
		12	has allowed me to form friendships with others in a similar situation	6(8.6)	10(14.3)	9(12.9)	34(48.6)	11(15.7)
		13	has made me feel that I make a positive contribution to society	4(5.7)	12(17.1)	21(30.0)	24(34.3)	9(12.9)
		14	has strengthened some of my relationships with family/friends	4(5.7)	18(25.7)	14(20.0)	24(34.3)	10(14.3)
Affective Affiliate Stigma	I feel...	15	embarrassed about them (my family member living with dementia)	30(42.9)	21(30.0)	12(17.1)	7(10.0)	-
		16	distressed about being associated with them	37(52.9)	25(35.7)	6(8.6)	2(2.9)	-
		17	guilty about having them in the family.	48(68.6)	17(24.3)	2(5.7)	1(1.4)	-
		18	uncomfortable when I have friends about because of them	28(40.0)	24(34.3)	10(14.3)	8(11.4)	-

			Endorsement of each response option n (%)					
Perceived Affiliate Stigma	I am...	19	treated differently by some people when I am with them	12(17.1)	9(12.9)	14(20.0)	29(41.4)	6(8.6)
		20	excluded from activities when other people find out about their dementia	14(20.0)	20(28.6)	13(18.6)	18(25.7)	5(7.1)
		21	aware of how some people look at me when I am out with them	11(15.7)	14(20.0)	14(20.0)	26(37.1)	5(7.1)
		22	treated differently by some people because of them	11(15.7)	6(8.6)	13(18.6)	34(48.6)	6(8.6)
Behavioural Affiliate Stigma	I avoid...	23	introducing my friends to them	28(40.0)	23(32.9)	8(11.4)	11(15.7)	-
		24	telling people that I am related to them.	45(64.3)	22(31.4)	3(4.3)	-	-
		25	making new friends because of them	31(44.3)	25(35.7)	8(11.4)	6(8.6)	-
		26	being seen with them	43(61.4)	22(31.4)	4(5.7)	1(1.4)	-

**5.3.5 Relationships between FAMSI Domains**

Relationships between FAMSI domains are summarised in Table 5.4. There was a moderate significant correlation between perceived family stigma and the affiliate stigma ( $r = .489, p < .001$ ) and the subscale perceived affiliate stigma ( $r = .624, p < .001$ ) indicating that carers who endorse courtesy stigma items are also more likely to experience affiliate stigma. The positive aspects of caregiving scale was negatively correlated with all other FAMSI domains and affiliate stigma subscales, however the correlations were non-significant. The affiliate stigma subscales are discussed in the next section.

*Table 5.4.*

*Relationships between FAMSI Domains*

FAMSI domains	PFS <sup>^</sup>	PAC	AS	AAS	PAS	BAS
PFS	-					
PAC	-.013	-				
AS	.391**	-.104	-			
AAS	.130	-.015	.772**	-		
PAS	.586**	-.053	.772**	.272*	-	
BAS	.064	-.200	.772**	.670**	.300*	-

\*Significant at  $p < .05$  \*\* $p < .001$  <sup>^</sup> nonparametric test- Spearman's Rank Correlations performed for this scale

PFS – Perceived family stigma; PAC – Positive aspects of caregiving; AS- Affiliate stigma; AAS – Affective affiliate stigma; PAS – Perceived affiliate stigma; BAS- Behavioural affiliate stigma

### 5.3.6 Factor Analysis of Affiliate Stigma

A CFA was performed based on the data of 70 participants who completed the affiliate scale. Maximum likelihood estimation was used because the data collected was normally distributed. There were consistent findings regarding model fit. The chi-square test for goodness of fit was non-significant ( $X^2= 68.05$ ,  $p >.05$ ) indicating good model fit for the data collected. The CFI had a value of 0.965 indicating good model fit and the RMSEA had a value of 0.069 indicating acceptable model fit of the three factors of affiliate stigma (see Table 5.5). The indicators showed significant positive factor loadings with standardised coefficients ranging from 0.326 to .884 (see Table 5.6). There were also significant positive correlations between all three latent factors, suggesting that carers experience affiliate stigma in line with the cognitive behavioural theory where carers who experience higher levels of perceived affiliate stigma also experience high levels of behavioural and affective affiliate stigma. The confirmed factor structure is presented in Figure 5.1.

Table 5.5.

*CFA global fit indices for affiliate stigma*

	$X^2$	df	CFI	TLI	RMSEA
Three-factor Model	68.051	51	0.965	0.954	0.069

$X^2$  = Chi-Square goodness of fit;  $df$  = degrees of freedom; CFI = comparative fit index; TLI = Tucker Lewis fit Index; RMSEA = root mean square error of approximation

Table 5.6.

*Factor loading for the three-factor model of affiliate stigma*

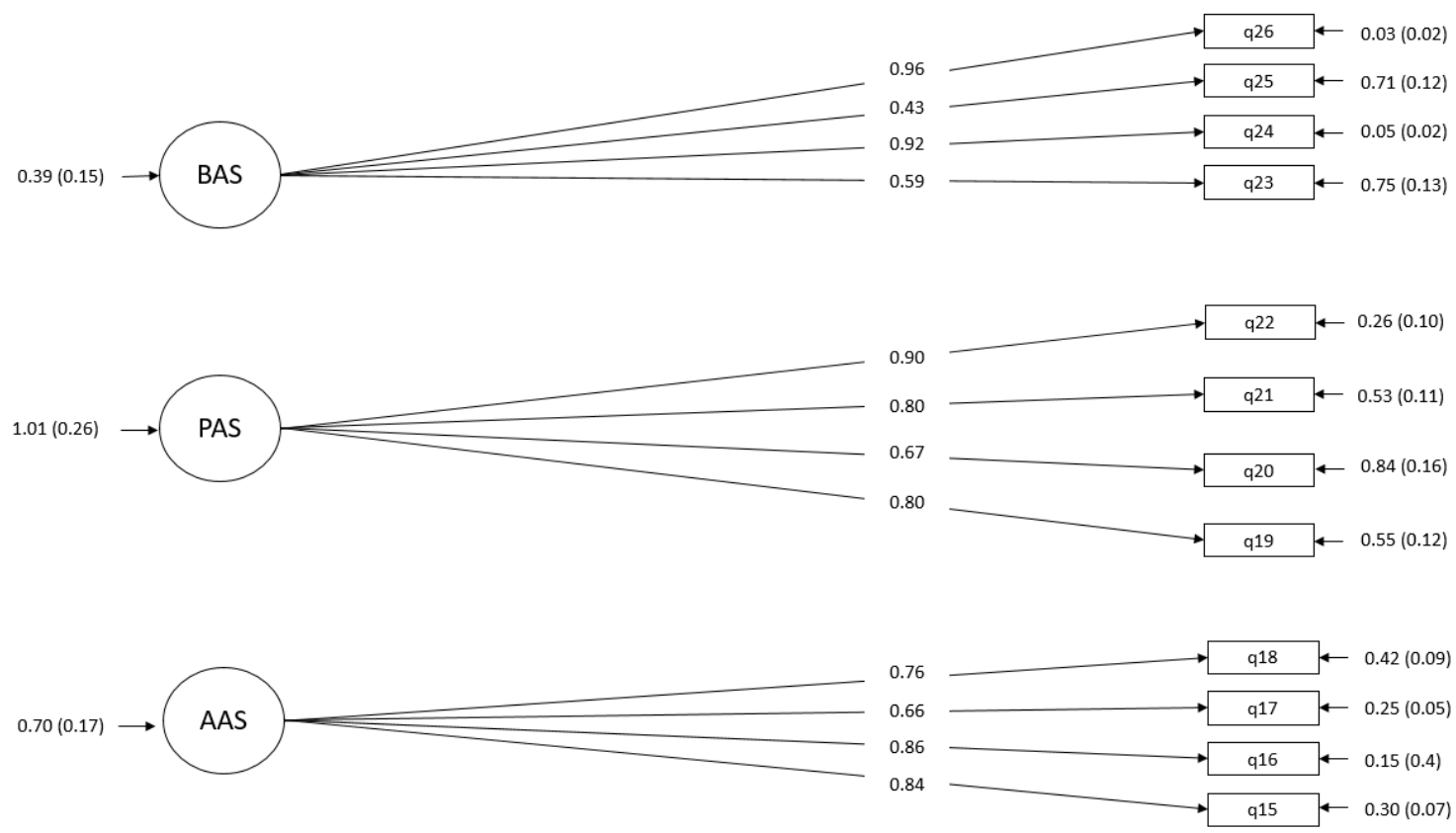
Latent Factor	Indicator (item)	$\beta$	B	SE	Z	p-value
Affective Affiliate Stigma	15. I feel embarrassed about them (my family member living with dementia)	0.836	1.000	0.000	-	-
	16. I feel distressed about being associated with them	0.859	0.784	0.094	8.331	0.000
	17. I feel guilty about having them in the family.	0.664	0.527	0.089	5.941	0.000
	18. I feel uncomfortable when I have friends about because of them	0.763	0.914	0.128	7.138	0.000
Perceived Affiliate Stigma	19. I am treated differently by some people when I am with them.	0.804	1.000	0.000	-	-
	20. I am excluded from activities when other people find out about their dementia	0.677	0.839	0.144	5.947	0.000
	21. I am aware of how some people look at me when I am out with them.	0.804	0.976	0.132	7.375	0.000
	22. I am treated differently by some people because of them	0.909	1.100	0.133	8.300	0.000



Behavioural Affiliate Stigma	23. I avoid introducing my friends to them	0.586	1.000	0.000	-	-
	24. I avoid telling people that I am related to them.	0.919	0.838	1.149	5.615	0.000
	25. I avoid making new friends because of them	0.429	0.641	0.198	3.241	0.001
	26. I avoid being seen with them	0.964	1.032	0.181	5.688	0.000

Figure 5.1.

Factor structure of affiliate stigma



## **5.4 Discussion**

### **5.4.1 Summary of Key Findings**

#### **5.4.1.1 Independent Assessment of the three FAMSI Domains**

Field notes indicated that the measures were straightforward to complete and resonated with participants, highlighting the face validity of the scales. All FAMSI domains had good internal consistency and test retest reliability in a population of carers of people living with dementia in the UK. Convergent validity with the RSES was not found within the data for any of the scales, which was not as expected.

As the link between stigma and self-esteem has been based predominantly on research in individuals with stigmatising conditions rather than their carers, it is possible that self-esteem is not strongly related to affiliate stigma (Burgener & Berger, 2008; Burgener, Buckwalter, Perkhounkova, & Liu, 2015). For instance, carers are fundamental to ensuring the needs of the person they care for are met on a daily basis, self-esteem as a construct in this case may be confounded by carers experiencing a strong sense of purpose, therefore thinking of the RSES items from the position of being a carer rather than an individual in their own right.

#### **5.4.1.2 Endorsement of FAMSI Domains**

Perceived affiliate stigma was the only scale in which carers chose the ‘strongly agree’ response option suggesting that carers have had experiences of being treated or looked at differently, and being excluded from activities, over and above others. Indeed, experiences related to perceived affiliate stigma were more heavily endorsed in comparison to affective or behavioural affiliate stigma, in line with findings from Mitter et al. (2018). Carers were almost 8 times more

likely to experience perceived affiliate stigma in comparison to other types of affiliate stigma as a result of caring for someone living with dementia. Similar to the findings by Mitter et al (2018), more than half of the carers perceived the role of being a family carer to be stigmatising.

A number of carers reported positive aspects of their caring roles (positive aspects of caregiving). It is possible, for example, that if carers frame their role positively, they may be more likely to be able to resist feeling and behaving negatively as a result of their caring role, and therefore over time may become less vulnerable to these aspects of affiliate stigma. This may also explain why the endorsement for perceived affiliate stigma was higher, as one's stigma resistance or framing one's role positively would be less likely to affect the perception of affiliate stigma. These findings suggest that affective and behavioural affiliate stigma rely on the carer to exhibit feelings and acts, while perceived affiliate stigma relies on external factors such as one's environment.

### **5.4.1.3 Relationships between FAMSI Domains**

Findings suggest that carers who perceive family stigma also experience affiliate stigma. This speaks to the two-step process outlined by Mitter et al. (2018) suggesting that carers first perceive the attitude of others as negative and then go on to internalise these negative attitudes to experience affiliate stigma consequences. More specifically, in the current study, there was a significant relationship between perceiving family stigma and experiencing affiliate stigma but not with the behavioural or affective subscales of the affiliate stigma scale. Therefore, being aware of negative perceptions from others about having a caring role may be related closely to stereotype agreement, rather than emotional or behavioural responses to others' negative attitudes.

The rationale for separating the FAMSI domains was reinforced by the inverse relationship between positive aspects of caregiving and all other FAMSI domains. However, the correlations were not of statistical significance therefore concrete conclusions cannot be drawn from the data of the current study. These findings do, however, highlight the importance of considering positive aspects of caring when quantifying the stigma experience and therefore a replication of this study may be useful future research.

#### **5.4.1.4 Factor Structure of Affiliate Stigma**

A CFA was conducted on the affiliate stigma scale only. This was because to be congruent with Chapter 4 and produce outcome measures for a disclosure decision-making intervention, self-stigma concepts needed to be explored and validated; hence affiliate stigma (the equivalent of self-stigma in carers) was assessed using a CFA.

In a CFA, the chi-square test statistic and global fit indices indicated that the data from the current study did confirm the factor structure found for affiliate stigma (Mitter et al., 2018). Although this was the case, the chi-square test statistic in particular should be interpreted with caution. It is often argued that in applications of structural equation modelling the chi-square test statistic should not only be used to determine model fit as it can be influenced by a number of factors such as multivariate non-normality, size of the correlation between observed variables, uniqueness of variable variances and sample size. In the case of the current study, it is unlikely that multivariate non-normality or uniqueness of variances influenced the chi-square test, as all observed variables follow patterns of normality and had adequate psychometric properties of reliability. It is possible the correlation size influenced the chi-square test, as, whilst the correlation

between observed variables of behavioural affiliate stigma and affective affiliate stigma was close to a strong positive correlation ( $r = 0.67$ ), others were weaker (perceived affiliate stigma and behavioural affiliate stigma, perceived affiliate stigma and affective affiliate stigma) which may have caused greater discrepancies between predicted and observed variables. Sample size may have under powered the chi-square test as the sample size of the current study was below what was originally calculated (i.e. 7 multiplied by the number of items = 84 participants), which may have caused both type I and type II errors and in this case it may have contributed to the latter (Petscher et al., 2013).

### **5.4.2 Methodological Considerations**

Although the FAMSI had not been used in carers of people with dementia the inclusion of positive aspects of caregiving and both affiliate and courtesy stigma built a rationale for first ever quantification of stigma concepts in carers of people living with dementia in the UK. It is important to acknowledge that the systematic process of identifying, selecting, adapting and modifying psychometric instruments for use in a new population as outlined in Chapter 4, was not employed in the current Chapter and that is a limitation of the current study. For this reason, it is possible that measures which may be relevant in quantifying courtesy and affiliate stigma as well as positive aspects of caregiving were missed. In addition to this, the lack of involvement from research experts and lived experience experts in appraising the items and the omission of a quality appraisal may have meant that the opportunity to improve the acceptability, suitability and relevance of the FAMSI was lost.

The majority of the data used in the current study was collected online. Given the sensitivity of the topics (e.g. embarrassment caused by person living with dementia), the use of online platforms to collect data may have decreased the presence of demand characteristics and social desirability. Furthermore, it was not possible to establish how long participants spent completing the measures which may have confounded the results.

The majority of participants identified as “white” and therefore the cohort lacked ethnic diversity. This may have affected the results, as it is known from other populations that culture can influence the extent to which carers experience affiliate stigma. For example, in Asian collectivist cultures where all members of the family are expected to fulfil predefined and culturally appropriate roles to uphold a reputable status, this might increase the risk of carers becoming distressed or uncomfortable about having a family member with a stigmatising condition (Mackenzie, 2006).

The CFA was limited by a small sample size and therefore global fit indices and the Chi-square value may have been affected as a result (Petscher et al., 2013). For the latter, a post-hoc sample size calculation in G Power indicated a sample size of at least 253 participants should be sufficient given a medium effect size (0.30) and power (0.95) and alpha level (.05). Future testing will therefore require a larger cohort of participants to address this limitation.

Although it was beyond the scope of the current study, further research in this field should aim to identify the impact of positive aspects of caregiving, courtesy and affiliate stigma on the person living with dementia as well as carers, particularly as the influence of positive aspects of caregiving on people living

with dementia is an understudied field (Quinn, 2016). It is plausible to predict that greater perceptions of positive aspects of caregiving may lead to health and social benefits for both carers and people living with dementia. However, recent literature has found that positive aspects of caregiving have been associated with benefits for carers (Quinn, Clare, McGuinness, & Woods, 2012) themselves but not people living with dementia (Quinn et al., 2019).

### **5.4.3 Conclusion**

To conclude, the aim of the study in this Chapter was to conduct an independent assessment of the psychometric properties of the three FAMSI domains when treated as a three-factor scale (courtesy stigma, affiliate stigma and positive aspects of caregiving). Findings suggest that the FAMSI is a suitable measure to quantify courtesy and affiliate stigma and positive aspects of caregiving in a UK population of carers of people living with dementia.



**6 “Who to tell, how and when?”: Development and preliminary feasibility of an intervention for people living with dementia who are fearful of disclosing their diagnosis**

A version of this chapter has accepted for publication:

Bhatt, J., Ruffell, T., Scior, K., & Charlesworth, G. (accepted). “Who to tell, how and when?”: Development and preliminary feasibility of an empowerment intervention for people living with dementia who are fearful of disclosing their diagnosis. *Clinical Interventions in Aging*

**6.1 Introduction**

In this Chapter, I describe the development and preliminary feasibility testing of the “Who to tell, how and when?” intervention for people living with dementia, an adaptation of the existing Honest Open Proud programme (see Chapter 3 for HOP description) for disclosure of concealable, stigmatised identities. I place a particular emphasis on intervention development being informed by coproduction principles with people affected by dementia and the importance of an iterative development process.

**6.1.1 Developing Complex Interventions**

The effectiveness of complex interventions relies on robust design and development (Wight et al., 2015). Medical Research Council (MRC) guidelines for developing complex interventions for the public health sector describe the advantage of a rigorous development process, including maximising effectiveness in terms of both cost and patient experience (Craig et al., 2008; Wight et al., 2015). This approach has been previously used to develop and test group-based

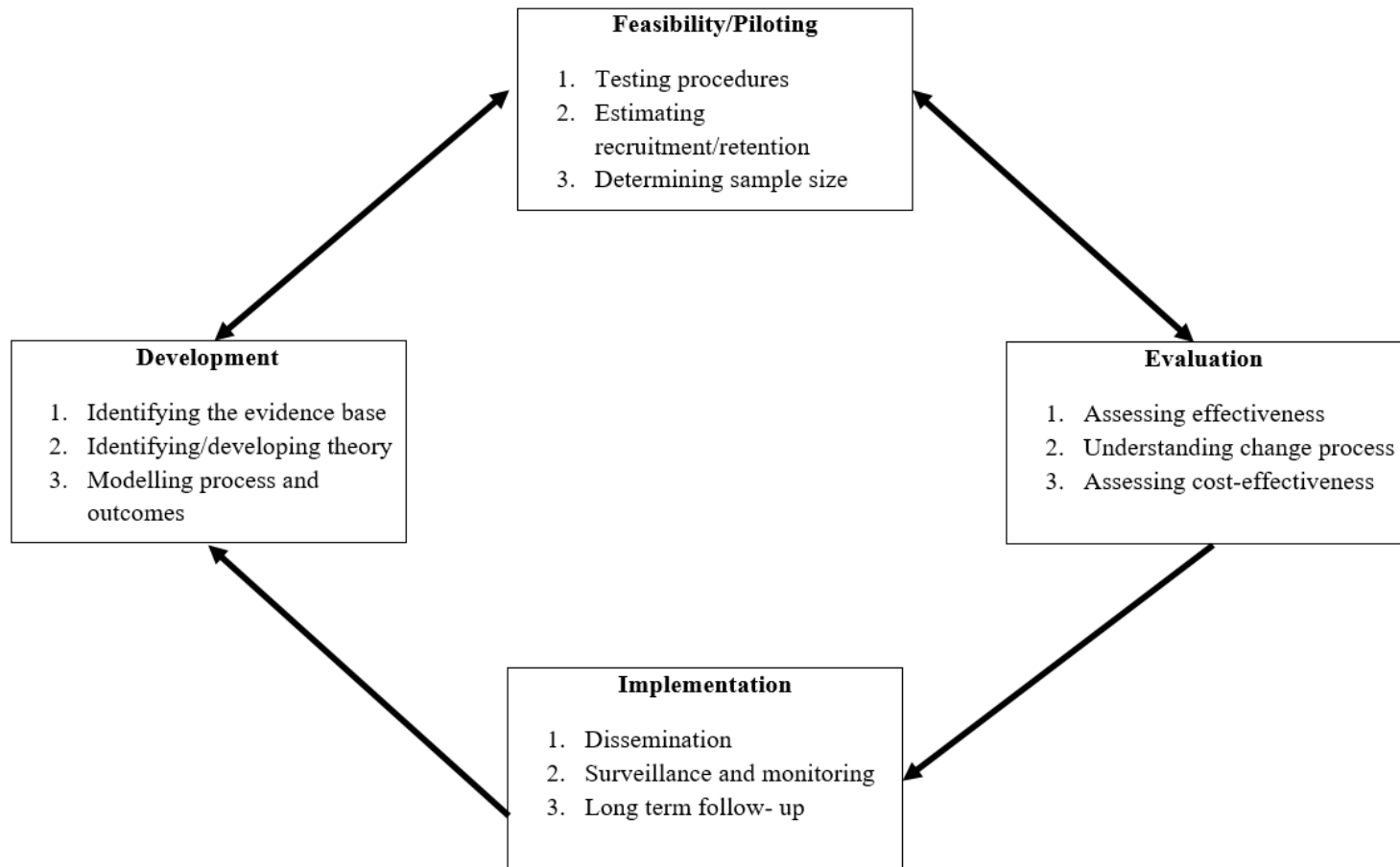
psychosocial interventions for people living with dementia (Quinn et al., 2014, 2016; Yates et al., 2019).

The key elements of the MRC guidelines (Craig et al., 2008) for development include: identifying the evidence base, identifying theory, modelling process and outcomes. Feasibility assessment includes testing procedures, estimating recruitment and retention, determining sample size (see Figure 6.1).

Identifying the evidence base includes reviewing relevant and existing evidence, or using a recently published review that covers the existing evidence base (Craig et al., 2008). Knowledge of existing lay theory and theoretical underpinning of an intervention is a prerequisite to understand what is expected to change when individuals engage in the intervention (Craig et al., 2008). The theory of change may not always be clear at the beginning and can be developed through existing literature or new primary research such as stakeholder consultations (Craig et al., 2008). The modelling process can provide important information about the design of the intervention and the way in which it will be evaluated. The modelling process should establish potential weaknesses and lead to refinement (Craig et al., 2008).

Figure 6.1.

Key elements of the development and evaluation process (Craig et al., 2008)



Feasibility and piloting includes testing the acceptability of intervention procedures and the feasibility of recruitment and attendance. Previous research has noted the importance of piloting as a fundamental phase of intervention development which is often methodologically overlooked (Eldridge, Ashby, Feder, Rudnicka, & Ukoumunne, 2004). The lack of feasibility and piloting have led to intervention evaluations becoming subject to problems of acceptability (Armstrong, Winder, & Wallis, 2006; Scheel, Hagen, & Oxman, 2003), compliance (Rowland et al., 2002) as well as, delivery, recruitment and attendance (Bower, Wilson, & Mathers, 2007; McDonald et al., 2006; Prescott et al., 1999).

### **6.1.2 Process Evaluation**

As intervention development is an iterative process that should be consistently informed by the production of new data, it is appropriate to extend the intervention development phase by performing an initial process evaluation (Craig et al., 2008; Moore et al., 2015; O’Cathain et al., 2015). Depending on the stage of development, implementation of evaluation, the function of a process evaluation may differ, however, typically process evaluations help to understand feasibility of intervention and how design and evaluation can be optimised for the future (Moore et al., 2015).

The 2008 MRC guidelines did not include detailed steps on the conduct or components of process evaluations. Moore et al. (2015), builds upon the 2008 guidance to deliver practical information on process evaluations, for a better preliminary understanding of how interventions work in practice as part of the

development and feasibility process through three related components:

implementation, mechanism and context.

As noted above the MRC guidelines, begin with the gathering information about the theory of change for an intervention, this directly links to implementation as outlined by Moore et al. (2015), where fidelity and dose are measured (e.g. observations, participant interviews) to understand how an intervention works. Next, intervention mechanisms of impact are considered such that future replication of the intervention can produce similar impacts (Grant, Treweek, Dreischulte, Foy, & Guthrie, 2013), where complex pathways of interventions can be measured within process evaluations using quantitative and qualitative methodology (Bonell, Fletcher, Morton, Lorenc, & Moore, 2012; Moore et al., 2015; O’Cathain et al., 2015). The final component that may be investigated in process evaluations is context, which considers external factors (e.g. anything apart from the intervention) and how they may act as barriers or facilitators to implementation, as it is possible for identical procedures to have varying affects in different contexts (Moore et al., 2015; Shiell, Hawe, & Gold, 2008). Moore and colleagues (2015) helpfully extend the 2008 guidance by including the value of qualitative methods (interviews and observations) and identifying key components when planning intervention process evaluations. Process evaluation techniques can be used when an intervention is adapted to a different clinical context, such as the way HOP will be adapted in this Chapter for people living with dementia. Further, the process evaluation can be used to make iterative changes to intervention content, format and delivery, and test suitable outcome measures thus decreasing the chances of implementation error (Moore et al., 2015; Vernooij-Dassen & Moniz-Cook, 2014).

### **6.1.3 Rationale**

Previously, MRC guidelines have been used in the development and testing of psychosocial interventions for people living with dementia (Quinn et al., 2014, 2016; Yates et al., 2019). However, to the author's knowledge, there are currently no post-diagnostic interventions available to support people living with dementia in disclosure decision-making. This must be urgently addressed as telling others about a diagnosis is often the first step of accessing appropriate and timely support. In addition, as previously mentioned, disclosure decision-making can be framed as a way of people living with dementia maintaining autonomy in decision-making and remaining connected with their social networks.

Recommendations from Moore et al. (2015) state that evaluators need to be in close proximity to the intervention in order to record problems, understand why problems may have occurred and keep records of this as passive observers, which can be fed back following intervention completion and used to improve further implementation. This is the rationale for using the observer data and feedback from facilitators to make necessary amendments to intervention delivery as testing unfolds.

### **6.1.4 Aims**

#### **6.1.4.1 Development**

***Phase 1: Identifying the evidence base and theory.*** The aim of phase one was to generate data to inform the dementia specific adaptation of HOP by identifying the key tenets for HOP and consider these in the light of findings on decision-making in dementia (from Chapter 3; see Figure 6.2).

**Phase 2: Modelling process.** Phase two aimed to create the “who to tell, how and when?” intervention materials for people living with dementia through adapting HOP using phase one data, stakeholder consultation preferences, careful cultural and dementia specific adaptation led by research and lived experience experts.

#### **6.1.4.2 Feasibility**

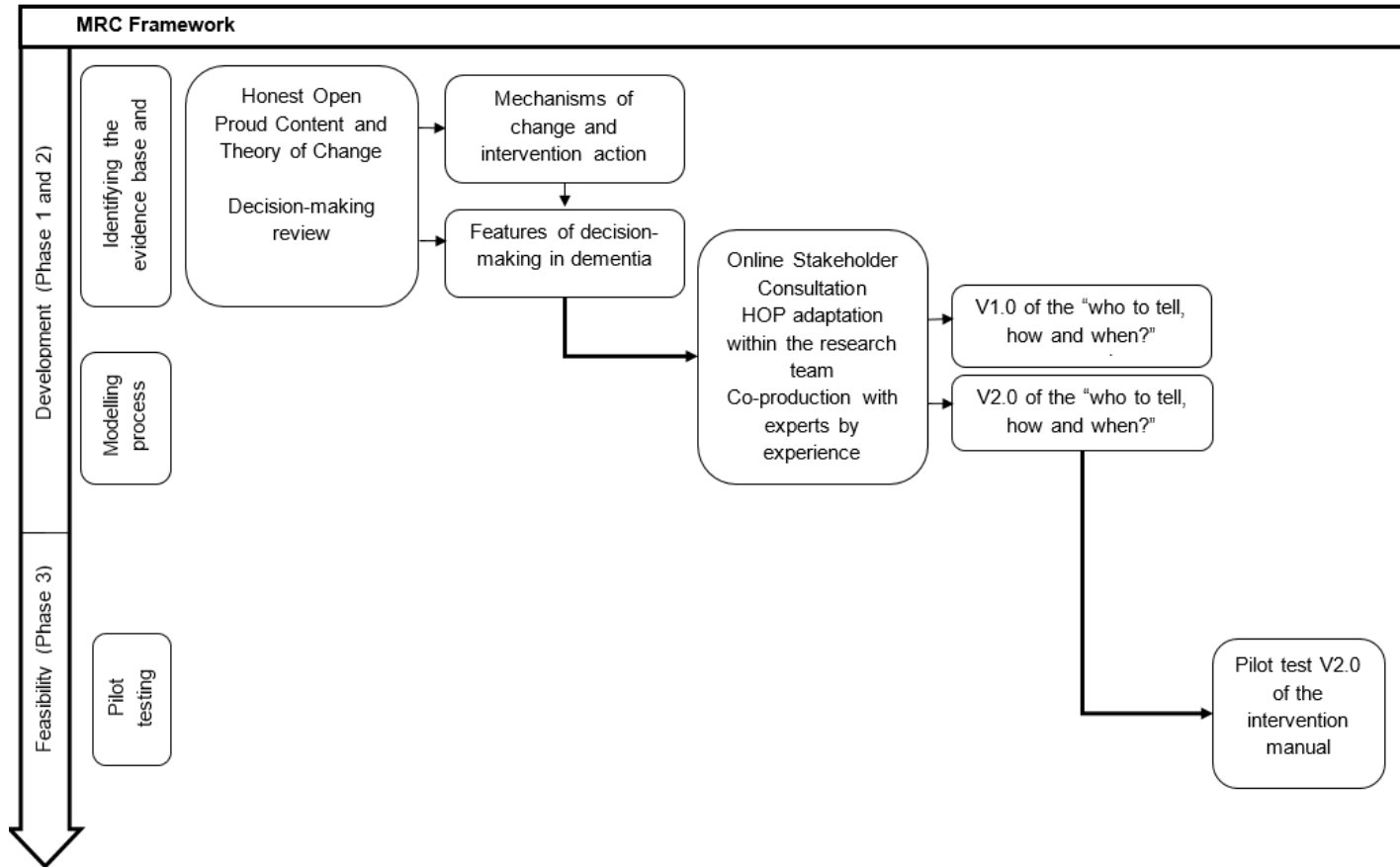
**Phase 3: Piloting.** In phase three we sought to understand the feasibility of recruitment and delivery of the “who to tell, how and when?” intervention.

Feasibility was assessed through records of recruitment and attendance.

Implementation of the “Who to tell, how and when?” intervention will be assessed through summarising qualitative observations and facilitator reflections as per the process evaluation guidance from Moore et al., (2015)

Figure 6.2.

Key elements from MRC Guidelines used to adapted HOP to the “Who to tell, how and when?” intervention





## **6.2 Identifying the Evidence Base and Theory**

### **6.2.1 *Honest Open Proud (HOP): Content and Theory of Change***

The key tenets of HOP are that disclosing mental health problems is a personal decision and disclosure is an ongoing process where costs versus benefits of disclosure are often revisited depending on context. HOP includes discussions around the positive and negative consequences of disclosure, encouraging participants to construct a personalised narrative of their mental health problems through a manualised, peer-supported format (see Table 6.1; Figure 6.3).

Disclosure decisions are supported through the HOP programme with peer support to reduce the negative consequences of secrecy (stress or fear of being found out) and self-stigmatisation whilst increasing levels of empowerment, self-efficacy in terms of coping with stigmatisation, and aid participants' movement towards optimal well-being and recovery (Corrigan et al., 2013; Scior et al., 2019). The aforementioned theory of change is partly supported by randomised controlled trials (RCTs) with adolescents and adults with mental health difficulties in the USA (Corrigan et al., 2015), Germany (Mulfinger et al., 2018) and Switzerland (Rüsch et al., 2014). Findings from RCTs are consistent with the HOP programme being related to reductions in stress caused by stigma (Mulfinger et al., 2018; Rüsch et al., 2014), reductions in self-stigma (Corrigan et al., 2015; Rüsch et al., 2014), decreased disclosure-related distress and perceived levels of secrecy (Mulfinger et al., 2018; Rüsch et al., 2014), and an increase in intentions to seek help from family/friends and professionals (Mulfinger et al., 2018).

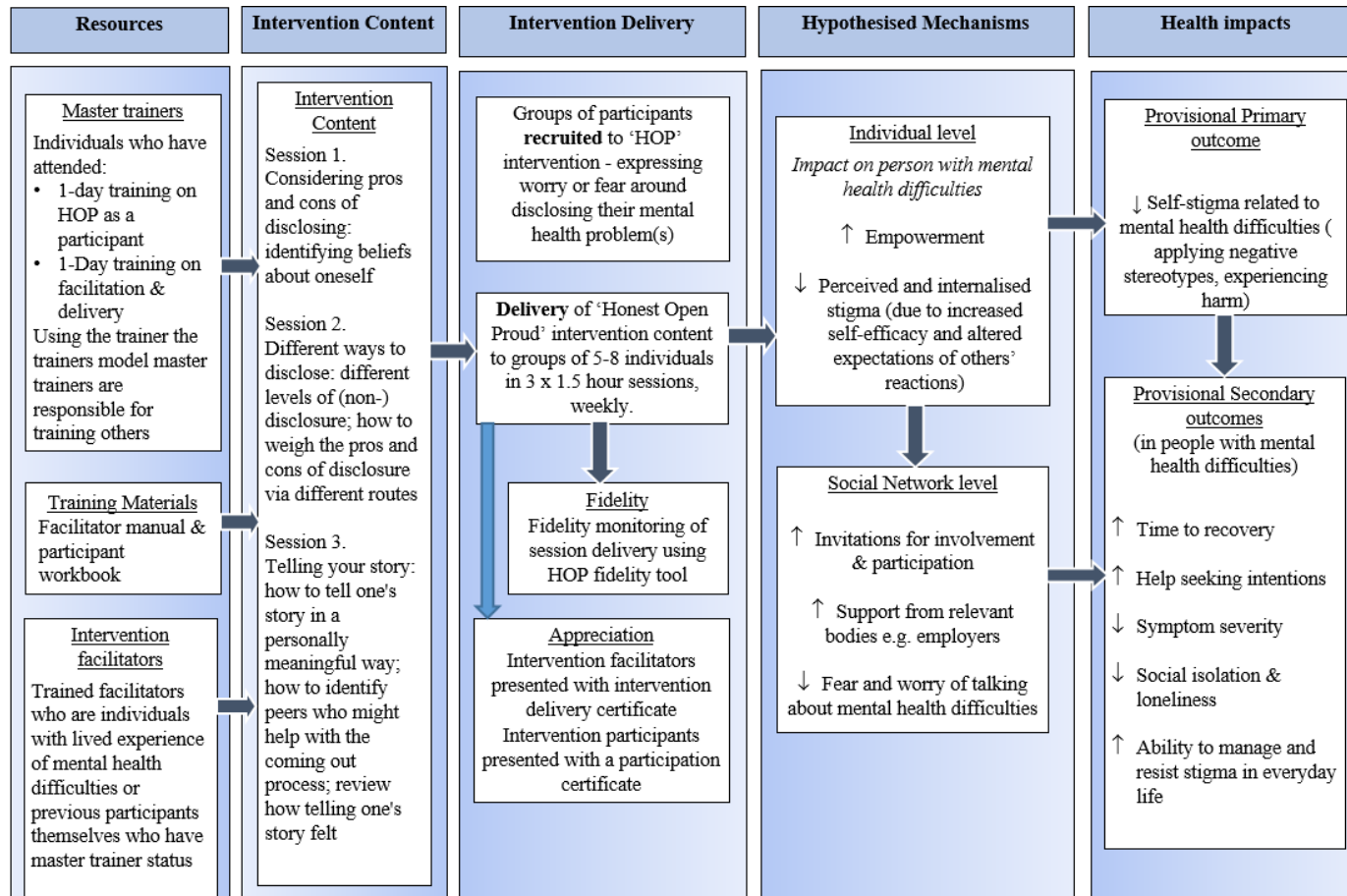
Table 6.1.

*Contents of the Honest Open Proud Programme*

Session	Title	Content
1	Considering the pros and cons of disclosing:	<ul style="list-style-type: none"> <li>• The stories we tell ourselves/ identify beliefs participants hold about themselves;</li> <li>• Hurtful and helpful attitudes about mental illness;</li> <li>• Challenge personally hurtful beliefs;</li> <li>• Weigh pros and cons of disclosure to facilitate a decision on whether to disclose.</li> </ul>
2	Different ways to disclose:	<ul style="list-style-type: none"> <li>• Different ways to disclose and weighing the pros and cons of each;</li> <li>• Selecting a person to whom one might disclose;</li> <li>• Consider how others might respond to a disclosure and how their response might affect one's self.</li> </ul>
3	Telling your story	<ul style="list-style-type: none"> <li>• How to tell one's story in a personally meaningful way;</li> <li>• Review how telling one's story went;</li> <li>• Peer support for disclosure;</li> <li>• Put together all that has been learnt in order to move forward.</li> </ul>

Figure 6.3.

HOP logic model (adapted from Scior et al., 2019)





### **6.2.2 *The Nature of Decision-Making in People Living with Dementia***

The systematic review into the nature of decision-making in dementia (presented fully in Chapter 3) provided vital points for consideration when adapting HOP for dementia. First, in order to create a meaningful decision-making environment for people living with dementia, the Freedom of Choice factors (being informed, being listened to, ability to express opinions, time for reflection, and reversibility of choice) must be upheld (Tyrrell et al., 2006). Secondly, the involvement of supporters (e.g. carers, spouses, family members) can be both facilitative and disruptive to the decision-making involvement of a person living with dementia therefore contextual factors (risk, relationships and resources) must be understood.

Accordingly, dyadic adaptation of HOP was felt to be appropriate given the well-documented advantages of a dyadic approach, including positive effects on quality of life and cognition for people living with dementia, reduced caregiver strain and psychological morbidity in caring spouses and improved relationship quality within the dyad (Braun et al., 2009; Menne, Judge, & Whitlatch, 2009; Moon & Adams, 2013). As the systematic review did not contain material on disclosure decision-making in dementia, a separate search was undertaken to identify disclosure decision models which is also presented in Chapter 3 of this thesis. Three models were found but none were specific to dementia (Chaudoir & Fisher, 2010; Greene, 2009; Omarzu, 2000). All three considered the psychological risks of disclosure, and ‘third party decision-making’ was mentioned in one model which has relevance for the decision-making process for people living with dementia (Omarzu, 2000). Two of the disclosure decision-making models emphasized the role stigma can play in disclosure decision-

making such that individuals with stigmatised labels (e.g. dementia) may choose secrecy as a way of avoiding public stigma (Chaudoir & Fisher, 2010; Greene, 2009). In order to better understand the views of people with dementia, family carers and the wider public on barriers to disclosure and intervention preferences, the learnings from the literature reviewed in Chapter 3 were carried forward to the online stakeholder consultation in the second phase of intervention development.

### **6.3 Modelling Process**

The modelling phase of intervention development included an online stakeholder consultation [UCL Data Protection Registration Number Z6364106/2017/10/118] followed by face to face consultations with HOP experts, the research team and experts by experience.

#### **6.3.1 Online Stakeholder Consultation**

HOP was originally designed for those with mental health diagnoses, therefore it was necessary to identify dementia-specific preferences in design, content and engagement. For the online survey of stakeholder opinions and preferences, no personally identifiable or sensitive information (e.g. demographics, health related information) was collected. Although the aim was to include as many people with direct experience of dementia as possible (having a diagnosis themselves or being a carer of someone who does) the views of all respondents were included, irrespective of degree of experience of dementia. The stakeholder consultation had three lines of enquiry. The first was to identify barriers to disclosing a diagnosis of dementia using multiple choice questions based on a psychosocial model of understanding the experience of receiving a diagnosis of dementia (Pratt & Wilkinson, 2003). Second, respondents were asked

about design preferences such as intervention and session length, delivery and format. The third was to identify barriers and facilitators to engagement when tailoring an intervention of this nature to people living with dementia and gather respondents' views on acceptability of the proposed intervention.

Questions for the stakeholder consultation were developed then reviewed by the Promoting Independence in Dementia (PRIDE) PPI group for acceptability, suitability and relevance for dementia. They suggested changing sentence structure to make questions less complex and adding further response options. The stakeholder consultation was conducted over a period of four months (November 2017 to February 2018) using the Qualtrics online platform. There were no selection or screening procedures. As there were no incentives for completion, it was assumed that those completing the survey (Appendix 10.4) were people with some knowledge or, of interest in, dementia. All respondents saw the same set of questions, with space for optional free text and there were no mandatory questions (i.e. respondents could move through the survey leaving items unanswered).

The survey was disseminated through social media outlets (Twitter, Facebook), the Contact Help Advice and Information Network (CHAIN) and websites (UCL Division of Psychiatry, Alzheimer's Society and UCL Unit for Stigma Research).

### **6.3.1.1 Respondents**

Over the 4 month period, there were 226 unique respondents including people living with dementia (n=18), carers of people living with dementia (n=85), health and social care workers (n=43), members of the general public (n=64),

researchers (n=13) and others (n=3). The survey results are presented in Table 6.2. The free text responses were used to contextualise the numerical findings and are presented below in italics within quotation marks.

### 6.3.1.2 Barriers to Disclosure

The survey provided evidence that all categories of respondent believed that there are barriers to people with dementia disclosing their diagnosis to others. There were similarities and differences between responders in different categories. All respondents rated ‘worry that others will view them differently (e.g. less able)’ as the top barrier to disclosing a diagnosis of dementia (See Table 6.2). People living with dementia also rated the following as dominant barriers to disclosure: scared of what might be ahead; worry that others may avoid or exclude them; not wanting to burden or upset others (*“feeling a failure to my family, that I had let them down”*); shame (*“people saying ‘don’t be silly there is nothing wrong with you’”*); unsure of what to say or what language to use and not knowing who to tell. The endorsement of the latter two barriers helped to build the rationale for a disclosure decision-making intervention as language and planning who to tell were existing tenets of HOP.

People living with dementia endorsed shame as a barrier to disclosure which speaks to the literature covered in Chapter 2 (people living with dementia experience self-stigma in the form of internalised shame) and 3 (self-stigma as a barrier to disclosure) but also further validates the findings of Chapter 4, where higher levels of internalised shame were related to higher levels of disclosure-related distress. Together, these findings suggest that self-stigma influences disclosure decisions for people living with dementia.



The loss of independence as a barrier to disclosure was noted in additional text comments by carers (*“losing independence”*), members of the public (*“fear of losing driving license”*) and researcher and academics (*“concern about any effect on their employment”*).

Carers and approximately half of respondents from all other categories, also rated the options of, ‘talking about it makes it more real’ and ‘not accepting or denying the diagnosis’, as barriers to disclosing a diagnosis, which were not as highly rated by people living with dementia. As previously noted, rather than people living with dementia not wanting to talk about the diagnosis or non-acceptance of the diagnosis, it is possible that not knowing whom to tell, what language to use and what to say may be stronger reasons for not disclosing dementia to others as these were endorsed by people living with dementia to a greater extent than non-acceptance. Therefore, it is plausible that what may appear as non-acceptance or denial may be a consequence of the lack of disclosure decision-making support for people living with dementia.

### **6.3.1.3 Preferences for Delivery**

Regarding method of delivery, face-to-face rather than self-guided was preferred across all respondent groups. Examples of ‘other’ responses included a mixture of face to face and self-guided delivery (*“perhaps a combination of the two, some face to face and some self-guided”*) suggested by all survey respondents. Of alternative face-to-face delivery approaches, respondents living with dementia preferred delivery in small groups (*“a group discussion would be good to have more thoughts towards the discussion”*) where all survey respondents mentioned in additional text comments that carers should also attend. Concerning session length, respondents unanimously preferred one session a

week for a three-week period with sessions lasting one to 1 ½ hours over other options (full day workshop, or two half days). All survey respondents acknowledged in the free text comments that “*flexibility is key*” and it depended on the person living with dementia preferences.

### **6.3.1.4 Barriers to Intervention Engagement**

People living with dementia identified the following barriers to engagement with the proposed intervention: embarrassment; wanting to ‘keep it in the family’; wanting to keep the diagnosis to themselves; not wanting to be in a group with other people who have dementia; and not knowing enough about dementia. In text comments people living with dementia noted the “*fear of doing something new*”, “*lack of insight into diagnosis*” and “*not believing the diagnosis*” were barriers to intervention engagement. The latter barrier may speak to the stigmatisation of dementia in society, where a person diagnosed with dementia may feel less able to believe the diagnosis due to the rife societal level narratives (public stigma) of what living with dementia looks like (e.g. vegetable and zombie metaphors reviewed in Chapter 1 and Chapter 2). Of course, it is also possible that people living with dementia do not believe the diagnosis for reasons other than stigma (e.g. have always considered themselves healthy, never had any previous health diagnoses with lasting ramifications, no dementia in the family etc...) which are not directly relevant to stigma but should be acknowledged. In additional comments, carers mentioned “*fear of failure and how others may view them*”, as a barrier to intervention engagement, which also speaks to the stigma surrounding dementia outlined in Chapter 2 and the findings of Chapter 4, where people living with dementia experience components of self-stigma (e.g. social rejection, internalised shame and social isolation) as a result of how others may

potential view them or how they have experienced being treated in the past.

Alongside Chapter 4 findings, the online stakeholder consultation results speak to self-stigma as a barrier to disclosure but also provide the foundation for why people living with dementia practice secrecy and concealment of symptoms.

In additional comments, health and social care workers wrote, “*not believing the diagnosis*”, “*seeing it as a part of normal ageing*”, “*family/friends not wanting to remind the person of the diagnosis*”, “*diagnosis made too late in the illness to benefit from the programme*” and “*not being aware they have dementia*” as barriers to intervention engagement. Interestingly, many of the comments from health and social carer workers are grounded in questioning the awareness of people living with dementia, as previously discussed in this thesis. Although people living with dementia at later stages are more likely to lack insight into their condition, many in early and mild stages do not, thus reinforcing the target population for the focus of this thesis and the current intervention. It is also possible that lack of awareness is attributed to people living with dementia by the mere presence of the diagnostic label, speaking to stereotyping and the stigma process outlined in Chapter 2.

### **6.3.1.5 Facilitators to Intervention Engagement**

People living with dementia endorsed the following facilitators to engagement: support from their family or friends; more information to decide if the program is for them; built-in involvement of primary carer; and groups to take place outside of clinical settings. One person living with dementia mentioned that it is “*difficult to encourage people with dementia to reach out. More options the better*” and one carer noted that facilitators may want to conduct a “*home visit... [for the person living with dementia] to have a familiar face for the first session*”.

Similar to the systematic review findings (Bhatt, Walton, Stoner, Scior, & Charlesworth, 2018), several respondents spoke to the importance of including carers ( “*shared experiences make it easier and stop the feelings of isolation. Carers should also attend*”). Accordingly, a dyadic adaptation of HOP was felt to be appropriate given the well-documented advantages of a dyadic approach (Braun et al., 2009; Menne et al., 2009; Moon & Adams, 2013). A group format for the intervention made up of dyads of people living with dementia and their carer and delivery outside of clinical settings was planned in line with the results of the stakeholder consultation. Finally, a large majority of respondents were of the view that people who are diagnosed with dementia would benefit from an intervention designed to support disclosure decisions (209/232).

Table 6.2.

*Summary of stakeholder consultation results*

Response Categories	PLWD (N = 18)	Family Carers (N = 85)	Health/Social Care Worker (N = 43)	Member of Public (N = 64)	Researcher/ Academic (N = 13)	Other (N = 3)
<b>Barriers to Disclosure N(%)</b>						
Worry that others will view them differently (example, less able)	11(61)	60(71)	35(81)	52(81)	12(92)	3(100)
Shame	7(38)	23(27)	22(51)	21(33)	8(62)	3(100)
Unsure of what to say or what language to use	7(38)	25(29)	21(49)	18(28)	4(31)	2(67)
Not wanting to use the word "dementia"	5(28)	39(46)	29(67)	17(27)	7(54)	2(67)
Not knowing who to tell	7(39)	11(13)	14(33)	14(22)	7(54)	1(33)
Scared of what might be ahead	9(50)	54(64)	27(63)	38(59)	10(77)	3(100)
Talking about it makes it more real	6(33)	44(52)	25(58)	35(55)	6(46)	2(67)
Not accepting/denying the diagnosis	3(17)	40(47)	30(70)	29(45)	10(77)	3(100)

Response Categories	PLWD (N = 18)	Family Carers (N = 85)	Health/Social Care Worker (N = 43)	Member of Public (N = 64)	Researcher/ Academic (N = 13)	Other (N = 3)
Worry about losing relationships	5(28)	15(18)	24(56)	16(25)	8(62)	1(33)
Worry that others may avoid or exclude them	9(50)	36(42)	27(63)	28(44)	11(85)	1(33)
Not wanting to burden or upset others	8(44)	50(59)	28(65)	48(75)	8(62)	3(100)
Carer or family not wanting them to tell others	4(22)	13(15)	20(47)	13(20)	8(62)	1(33)
Other	2(11)	7(8)	3(7)	2(3)	1(8)	1(33)
<b>Preferred Delivery Method N(%)</b>						
Face to Face	13(72)	74(87)	30(70)	53(83)	10(77)	2(67)
Self-Guided	8(44)	21(25)	12(28)	13(20)	6(46)	1(33)
Other	4(22)	15(18)	11(26)	8(13)	5(38)	1(33)
<b>Barriers to Engagement N(%)</b>						
Not knowing enough about dementia	9(50)	18(21)	14(33)	23(36)	4(31)	1(33)
Embarrassment	14(78)	55(65)	31(72)	42(66)	7(55)	3(100)

Response Categories	PLWD (N = 18)	Family Carers (N = 85)	Health/Social Care Worker (N = 43)	Member of Public (N = 64)	Researcher/ Academic (N = 13)	Other (N = 3)
Wanting to "keep it in the family"	10(56)	55(65)	32(74)	28(44)	8(62)	2(67)
Not wanting "outside help"	7(39)	62(73)	31(72)	38(59)	10(77)	2(67)
Fear of diagnosis	7(39)	47(55)	37(86)	35(55)	6(46)	3(100)
Wanting to keep the diagnosis to themselves	10(56)	42(49)	31(72)	28(44)	10(77)	2(67)
May have other ways of deciding who to tell, how and when	6(33)	15(18)	15(35)	7(11)	8(62)	1(33)
Not knowing the programme exists	10(56)	65(76)	37(86)	53(83)	10(77)	2(67)
Worrying about travelling (if it is a group programme)	6(33)	34(40)	28(65)	22(34)	9(69)	1(33)
Not wanting to be in a group with other people who have dementia	10(56)	56(66)	29(67)	27(42)	11(85)	2(67)
Other	0(0)	3(4)	6(14)	3(5)	3(23)	1(33)
<b>Facilitators to Engagement N(%)</b>						
Previous knowledge about dementia	8(44)	24(28)	10(23)	20(31)	4(31)	0(0)
Support from their family or friends	15(83)	79(93)	39(91)	49(77)	12(92)	3(100)

Response Categories	PLWD (N = 18)	Family Carers (N = 85)	Health/Social Care Worker (N = 43)	Member of Public (N = 64)	Researcher/ Academic (N = 13)	Other (N = 3)
Trained facilitator with personal experience of dementia	16(89)	59(69)	35(81)	48(75)	8(62)	2(67)
More information to help them decide if it is for them	10(56)	44(52)	28(65)	33(52)	10(77)	1(33)
Group delivery to take place outside clinical settings (e.g. community centre)	8(44)	35(41)	30(70)	25(39)	9(69)	0(0)
Built-in involvement of primary supporter	8(44)	42(49)	18(42)	25(39)	9(69)	1(33)
Other	3(17)	3(4)	5(12)	2(3)	2(15)	0(0)



### **6.3.2 *Researchers and Experts by Experience Consultations***

In the first instance, consultation within the research team on the HOP adaptation took place focussed on cultural adaptation, dementia-specific adaptation and readability. HOP was originally designed for a North American population with mental health diagnoses and therefore needed to be appropriate and relevant for a UK population of people affected by dementia, and for delivery to both people living with dementia and their chosen supporter. Changes to HOP were also discussed through the lens of readability (the ease through which one can understand and decipher written text). For example, sentences longer than 20 words require greater reliance on memory and often have a complex syntax adding a further layer of difficulty (Weih et al., 2008). Readability was formally assessed using the readability statistics function in Microsoft Word 2016 such as the Flesch-Kincaid reading (Flesch, 1952; Stockmeyer, 2009). Amendments or additions were made where necessary for example, the HOP manual was reduced in length and sentences shortened to increase readability and the vocabulary was amended from American to UK English to create “Who to tell, how and when?” workbook version one (V1.0).

Following consultations within the research team, with input from four carers of people living with dementia (hereafter referred to as ‘experts by experience’ (EbEs)), version two (V2.0) of the workbook was created for preliminary feasibility testing. EbEs were members of an existing Public and Patient Involvement (PPI) group at University College London and one Research Network Member from the Alzheimer’s Society. A meeting informed by coproduction principles was held with EbEs, the author and one other member of the research team (GC) over half a day. The structure of the meeting followed the

chronological order of the workbook. The following questions were put to EbEs for each intervention section: (1) is this acceptable and suitable for people living with dementia; (2) what parts are good and from these which should be kept; (3) what should be changed, improved or removed from the manual. Based on the discussions with the EbEs, the author and another member of the research team (TR) made changes to the participant workbook and a facilitator's guide was created.

### **6.3.2.1 HOP Adaptation within the Research Team (V1.0)**

***Cultural Adaptation.*** To avoid potential negative interpretations of the terms “Honest”, “Open” and “Proud” (e.g. suggestions that someone is dishonest or not proud if they do not disclose), the title was changed to “who to tell, how and when?”. References in HOP to ‘coming out’ were replaced with ‘telling’ as, at least in the UK, the term ‘coming out’ is still heavily associated with sexuality disclosure. Furthermore, the purpose of the intervention was not to promote ‘coming out’ but rather to empower participants to reach decisions about disclosure themselves.

***Dementia Specific Adaptation.*** Throughout the HOP workbook, “mental illness” was replaced with “dementia”. To ensure examples were grounded in real life experiences of people living with dementia, qualitative data from the PRomoting Independence in DEmentia (PRIDE) intervention manual was used to develop suitable examples (Yates et al., 2019). Examples in the original HOP workbook (e.g. advantages and disadvantages of disclosing a diagnosis of schizophrenia) were changed to be dementia specific. For example, short quotes were used in the workbook to communicate possible advantages (e.g. “When I get muddled with change at my local shop, the shop keeper reaches over to help me... It relaxes me

that he knows”; workbook p10; Appendix 10.5.1) and disadvantages (e.g. “After telling my family, I have been feeling that people have put me down. They don't listen to my opinion”; workbook p11) of sharing a dementia diagnosis.

*Dyadic adaptation:* Care was taken so that wording could relate to both a person living with dementia and their chosen supporter. Hence, personal pronouns that spoke directly to a person with the diagnosis were removed. The workbook examples aimed to speak to the dyad’s respective dementia disclosure experiences alongside discursive exercises designed to facilitate communication between the dyad and within the group around the issue of dementia disclosure.

**Readability.** Changes to HOP were discussed through the lens of readability (the ease through which one can understand and decipher written text). For example, sentences longer than 20 words require greater reliance on memory and often have a complex syntax adding a further layer of difficulty (Weih et al., 2008). Complex sentences such as these were removed to improve readability along with increasing the font size and using sans serif font.

Next, the content of the original HOP workbook was condensed to reduce the content presented on each page. For this reason it was decided that content removed from the workbook would appear in a ‘facilitator’s guide’ instead. Therefore, facilitators could cover this information verbally, so that the workbook did not require large amounts of cognitive capacity for people living with dementia to engage, essentially improving its readability. All essential information was kept such as session objectives, sub-section introductions, and task objectives and embedded worksheets. Although the aim here was to condense the contents to improve readability, it was necessary for the workbook

to flow as a standalone document if attendees were to read it outside of group sessions. Therefore a special effort was made to have the objectives and outcomes of each session clearly stated. Readability of HOP and the “who to tell, how and when?” workbook was formally assessed using the readability statistics function in Microsoft Word 2016 such as the Flesch-Kincaid reading (Flesch, 1952; Stockmeyer, 2009). Readability across all statistics improved in the “who to tell, how and when?” workbook (Table 6.3).

*Table 6.3.*

*Summary of readability statistics for the Honest, Open, Proud Program and the “Who to tell, how and when?” dementia adaptation*

<b>Readability domains</b>	<b>Honest, Open, Proud, Program (N/%)</b>	<b>The “who to tell, how and when?” intervention (N/%)</b>
Words	25126	2542
Characters	124461	14034
Paragraphs	1130	217
Sentences	1576	135
Sentences per paragraph	2.7	1.9
Words per sentence	14.3	12.4
Characters per word	4.7	4.4
Passive sentences	8%	3%
Flesch reading ease	60.6	71.3
Flesch-Kincaid grade level	8.2	6.4

### **6.3.2.2 Development with Experts by Experience (Creating V2.0)**

***Participant Workbook.*** Language changes were recommended by EbEs such as using the terms “advantages and disadvantages” rather than the HOP wording of “costs and benefits” when weighing up whether or not to disclose a diagnosis. Further, in the first session, when language and its potential impact on a person’s identity is discussed, EbEs felt that “identity” was very abstract and that the term “outlook” was preferable as it encompassed behavioural effects as well as emotional and psychological consequences of the diagnosis. In the original HOP manual, tables were used for exercises, for example a table where participants can list the ‘costs and benefits’ of telling others about a diagnosis. EbEs were of the opinion that these should be replaced by notes sections as tables can be difficult to navigate and force contributions more so than a blank notes section alongside a meaningful conversation. EbEs generally liked the examples in the booklet; however, they recommended that when more than one person was included in an example that they were of different genders with names that sounded different so as not to confuse participants when the example was discussed.

***Facilitators’ Guide.*** EbEs endorsed the idea of a facilitator booklet to go alongside the participant version. They felt sensitivity to the potential harm language can do was of prime importance. For this reason, the facilitator booklet avoided any negative language around dementia such as “sufferer” or “patient”. The term “caregiver” was contested during our discussions and therefore the term “carer” was used. Although EbEs were content with the session summaries, they requested the facilitators ask whether participants wanted to cover specific topics in the next session. This is was key to making the intervention as person-centred and individualistic as possible. EbEs emphasized that the role of the facilitator

should not just be to deliver the intervention but also to perform a “signposting” role supplemented by the ‘sources for support’ page at the end of the booklet.

In summary, unlike HOP, which is peer-led, the dementia-adapted intervention was designed to be delivered by facilitators skilled in working with people affected by dementia, such as, Admiral nurses (paid professionals who support people living with dementia in the community), Age UK employees and trained Alzheimer’s Society volunteers. Another fundamental difference in format between HOP and “who to tell, how and when?” is the inclusion of a carer during the intervention sessions. As a carer is seen in their own right as a participant and often shares the effects of a diagnosis dementia, changes in the language of the intervention materials were made and novel topics introduced, such as “whose diagnosis is it” to reflect this. Many features of HOP were still implemented in the “who to tell, how and when?” intervention, such as weekly sessions over a three week period and the notion of a manualised approach for participants to follow. For a comparison of content between HOP and “Who to tell, how and when?” (see Table 6.4).

Table 6.4.

Comparison between original HOP and “Who to tell, how and when?” adaptation for people living with dementia

Honest Open Proud		“Who to tell, how and when?”	
Session Title	Contents	Session Title	Contents
<b>Considering the pros and cons of disclosing:</b>	<ul style="list-style-type: none"> <li>○ The stories we tell ourselves/ identify beliefs participants hold about themselves;</li> <li>○ Hurtful and helpful attitudes about mental illness;</li> <li>○ Challenge personally hurtful beliefs;</li> <li>○ Weigh pros and cons of disclosure to facilitate a decision on whether to disclose.</li> </ul>	<b>Session 1</b>	<b>Talking about dementia</b> <ul style="list-style-type: none"> <li>○ Talking about dementia – what’s in a name?</li> <li>○ What might a diagnosis mean for a person’s sense of “who they are” and their outlook on life?</li> <li>○ What are the advantages and disadvantages of telling or not telling others</li> </ul>
<b>Different ways to disclose:</b>	<ul style="list-style-type: none"> <li>○ Different ways to disclose and weighing the pros and cons of each;</li> <li>○ Selecting a person to whom one might disclose;</li> <li>○ Consider how others might respond to a disclosure and how their response might affect one’s self.</li> </ul>	<b>Session 2</b>	<b>Who to tell, how and when?</b> <ul style="list-style-type: none"> <li>○ Different ways to tell others</li> <li>○ Who already knows and who in your life do you want or may want to tell. Who are you unsure about and must not be told</li> <li>○ How and when to tell others?</li> <li>○ What may the reactions of others be?</li> </ul>
<b>Telling your story</b>	<ul style="list-style-type: none"> <li>○ How to tell one's story in a personally meaningful way;</li> <li>○ Review how telling one's story went;</li> <li>○ Peer support for disclosure;</li> <li>○ Put together all that’s been learnt in order to move forward.</li> </ul>	<b>Session 3</b>	<b>Support for me, for you, for us</b> <ul style="list-style-type: none"> <li>○ Sharing experiences of telling others</li> <li>○ Planning to tell someone (who, how and when?)</li> <li>○ Whose diagnosis is it?*</li> <li>○ When other people do the telling*</li> <li>○ Where may you find sources of support*</li> </ul>
*elements unique to “Who to tell, how and when?”			

## **6.4 Preliminary Feasibility Testing**

The “who to tell, how and when?” intervention (workbook V2.0 and facilitators guide V1.0, Appendix 10.5.1 and 10.5.2) developed from phase 1 and 2 was piloted in third (voluntary) sector settings and in the National Health Service (NHS). Quantitative data on recruitment and attendance was supplemented by a qualitative process evaluation in which data was collected from participants, facilitators and a non-participating observer of the groups (TR).

### **6.4.1 Methods**

#### **6.4.1.1 Recruitment and Eligibility**

The main recruitment strategy for community groups was use of Join Dementia Research (JDR, <https://www.joindementiaresearch.nihr.ac.uk/>), an online register of volunteers who are interested in taking part in dementia research. In the NHS, Clinical Studies Officers undertook recruitment activities through included attendance at memory clinics and contact with clinicians in an outer London borough. There was no direct communication between potential NHS participants and the author. Participant parameters were: adults over the age of 18; with a formal diagnosis of a primary progressive dementia or a family carer or chosen carer of someone with such a diagnosis; ability to understand, communicate, read and write in the English language; willingness to participate in the intervention and a follow-up interview. Participants were excluded if they did not have the capacity to give informed consent, if they were in the latter stages of a chronic terminal medical condition or, had a sensory impairment of such a severity that they would not be able to engage, or if they were expressing suicidal ideation or intent.

#### **6.4.1.2 Ethics**



The author's institutional ethics committee [UCL REC:14001/001; Appendix 10.1.2] and the NHS Surrey Borders Research Ethics Committee [19/LO/1163, IRAS: 254026, NIHR portfolio number: 42201; Appendix 10.1.3] and the Health Research Authority [protocol number: 122232; Appendix 10.1.4] granted ethical approval for this research.

### **6.4.1.3 Intervention Delivery**

A consultant clinical psychologist and a trainee clinical psychologist co-facilitated group 1. The author and a Dementia Wellbeing Lead based at Age UK facilitated group 2. All facilitators had experience of working with people affected by dementia. Each group underwent one intervention session a week (90 minutes) for a three-week period, delivered alongside the participant workbook (V2; Appendix 10.5.1).

### **6.4.1.4 Measures**

A set of measures intended for use as pre-post testing measures for the NHS recruitment stream included the Stigma Stress Scale, Secrecy Scale and Disclosure Related Distress Scale for people living with dementia, as described in Chapter 4, and the Family Stigma Instrument found in Chapter 5. In addition the following were also included for pre and post testing:

***Decisional Conflict Scale (O'Connor, 1995).*** This scale measured personal perceptions of (a) uncertainty in choosing options; (b) modifiable factors contributing to uncertainty such as feeling uninformed, unclear or unsupported; and (c) effective decision-making such as feeling satisfied with the choice. Decisional conflict can be lowered with decision supporting interventions (O'Connor, 2005) as reported in a trial of the DECIDE intervention for carers of people living with dementia (Lord, Livingston, & Cooper, 2017) and CORAL a

disclosure decision-making aid to help those with a mental health diagnosis disclose to their employers (Lassman et al., 2015). Five subscales are measured on a 5 point Likert scale (0 – strongly agree to 4 – strongly disagree): uncertainty (3 items), effective decision-making (4 items), informed (3 items), values (3 items) and support (3 items). Internal consistency of the measure was high in subscales (Cronbach's alpha 0.78-0.92) and total scoring (Cronbach's alpha 0.58-0.92) of the DCS (O'Connor, 1995).

***Stage of Decision Making Scale (O'Connor, 2003).*** This Scale was used to quantify readiness to engage in decision-making, progress in making a choice, and receptivity to considering or re-considering options. The scale has one item: "How far along are you with deciding who to tell, how and when, about your diagnosis of dementia?" with the following response categories: I have not yet thought about the options (1), I am considering the options (2), I am close to choosing one option (3) and I have already made a choice (4).

***Quality of the carer-patient relationship (Spruytte, Van Audenhove, Lammertyn, & Storms, 2002).*** This measure was to be completed by both the carer and the person living with dementia and quantifies relationship quality, comprising 14 items designed to assess warmth, levels of conflict and criticism in the caregiving relationship. The response categories range from totally disagree (0) to totally agree (4). The scale has previously shown good internal consistency (Cronbach's alpha 0.82; Spruytte et al., 2002) and has since been used in the evaluation of Individual Cognitive Stimulation Therapy (Orrell et al., 2012, 2017).

#### **6.4.1.5 Qualitative Observations and Facilitator Reflections**

Qualitative observations of the intervention sessions were made by a clinical psychology doctoral trainee (TR), covering timing, structure, delivery, content and practicalities in line with guidelines (Kawulich, 2012). Observations aimed to capture anything that could inform further intervention development such as ways to improve intervention delivery. Detailed methods and findings from qualitative follow-up interviews are presented in Chapter 7 of this thesis.

## **6.4.2 Results**

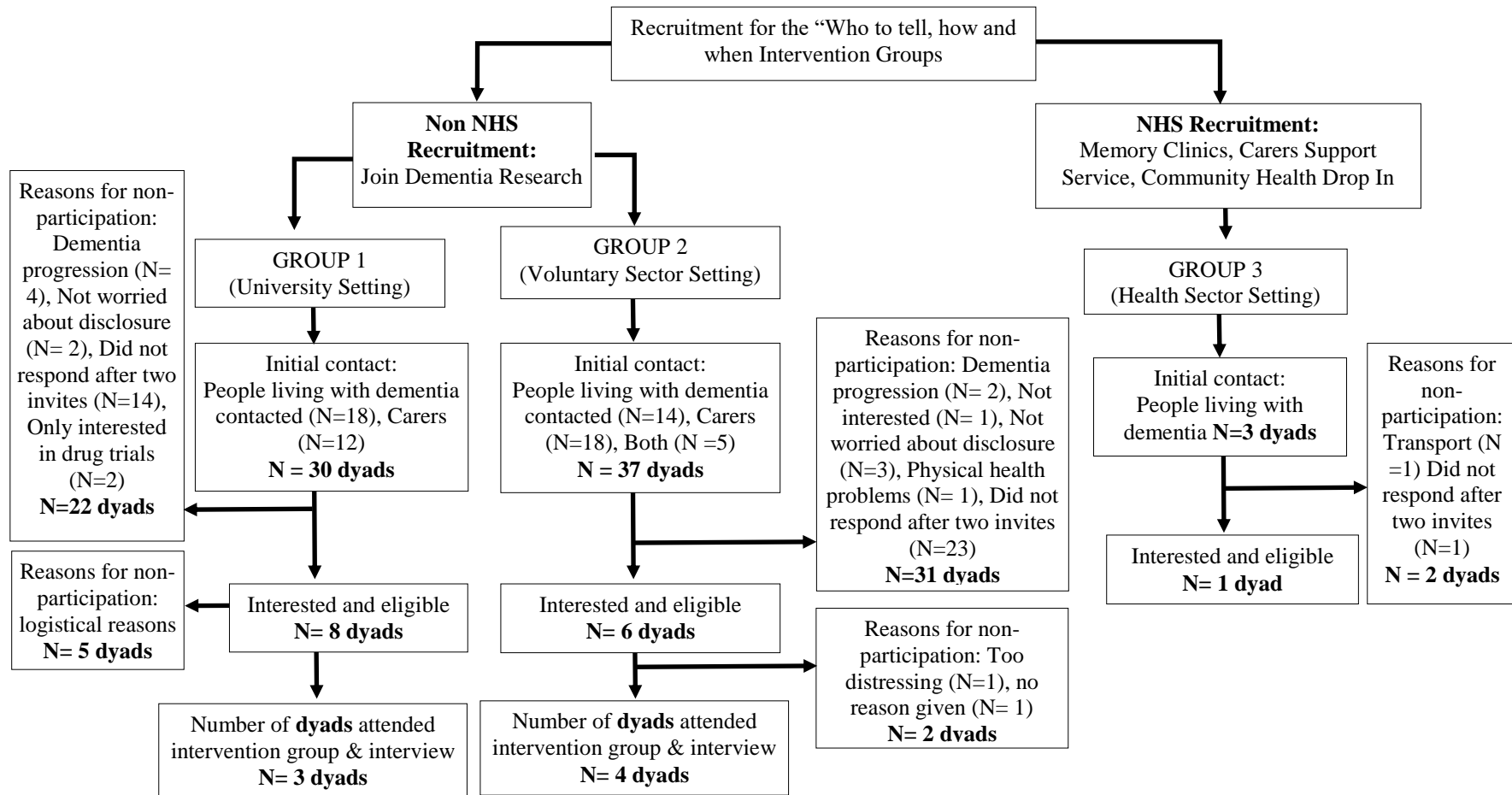
### **6.4.2.1 Feasibility of Recruitment and Attendance**

**Community Recruitment.** Sixty-seven dyads in total were identified of whom 14 were eligible, interested and responded to study invitations. Eight of the 14 participants agreed to take part with their chosen support, but one person living with dementia did not attend the intervention (reasons for non-attendance see Figure 6.4). Seven dyads took part in two smaller groups (group 1: 3 dyads; group 2: 4 dyads). Both intervention groups had over 70% attendance (group 1: 72.2%, group 2: 87.5%), suggesting that, once recruited, retention of participants was good (see Table 6.5).

**NHS Recruitment.** The NHS group did not take place as there were too few participants for a group to run. Reasons for not taking part included not responding to the invitation for the study, logistical reasons such as travel expenses. Clinicians who gave their feedback suggested that elderly patients with multi-morbidities either have no awareness of their cognitive difficulties or are more concerned with other health issues. Participants who are fearful or worried about talking about their diagnosis may see the group format as a barrier to participation.

Figure 6.4 .

Recruitment and attrition of participants attending the "Who to tell, how and when?" intervention



Study recruiters noted that: many potential participants were not English speaking; carers expressed and wanted to attend without the person living with dementia, and; the majority of patients approached did “not have insight”. This feedback will be further discussed in the next section.

*Table 6.5.*

Participant characteristics for “who to tell, how and when?” intervention groups

Sociodemographic Characteristics	Group 1		Group 2	
	PLWD	Carers	PLWD	Carers
Age, years Mean (SD)	77.22 (11.55)	71.33 (8.37)	72.52 (5.94)	72.31 (2.47)
Gender (M/F)	1/2	1/2	2/2	2/2
Months since diagnosis	16.66	-	25.75	-
Type of dementia				
Alzheimer’s Disease	2	-	4	-
Vascular Dementia	1	-	0	-
Relationship between PLWD and carer				
Spousal	2		4	
Other	1		0	
Ethnicity				
White	2	3	4	3
Other Ethnic Group	1	0	0	1
Participant Session Attendance				
All Sessions	2	1	3	3
Two Sessions	1	0	0	1
One Session	0	2	1	0

PLWD = People living with dementia

#### **6.4.2.2 Pilot Group 1: Qualitative Observations and Facilitator Reflections**

*Timing and Structure of the Sessions.* During the first group, all three intervention sessions began 10 to 20 minutes later than scheduled; reasons for this were outside the control of facilitators and included late or staggered arrival of participants and needing to cover material to summarise a previous session that some attendees had missed. In all three sessions, participants declined refreshment breaks offered in the middle of the sessions and instead wished to continue with the session without interruption.

*Delivering the Content.* All intervention content was delivered during each session despite the late starts, although this was made harder when participants had not attended a previous session as each session builds upon the knowledge obtained from the last. Facilitators had to repeat material to accommodate non-attendance at the beginning of the second session for 10 minutes. The repetition of materials at the beginning and tangential discussions in other parts of the session led away from session content and a lack of clarity around the goals for each session. Some participants appeared to “switch off” for the rest of the session and workbook exercises were not completed as a result. The liveliest discussion was the result of the network circles exercises (Appendix 10.5.1) and the observer noted that allowing participants to work independently and in pairs was beneficial to the overall discussion. The observer noted that the participant workbook lacked carer specific quotes. The network circles exercise (Appendix 10.5.1), did not include the opportunity for participants to think about who must be told about the diagnosis, as a result discussions occurred around this but the network circles needed to also encompass this.

***Facilitator Reflections.*** The room booked for the intervention sessions was accessible but due to its awkward lay out and lack of space, facilitators felt they had to be imaginative when setting up the room for each intervention session. Participants in this group were very diverse; some were highly capable academically whilst others had vocational and practical strengths; in addition, participants had different perspectives about their diagnosis. For example, one facilitator said “there was one person with dementia who, by their own admission, was majoring on avoidance, and another who continued to struggle with the aftermath of being told their diagnosis in an insensitive fashion”. As a consequence of participants arriving late to the second session, facilitators felt they did not quite get to give the final section full justice. Facilitators noted that some sections were more emotionally charged and engaged participants in lively discussions, one example being the network circles exercise.

### ***Recommendations from Group 1.***

1. Future groups should be organised to allow for a 30-minute window before session start such that participants can arrive in plenty of time with a chance to have refreshments and socialise with each other before the formal session starts.
2. Discussions were sometimes of a tangential and unfocussed nature; to curb this in the future facilitators could encourage the focus of the group clearly stating the session aims and exercise aims so that discussions remain focussed.
3. Workbook exercises should be presented with visual cues and the discussion format varied (pairs, small groups, whole group) to avoid participants disengaging.

4. Intervention sessions should take place in a room with a typical square layout where all walls can be seen and therefore used to display memory prompts or reality orientation materials.
5. To allow carers to engage more with the workbook, carer specific examples/vignettes should be added.
6. The network circles diagram (Appendix 10.5.1) should be amended to include those who participants feel 'must be told' about the diagnosis.

#### **6.4.2.3 Pilot Group 2: Qualitative Observations and Facilitator Reflections**

Recommendations 1- 4 listed above were implemented for the second pilot group whilst the workbook remained unchanged.

*Practicalities.* During the second group, two sessions began on time and one started 20 minutes later than scheduled whilst facilitators waited for one dyad to join. In all three sessions, participants again declined refreshment breaks.

*Delivering the Content.* All intervention content was delivered for each session despite one session starting late. One particular discussion in session 3 veered away from the session focus when participants began talking about the way in which their diagnosis or label of *carer* had been communicated to them. For this reason introducing an earlier discussion about delivery of diagnosis may be beneficial. Strategies to deal with the negative reactions of others were briefly touched upon but reference to written support strategies was missing. The observer noted that the contents of session three caused emotionally charged discussions where the facilitator had to be equipped in dealing with dominant dyads, conflict within dyads and high levels of emotional expression. The



facilitator had the responsibility of managing conflict within a dyad without prior knowledge of their history.

***Facilitator Reflections.*** Facilitators noted that it was hard to encourage quieter participants to speak more in the presence of more dominant dyads, highlighting the benefit of switching between small group or paired work and the full-group discussions. Further, participants appreciated changing the exercises to allow dyads to work in pairs or carers to speak to one another. Facilitators felt that time allocated for arrival and refreshments prior to starting each session helped delivery flow and allowed participants to build a rapport with social exchanges happening before the session started. There were times when participants appeared distressed or upset and disagreed either within dyads (network circle exercises) or with each other (how a diagnosis affects the wider system). Facilitators felt that they were in a position of needing to manage the dyadic relationship as well as the overall group dynamic.

***Recommendations for Future Groups.***

1. If participants are running late, a ten-minute wait at the start is reasonable otherwise there is not enough time to cover intervention content at the right pace.
2. Carer specific quotes should be included in the workbook.
3. Space to discuss the experience of receiving a diagnosis should be provided.
4. Resources should be included regarding strategies to deal with the negative reactions of others.

5. The facilitator manual and associated training should include strategies for managing emotionally charged situations and disagreements within the group in a manner that is constructive and adds to the flow of discussion.

## 6.5 Discussion

In this Chapter, I described the development and preliminary feasibility evaluation, of an intervention to support people living with dementia and their carers to make decisions around disclosing a diagnosis. The “Who to tell, how and when?” intervention was field tested in the community as a dyadic, group based, manualised intervention led by a trained facilitator, following a three stage development and testing process where the views of those affected by dementia informed design and delivery features. Data gathered from recruitment and attendance across community and NHS settings speaks to the way in which context influences intervention engagement (Moore et al., 2015).

Qualitative observations and facilitator reflections were recorded and used as per the MRC process evaluation guidance to understand how the intervention was implemented (Moore et al., 2015). One of the key aims of process evaluations is to optimise the delivery of content through using qualitative data to understand what would be more acceptable (Moore et al., 2015). Changing the format of activities was a powerful tool to involve all participants. For example, when discussing examples of disclosure, facilitators cut out paper extracts from the workbook to be discussed and ordered within smaller groups, followed by participants sharing their thoughts. Including activities other than whole group discussions was a gateway for participants to contribute to discussions, especially those who felt less confident in a whole group scenario however, this would need to be explored through qualitative interviews rather than based on observations of groups.

As the “Who to tell, how and when?” intervention was delivered to dyads, a greater responsibility is put upon the facilitator to deal with the added complexity of dyadic relationships. This responsibility includes dealing with conflict within and between dyads that can come to the fore within the context of the intervention. Dealing with conflict within a dyad was especially challenging for facilitators, as they did not have an existing relationship with participants and were not aware of the experiences that led them to the group. Having participants who were often from long-standing relationships (e.g. marriages) put the facilitator in a place similar to a family therapist - it is important to remember the remit of the intervention and not go beyond the scope of content. At the same time, facilitator reflections from group 1 and 2 have implications for the way in which facilitator training is delivered in the future, for example, it will be necessary to cover group conflict resolution and how to maintain focus in the presence of conflict within a group.

### ***6.5.1 In the Context of Current Post-Diagnostic Support Services***

Although variation exists globally on attitudes to dementia and the services available to those affected, it can be agreed that, in order for post-diagnostic support services to be accessed, people living with dementia are often required to (still) be able to talk about their diagnosis (Alzheimer’s Disease International, 2019; Alzheimer Europe, 2017). Therefore, in the face of a life changing, stigmatized diagnosis, people living with dementia and carers are often left to negotiate decision-making around telling others in their social networks about the diagnosis, with no post-diagnostic support in place (O’Connor et al., 2018).

The expectation of people diagnosed with dementia is that they are able to identify with their new diagnostic label, resist the stigma related to it by being able to tell others about their diagnosis in order to maintain a supportive social network. The post diagnostic support outlined in the National Institute of Health and Care Excellence guidelines for dementia does not encompass specific support around telling others about a diagnosis (National Institute for Health and Care Excellence, 2018), but should do in light of the negative connotations of dementia that repeatedly fill societal discourses.

The recent emphasis on promoting the social health of people affected by dementia calls for timely interventions to promote empowerment through decision-making to maintain social networks (Vernooij-dassen et al., 2019). Improvement in psychological well-being for both partners in the dyad, improved quality of life, and increased knowledge of one another's coping skills, have been found by previous dyadic interventional studies, thus providing an evidence base for a dyadic psychosocial approach over more individualized interventions (Moon & Adams, 2013). Together, the literature suggests an important gap in the diagnostic pathway that can be filled with an empowerment based approach-supporting dyads affected by dementia. The "Who to tell, how and when?" intervention may be framed as an empowerment intervention to support disclosure decision-making in people affected by dementia, and was endorsed by the majority of respondents in the online stakeholder consultation.

### ***6.5.2 Methodological Considerations and Limitations***

The benefit of a rigorous development and feasibility procedure, as outlined by the MRC framework, is that intervention materials can be developed

and tested to maximize any worthwhile effect and foresee implementation issues before potential examination in a full-scale trial. This is recommended by the MRC to minimize the later problems of acceptability, intervention delivery, recruitment and attendance. Speaking to the importance of rigorous development, the involvement of people affected by dementia (the online stakeholder consultation, intervention production), increases intervention validity, such that materials are more likely to be grounded in the values of the target population. The results of the online stakeholder consultation highlighted the importance of having the choice of people living with dementia rather than assuming that carers are an adequate proxy. However, it is important to acknowledge that EbEs who co-produced intervention materials were all carers rather than people living with dementia and therefore future iterations may benefit from the inclusion of people living with dementia in intervention development.

Organisational factors of NHS memory services may have contributed to the lack of recruitment within the NHS for several reasons. For example with a recent push for diagnoses, many memory services work on an ‘assess, diagnose, discharge’ model. Firstly, this means researchers typically meet potential participants immediately following diagnosis, which does not leave enough time for someone to have develop worry or fear about telling others about dementia; secondly, clinicians are often not able to get to know their patients enough to discuss the benefit of taking part in the “who to tell, how and when?” intervention. Clinicians who gave feedback about the intervention said that the intervention would be a valuable asset to post-diagnostic support, particularly as some clinicians also acknowledged that they had not had conversations with patients around whether they were worried about telling others.

Individual factors that may have contributed to the lack of recruitment in NHS settings range from the nature of the target population, transportation and multi-morbidities. One inclusion criterion for attending the “who to tell, how and when?” intervention group was that a person living with dementia should be fearful or worried about telling others their diagnosis. If potential participants are indeed fearful or worried about telling others, they may not be inclined to accept an invitation to a group-based intervention that explores fears and worries around telling others. For this reason, the target group for the “Who to tell, how and when?” intervention may be harder to reach in comparison to other dementia-related psychosocial interventions. Evidence for this was found in the online stakeholder consultation previously presented that highlighted several barriers to disclosure and also barriers to intervention engagement, these collectively may have led to low levels of recruitment in the NHS pathway in comparison to JDR recruitment. For example, if potential participants were indeed fearful or worried about telling others, as suggested by the stakeholder consultation results, they might be reluctant to attend a group-based intervention that explores fears and worries around telling others and therefore another form of intervention delivery may be more suitable for these individuals. Although when developing the intervention efforts were made to reduce barriers and promote factors of engagement, there is clear need to revisit this in the future working alongside people affected by dementia to improve recruitment.

In terms of transportation, one dyad was unable to commit financially to taxi transportation to and from the intervention venue and the study could not cover such finances. Lastly, many people attending memory services for a diagnosis of dementia may have other health conditions that require more

attention or have a greater impact on daily life including psychological well-being, hence, a diagnosis of dementia may not be the most concerning diagnosis for some.

Whilst recruiting for the “Who to tell, how and when?” intervention in NHS settings, some instances occurred where carers were interested in attending but the person living with dementia was not. Although, the group was still offered to carers who wanted to attend, carers were not able to find care and provision for the person they supported in order to attend the group once a week for a three week period.

Concerning the geographical comparison between recruitment strategies, the community intervention groups were located in central London with good transport links. In contrast, the NHS site used to recruit for this study was located in the outer London area with reduced transport links. Importantly, the NHS site was located in an area with a large population of ethnic minority communities particularly of South Asian origin whom may have more specific or differing barriers to disclosure and engagement. Whilst several stages informed the “who to tell, how and when?” intervention, this process does not guarantee recruitment feasibility across settings and different participant characteristics (e.g. ethnic minority groups, types of dementia), particularly, given the nuanced target population we sought to recruit. The majority of participants recruited for both intervention groups identified as white, therefore questions still remain around whether the “who to tell, how and when?” intervention would benefit members of other ethnic groups.



The “Who to tell, how and when?” intervention was adapted from HOP, a mental health intervention, therefore it is important to consider whether both interventions have the same theory of change and underlying causal mechanisms. Due to the clinical differences between mental health and dementia, the theory of change in a dementia-related audience might differ. During the feasibility-testing phase, outcome measures were due to be tested on the NHS intervention groups however as these groups did not take place it is not possible to understand the underlying mechanisms of action for the “Who to tell, how and when?” intervention. It is beyond the scope of this study to confirm potential causal mechanisms, however based on the research presented in this thesis thus far, they may be hypothesised. For example, the “Who to tell, how and when?” intervention may improve levels of empowerment indirectly through reducing decisional conflicts rather than reducing self-stigmatisation. Therefore, decisional conflict or peer-support related concepts might be better-fit primary outcomes based on the body of empirical work around decision-making in dementia in comparison to the very little work done in the dementia-related self-stigma field. (Nguyen & Li, 2018). In sum, a major limitation of this study is that no quantitative measures can speak to the underlying components of the newly developed and tested intervention.

### ***6.5.3 Recommendations for Future Research***

With regards to future recruitment, researchers attending pre-existing groups in non-NHS settings (e.g. peer support or voluntary sector organized activities) to build relationships with potential participants may prove more fruitful than using an online approach. Further, recruiting a more ethnically diverse population will help to understand the transference of the “who to tell,

how and when?” intervention but only once consultations with ethnic minority communities about potential intervention benefits and iterations to suit more nuanced needs have taken place.

For future recruitment in NHS settings, it is important to focus on recruiting potential participants during follow-up visits rather than after diagnostic interviews and focus efforts within primary care (e.g. GPs). Additionally, speaking to clinicians beforehand to encourage them to ask whether patients are worried or fearful of telling others may lead to an increase in referrals. Lastly, it may be plausible to integrate the “Who to tell, how and when?” intervention into existing infrastructures such as post-diagnostic groups which are already run by some memory services. It may also be useful to feasibility test recruitment from NHS settings in other geographical areas.

Although the majority respondents of the online stakeholder consultations preferred face-to-face delivery, other delivery formats were less popular, but still selected by respondents. For this reason, it may be necessary for future testing to consider alternative forms of delivery (self-guided, remote facilitation, combinations of face to face and self-guided) to accommodate for participants who do not wish to attend a group but would benefit from engaging with the intervention content. It is important to note that the intervention content was based on disclosure within one’s social network; however, two participants were still in employment at the time of attending the group. Therefore future research is needed to understand and support people living with dementia through the complexities for sharing a diagnosis at work, which is currently beyond the scope of the “Who to tell, how and when?” intervention content.

The qualitative observations and facilitator reflections presented earlier in this Chapter have implications for future iterations to intervention materials. Future iterations of the participant workbook should include strategies to deal with the negative reactions of others, the topic of receiving a diagnosis and carer specific examples. Future iterations of the facilitator guide should include strategies for managing conflict within the group and dyad.

### **6.5.4 Conclusion**

Honest, Open, Proud was adapted to form the “Who to tell, how and when?” intervention, a dyadic, decision-making intervention to support people affected by dementia through diagnostic disclosure. Based on the results of the pilot study, the intervention groups were feasible in terms of participant recruitment and attendance, in community settings but not in NHS memory services in outer London. This provides important context to delivering the intervention. By utilising guidance from Moore et al., (2019), iterations were made between group 1 and 2 to improve intervention implementation by introducing earlier start times for participants to socialise, reiterating session and exercise aims to keep group discussions focussed, changing the delivery format of exercises to avoid participant disengagement and the venue for the intervention groups has a regular shape to allow for memory prompts and orientation materials to be displayed. Previous evaluations of HOP did not include qualitative data collection and therefore, it is now necessary to understand participant experiences of the intervention that are presented in Chapter 7 using qualitative analysis.

## **7 The experience of attending the “who to tell, how and when?”**

### **intervention; a qualitative study**

#### **7.1 Introduction**

Understanding the qualitative experiences of interventions is a vital aspect of intervention development, yet is often overlooked when evaluating novel interventions (Moore et al., 2015; O’Cathain et al., 2015). Indeed, there are no existing qualitative evaluations of HOP interventions. In contrast, qualitative evaluations are a relatively common methodology in the evaluation of psychosocial interventions in dementia. In Chapter 6, I presented qualitative observations and facilitator reflections from the “Who to tell, how and when” intervention groups. I will present qualitative data to understand the experiences of participants who have attended the “Who to tell, how and when?” intervention.

##### ***7.1.1 Qualitative Evaluation of Psychosocial Interventions in Dementia***

Dugmore, Orrell and Spector (2015) conducted a systematic review of studies to investigate the underlying effects, intervention process and the implementation of qualitative psychosocial interventions for dementia. Studies were eligible if they were qualitative, published in English, from 1996 to 2011 and were evaluating a psychosocial intervention for people living with dementia. Intervention studies were excluded if they were for carers, or part of an existing service model, pharmacological or environmental intervention (Dugmore, Orrell, & Spector, 2015). Sixteen studies were eligible of which eight were group-based interventions, seven individual intervention studies and one intervention of unspecified format. Methods used within the studies ranged from observation, case study, focus groups and interviews. A thematic synthesis of study findings resulted in the identification of three common themes across studies: factors

influencing the implementation of the intervention; perceived impact of the intervention, and; active mechanisms. The themes related to the benefits of engaging in psychosocial interventions included: making connections with others; having the opportunity to reminisce; and, having the opportunity to make meaningful contributions. These benefits can be related back to the findings of the systematic review presented in Chapter 3, where I presented the freedom of choice framework (being informed, being listened to, ability to express opinions, time for reflection and reversibility of choice), which enabled for people living with dementia to meaningfully engage in decision-making (Tyrrell et al., 2006). Taken together, it can be hypothesised that one of the benefits of psychosocial interventions for people living with dementia is the opportunity to experience a ‘freedom of choice’ framework.

### ***7.1.2 Aim and Research Questions***

The aim of this study was to understand to the experience of participants who attended the “Who to tell, how and when?” intervention groups.

## **7.2 Methods**

### ***7.2.1 Design***

Post-group semi-structured qualitative interviews were carried with open-ended questions to explore participants’ experiences of attending the intervention.

### ***7.2.2 Ethics***

University College London research ethics committee [UCL REC: 14001/001; Appendix 10.1.2] granted ethical approval for this research.

### ***7.2.3 Development of the Semi-Structured Interview Schedule***

The interview schedule used in this study was developed based on guidance for using qualitative research in feasibility studies (O’Cathain et al., 2015) as an extension to the original MRC guidance on developing complex interventions (Craig et al., 2008). In the initial stages of developing the interview guide, the list of potential questions outlined by O’Cathain et al. (2015) for intervention content and delivery were considered, specifically the questions in relation to intervention development, perceived value, and benefits, acceptability of intervention and mechanisms of action. After reviewing the potential questions, an interview schedule (Appendix 10.3.3) was created to focus on participant experiences of attending the group rather than the mechanisms of actions about how the intervention may be working.

### ***7.2.4 Sampling Approach and Procedure***

In an attempt to interview both attendees and non-attendees, all individuals who were invited to attend the intervention groups were also invited to take part in the qualitative interviews. Despite efforts of the research team, only the participants who attended the intervention agreed to participate in the interviews; those who declined did not respond with an explanation. After the third intervention session had been delivered, participants were contacted to take part in interviews exploring the experience of the intervention. If participants expressed an interest in the interview and eligibility was established, they were provided with a participant information sheet and consent form (at least 24 hours prior to participation; Appendix 10.3.1), and a date and time for the interview was agreed.

### **7.2.5 Interview Procedure**

All interviews took place in participants' homes, although the option for conducting them elsewhere was offered. Tamatha Ruffell (TR), a member of the research team, conducted all the qualitative interviews. A conversational style was used to conduct the semi-structured interviews such that participants felt enabled to discuss a range of experiences, including critical reflections of attending the intervention groups. Both members of the dyad (person living with dementia and carer) took part in the interview at the same time. Each question was addressed to each member of the dyad separately so that the views of both members of the dyad were heard. Before beginning each interview, the information sheet and consent form were reviewed and an opportunity to ask any questions was given. Once participants had provided written informed consent, demographic information was collected before the audio-recorded interview began.

### **7.2.6 Data Analysis**

The author conducted the qualitative analysis. A thematic analysis based on the six stages described by Braun and Clarke, (2006), presented in Table 7.1, allowed an in-depth exploration of themes and sub-themes relating to the experience of attending the intervention. Interviews were transcribed verbatim, TR transcribed four manually and three were transcribed electronically using the Trint (2019) software. The accuracy of each transcript was checked against the interview recording by the author. Transcribed data were downloaded to NVivo (QSR International Pty Ltd. Version 12, 2018) to support management of the analysis. An inductive, data-driven approach was used in the analysis process by the author. After familiarisation with the seven qualitative interviews, annotations

of key points were made which formed the initial codes. Codes were clustered based on shared experience/meaning, after which themes and sub-themes were identified. Reviewing the transcripts during this iterative process ensured that themes and sub-themes were a good fit for the data. A final set of themes and sub-themes were agreed upon within the research team (see Table 7.2).

*Table 7.1.*

*Six steps to conducting a thematic analysis outlined by Braun & Clarke, (2006)*

Phase	Description of Process
1. Familiarising yourself with your data	Reading and re-reading transcribed data whilst noting down initial ideas
2. Generating initial codes	Systematically coding interesting features within data, collating quotes relevant to each code
3. Searching for themes	Gathering codes to create themes
4. Reviewing themes	Understand whether coded extracts speak to the overall them using a thematic map
5. Defining and naming themes	Refine the overall story told by the analysis through revisiting themes and definitions
6. Producing the report	Select vivid and compelling quotes, last opportunity for analysis, then write up in aa scholarly report



Table 7.2.

*Summary of qualitative themes generated from participant experiences of attending the “Who to tell, how and when?” intervention groups*

Theme	Subtheme
1. Value of peer support	‘It felt comforting to be part of a group’.
	‘A camaraderie’
	‘I wouldn't mind meeting them again’
2. Sharing dementia	‘Listening to other people’s experiences’
	‘But all of a sudden we are in the same boat’
	Uncertainty around sharing the space with others
3. Participant views on implementation	Changing the delivery format of workbook
	Having enough and wanting more
	Wanting to do sharing differently
	Acceptability of intervention design, format and materials
4. Intervention impact and outcomes	‘It opened my eyes more’
	‘We don’t talk about this at home’
	Impact of hearing the experiences of others

### 7.3 Results

#### 7.3.1 Value of Peer Support

All participants commented on the value of peer support that was created during intervention sessions (for participant identifiers see Table 7.3). Participants noted a sense of comfort, openness, safety and having a joint understanding. Participants felt able to open up about their symptoms and difficulties, despite this not being the norm outside of the group setting. Participants established a network of support during the intervention sessions. As an extension of this, some participants felt that the network would be maintained beyond attending the intervention groups.

*Table 7.3.*

#### *Participant characteristics*

Group	Participant No.	Gender
1	P1*	M
	P2^	F
	P3*	F
	P4^	F
	P5*	F
	P6^	M
2	P7*	M
	P8^	F
	P9*	M
	P10^	F
	P11*	F
	P12^	M
	P13*	F
	P14^	M

Note. Abbreviations: P = Participant; \* person living with dementia; ^ = chosen supporter/carer, M = male; F = female

### **7.3.1.1 'It felt comforting to be part of a group'.**

Intervention delivery was described as the 'selling point' as participants were able to meet and socialise with other people. Participants described the group environment as feeling comfortable, approachable and welcoming. A sense of hospitality was created described as 'open' (P11), 'safe' (P14), 'non-judgemental' (P9) and 'comfortable' (P3). Participants also felt the facilitation style added the component of safety to the group environment.

It felt comforting to be part of a group where you could be open about many of the things that you don't discuss with anyone else. (P11 – person living with dementia)

It was good, X (facilitator's name) made it feel safe, I can't say how, but it felt safe. It's just me, I'm a very private person so it helped. (P13 – Person living with dementia)

### **7.3.1.2 'A camaraderie'.**

The group environment created a sense of honesty and mutuality that allowed participants to exchange experiences. Although participants acknowledged that nuances existed between them (e.g. age, time since diagnosis), mutual trust was generated through spending time with each other during the intervention groups.

I think perhaps there was a camaraderie in the fact that everyone really was facing many of the same issues albeit maybe in different ways. (P11 – Person living with dementia)

### **7.3.1.3 'I wouldn't mind meeting them again'.**

The group setting was described as 'friendly' (P2), 'relaxed' (P3) and 'welcoming' (P12), allowing bonds to be created where conversations with others

were 'informative' and 'beneficial'. Relationships were created through the intervention groups that outlived the intervention itself.

And it was nice to you know... the people in the group were you know easy to get on with, I wouldn't mind meeting them again. I've got their numbers... I'm sure if the phone call came we'd meet no problem at all, ... I found it very beneficial and ... informative. (P12)

### **7.3.2 *Sharing Dementia***

The theme 'sharing dementia' describes sharing in terms of both physical space and experiences. This theme explores the value of listening to others' experiences and the feeling of sharing common ground such as being affected by dementia, but also describes how participants had other ideas for sharing the space that were not necessarily met during the intervention groups.

#### **7.3.2.1 'Listening to other people's experiences'**

Many participants gained knowledge from or resonated with the diverse disclosure experiences shared by members of the group (n = 10). Some valued hearing 'comments from other spouses' (P12) and found the exercise of listening 'instructive' (P9).

Well just the chance to talk to others and see what their experiences were I suppose. At the moment we've got our experience but nothing else to relate it to. (P14 – Carer)

#### **7.3.2.2 'But all of a sudden we are in the same boat'**

A number of participants acknowledged that they were in the 'same boat' as other attendees. This subtheme represents how participants shared their feelings and experiences of tackling similar issues (n = 10).

I like the idea that these other people have the same problems, probably not exactly the same but they're... they know what it's like. (P5 – Person living with dementia)

Participants valued speaking to others in the 'same situation' (P14), more specifically being around others who had a diagnosis and were also worried about telling others, particularly when they had not spoken openly about this beforehand. Participants were able to problem-solve as a collective and 'pick up pointers' from one another around coping strategies.

I like the idea of being able to talk to other people in the same situation and see how they're coping and maybe even pick up pointers I don't know. But you know I enjoyed the chance to talk to other people in the same boat. (P14 - Carer)

### **7.3.2.3 Uncertainty around Sharing the Space with Others**

Some participants expressed uncertainty or doubts about attending the intervention sessions because they wanted to be 'blindfolded' (P11) from others who have more severe dementia-related symptoms. Blindfolding can be seen as a way to protect someone at the early stages of dementia from future images of deterioration. Agreeing to attend the sessions without knowing the symptom severity of other participants was seen as a risk. There was a sense of stepping into the unknown that built uncertainty and fear about attending.

I think I made it fairly clear at some of the meetings that one of my big concerns was meeting people who were further down the line to me because I wanted to be slightly blindfolded by choice. ... Obviously I've got no control over who's in the group. So you're going in, you're

stepping into the unknown... That was my anxiety of how I was going to deal with this, opening up, telling strangers. As it happened, you know the people in the group were lovely it all went really well. (P11 – Person living with dementia)

Contrary to this, participants also spoke to the value of having attendees at different stages of dementia as a way of acknowledging the change that is to come. In particular, meeting others with more severe dementia was seen as preparatory.

I think it's sensible to have... a range of people that are going to have differences because... they will, perhaps in many cases feel that there are some people in a worse situation than others who are not in such a difficult situation. I think it helps to know that things change and our attitudes change. (P7 – Person living with dementia)

### ***7.3.3 Participant View on Implementation***

#### **7.3.3.1 Changing the Delivery Format of Workbook Exercises: 'I liked when we were in smaller groups'**

As a result of changing the delivery format of some activities (pair work, small groups of two to three), participants who may have been less comfortable speaking in a group were able to get involved in discussions, allowing meaningful contributions from all group members.

I liked the way the facilitators laid them all out across the table [examples of disclosure in the workbook], got us into little groups, it helped X [person living with dementia] get involved because she doesn't feel confident speaking up in a big group. (P14 – Carer)

Smaller activity groups were seen as an opportunity for carers to discuss and share experiences about the person they supported.

Well I found it interesting in one particular session where we've sort of shifted round seats and I sat next to X (carer's name) and talking to her it was interesting because Y (spouse's name) has, does have mood swings and she gets angry quite quickly sometimes. She was saying exactly the same about Z (attendee's name) that he ... finds it difficult. (P12 – Carer)

### **7.3.3.2 Having Enough and Wanting More**

Participants felt that three intervention sessions were appropriate, as this was enough time to become comfortable in a group whilst also being short enough to maintain the attention of attendees.

I think the sessions' size was brilliant... For me the number was fine the length was fine. I'm aware that concentration can be a problem and were they longer than 90 minutes it could have created problems, so everybody's different. But as you know with dementia concentration can be a bit variable. So 90 minutes suited us. (P10 – Carer)

A number of participants noted the need for additional sessions following the three-week intervention.

I think perhaps more weeks would have been quite good as well. So more, a few more weeks yeah. (P11 – Person living with dementia)

I could have gone on longer. (P14 – Carer)

For future intervention groups, some participants suggested that it might be useful to have a larger group, as this might lead to livelier discussions and bring out nuances in the experience of living with dementia.

I imagine it could be a bigger group to be honest. You'd probably get more interaction from people if I mean what were there, eight of us? Yeah you might if you could cram 12 in, get more different views. (P14 – Carer)

On the other hand, the person living with dementia that the above carer supported stated the opposite, saying they would not have attended if the group had been any larger:

I wouldn't have wanted bigger, personally. Eight was enough. I wouldn't have gone if there had been more people there. (P13 – Person living with dementia)

### **7.3.3.3 Wanting to do Sharing Differently**

Some participants suggested that future intervention groups should be more diverse, as this might generate more varied discussions.

I think it would have been perhaps better if we had more people with more diverse backgrounds and experiences and age group perhaps and not as many people of my age who've been affected by this that were willing to come or knew about it because that would have been interesting to have had a younger age group there as well. (P11 – Person living with dementia)

### **7.3.3.4 Acceptability of Intervention Design, Format and Materials**



The activities within the workbook were seen as “clear” and “easy to understand” and the content was presented in a “logical” order (P9).

Yeah I suppose I'm not a bookletty type person either I'd prefer just to do it talking but yeah it was, you know, I filled in bits, these circles (referring to the network circles exercise), participated that way, it was clear, easy to understand, the pros and cons were good. (P14 – Carer)

Facilitators were seen as key for making the content of the workbook accessible such that the discussions generated in sessions were focussed and followed the workbook content.

The facilitator can make or break something and I think X (facilitator's name)... kept the thing at the right sort of level. Brought me back on track at one point I seem to recall. (P9 – Person living with dementia)

However, even outside of the group setting, participants felt the workbook was easy to navigate.

It's quite easy to go through it and you know... if I'm watching the television sometimes and I had that booklet, I think it's upstairs, I'm sure, and I might have a look through it... Yeah I think, it's very good, I think it's well put out. (P5 – Person living with dementia)

In contrast, some participants felt the workbook language and presentation was too simplistic, although they acknowledged that this was necessary to cater for a variety of people.

It (participant workbook) was a bit childlike, I thought. So ur, ur, you know I know you've got to cater to a wide range so I think it's fine. I think

when I looked at it I thought this ur big lettering and so on is... it certainly attempts to cater for a range. Ur, yeah, a bit school like. (P8 – Carer)

Participants noted the importance of discussing the word ‘dementia’.

Questions that were broader such as “what words would you use to define dementia?” (Appendix 10.5.1) fed into more specific discussions around stereotypes of dementia and how these may influence who to tell, how and when about a diagnosis.

It seems pretty logical, and the order of it; you know the whole question around starting with the definition, getting the definition right and those sorts of things. So I wouldn’t change it from the experience I had. (P9 – Person living with dementia)

Some participants felt that further space to discuss how clinicians delivered the diagnosis would have been beneficial.

One thing that I thought also should perhaps have been discussed further is um, the question of how the doctor gives you that wonderful news that you’ve got dementia. Because the word dementia I suppose in most people’s mind carries images that are really frightening. (P3 – Person living with dementia)

Participants suggested that more time should be spent on hearing how other attendees managed difficulties.

At the end of the session we were... talking about solutions they'd found to certain things. I think perhaps having spent more time on that would have been quite useful. (P11 – Person living with dementia)

### **7.3.4 *Intervention Impact and Outcomes***

The intervention generated discussions that allowed participants to feel validated in their experiences but also to think differently about disclosure. There was also a sense of discussing something novel, a chance to articulate one's thoughts through listening to others and that the intervention materials laid the foundation for discussions around disclosure.

#### **7.3.4.1 'It opened my eyes more'**

The intervention content generated discussions around several topics related to diagnostic disclosure (e.g. who, how and when to disclose). During the intervention sessions, participants reassessed previous disclosure decisions after listening to others and having an opportunity to think about considerations that had not been thought about before. Examples were, 'have we thought about the effect it might have on other people?' (P10), and 'I was perhaps a little too cavalier' (P9). Participants also used the discussion to formulate and refine future disclosure decision-making within their family.

I would never have not considered telling her. But I think what I might well have wanted to do and I felt the session confirmed for me was that I wanted to tell her face to face. (P11 – Person living with dementia)

Discussions generated reflection around how participants were coping in the present and whether further support was necessary. Some participants used the discussions as a starting point to plan for foreseeable changes.

I think we can still cope right now but it's made us talk about the future and when that might change and when we might have to think about changing that. (P13 – Person living with dementia)

7.3.4.2 'We don't talk about this at home'

The intervention introduced novel topics into the dyadic relationship, opening up the space to share (within the dyad) thoughts and feelings around disclosure as well as focussing on airing such tensions ('whose diagnosis is it?'; Appendix 10.5.1).

What sticks in my mind about the sessions... being able to share with [spouse's name] things that we, well we wouldn't normally discuss at home. (P11 – Person living with dementia)

Carers noted that the person they supported would not typically be open about their diagnosis, as many close family members did not know, however they felt able to open up during the group sessions.

Of course everybody we know doesn't know. And it was good to hear (spouse's name) admit to her situation which she normally wouldn't do, only to me but never to anybody else. (P12 – Carer)

It was good to see [spouse's name] go to something and open up. She's never done that before. (P14 – Carer)

The discussions generated by workbook content allowed dyads space to be open about their positions on disclosure. Participants within dyads saw the intervention sessions as an opportunity to talk about conflicting views on disclosure, whilst acknowledging the benefits of disclosure such as allowing a carer to gain support.

So. I suppose I'm telling or would tell people on a need to know basis.  
(P14 – Carer)

I'd rather he didn't (tell others). I'm glad we now talk about it and I understand why. I suppose because I don't tell anyone he has to say something maybe to explain, or or get his own support. (P13 – Person living with dementia)

#### **7.3.4.3 Impact of Hearing the Experiences of Others**

Participants identified themselves in the experience of others, 'I understood exactly that's how I felt' (P5) and that 'it completely justified my own opinion' (P11). Participants noted that discussions generated from workbook examples (e.g. vignette about not wanting to use the word dementia; Appendix 10.5.1) allowed for sharing of experiences.

She was very good in explaining... that she's not the only person in the world that's got it so that made me feel good because I, I don't like the word dementia. I don't like it. Just makes me feel, you know, that I got something wrong with me so that for me when she was talking and explaining how she (emphasis) felt, I understood exactly that's how I felt. (P5 – Person living with dementia)

## 7.4 Discussion

### 7.4.1 *Summary of Findings*

In this Chapter, I presented the experiences of participants who attended the “who to tell, how and when?” intervention. From the findings above, attending the intervention groups represented a space where participants acknowledged the value of social support, reciprocity in sharing experiences of dementia and acceptability of intervention design, format and materials. Participants felt that the intervention content introduced novel topics to the dyadic relationship and through the context of hearing the experiences of other group members, participants reconceptualised previous disclosure decisions and had the space to consider future decisions. Concerning implementation, the iterations recommended after the first group on the basis of facilitator and observer feedback improved the delivery of the intervention exercises in group 2.

Session length was seen as acceptable and in line with the needs of people living with dementia who can have difficulty concentrating for sustained periods. In addition, design choices were largely endorsed by participants who spoke to the appropriateness of session length, size and facilitation style.

Participants offered some suggestions to improve the implementation of the intervention, for example, participants in the second intervention group noted that additional sessions would have been beneficial and several participants across both groups mentioned the value of broader problem solving discussions around coping strategies. As I covered in Chapter 6, the participant workbook was designed to be as accessible as possible however one participant noted that the workbook appeared ‘childlike’ which speaks to the importance of finding a

balance between accessibility and appropriateness. A further suggestion from the qualitative data was to diversify future intervention groups to include people living with dementia at different stages however it should be noted that the target audience for the intervention was those with early to mild stage dementia.

#### ***7.4.2 Findings in the Context of Literature***

Similar to the findings of this study, previous psychosocial group intervention studies in dementia have found a repeating theme on the importance of being connected to others (Dugmore et al., 2015). As well as sharing experience of dementia, connectedness between participants may have been a result of sharing the same fear and worry about disclosing a diagnosis of dementia.

The value of social support was a dominant theme in the analysis presented above. The findings of the current study are supported by previous literature that suggests group based interventions for people living with dementia foster social support and form the basis of reciprocal relationships where experiences are shared and new perspectives gained (Quinn et al., 2016). Sharing perspectives may also be a way of making sense of the diagnosis as reflected in the assessing information component of the health disclosure decision-making model (Greene, 2009). The perspectives of others were used by participants to reassess previous disclosures to inform future decisions as highlighted by the subtheme ‘it opened my eyes more’, which is reminiscent of the feedback loop component of disclosure decision-making (Chaudoir and Fisher, 2010).

People living with dementia have reported the notion of being in the ‘same boat’ in previous qualitative studies (Keyes et al., 2016; Melunsky et al., 2015;

Price, 2010; Spector, Gardner, & Orrell, 2011). The difficulties experienced because of dementia gave a sense of group membership where participants felt as though they were in the ‘same boat’ (Keyes et al., 2016; Melunsky et al., 2015; Price, 2010; Spector et al., 2011). Similar to the findings of the current study, the phrase ‘being in the same boat’ relates to sharing common experiences of dementia and collectively being in a position to manage the demands of the condition. Being in the same boat was reported in the context of peer support groups (Keyes et al., 2016) and attending cognitive stimulation therapy groups (Spector et al., 2011), but was also identified as a theme when investigating the service engagement of people living with dementia and carers in focus groups (Price, 2010).

### **7.4.3 Comparison between HOP and the “Who to tell, how and when?”**

#### ***Intervention***

The research presented in Chapter 6 established a preliminary understanding of implementation based on participant recruitment, attendance, group observations and facilitator reflections. In the current Chapter, I addressed questions of intervention implementation through the analysis participant experiences of attending the intervention groups. It is not always useful to draw rigidly from existing theories and knowledge where an intervention has been adapted from one clinical context to another (Moore et al., 2015). In line with this recommendation from Moore et al. (2015), it is now important to understand the differences between HOP and the “who to tell, how and when?” interventions. To highlight the differences, a logic model was created based on the preliminary findings of the current Chapter and Chapter 6. A logic model was created based on established guidance for developing logic models of complex interventions (see

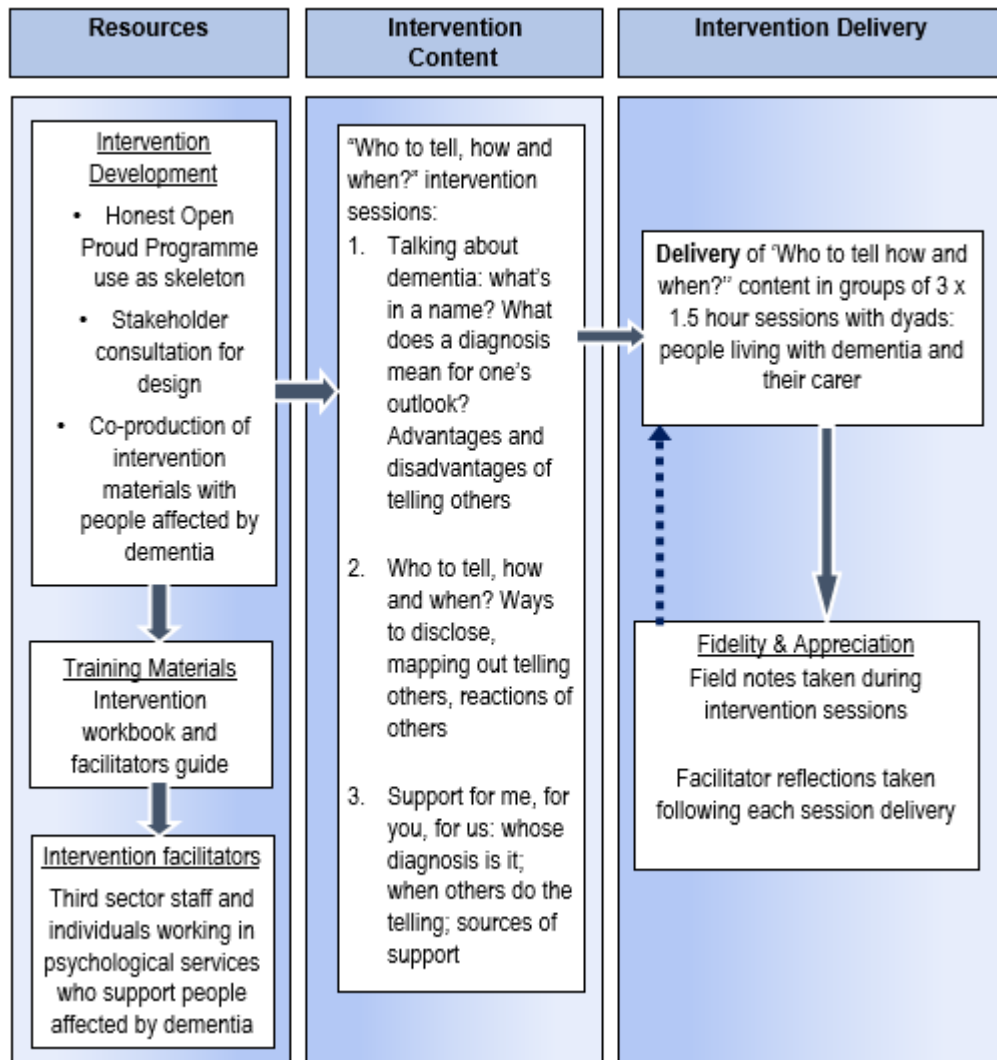


Figure 7.1; Mills, Lawton, & Sheard, 2019), however hypothesised mechanisms of change and impact were omitted as it is beyond the scope of this thesis to establish these components.

Key content differences between HOP and the “who to tell, how and when?” intervention are summarised in Chapter 6. The key contextual differences were country of origin (UK population), clinical difficulties (mental health versus dementia related issues) and the nature of support required (independent versus dyadic). To cater for a UK population of dyads affected by dementia, careful thought was given to topics such as “whose diagnosis is it?” that is not included in the HOP intervention where participants take part on their own. As noted in Chapter 6, the delivery of the “who to tell, how and when?” intervention has added complexities because of the existing history within a dyad. Facilitators were tasked with dealing with emotionally charged discussion both between and within dyads, which unlike HOP, is unique to the inclusion of carers.

Figure 7.1.

Hypothesised logic model for the “Who to tell, how and when?” intervention



#### **7.4.4 Methodological Considerations**

Older adults are more vulnerable to loneliness and social isolation as a consequence of changes in lifestyle (e.g. retirement) or health problems (Windle, Francis, & Coomber, 2011). Barriers such as illness, disability, loss of friends, and lack of social opportunities may prevent lonely older adults from engaging in various forms of social participation (Goll, Charlesworth, Scior, & Stott, 2015). Interventions to tackle loneliness and isolation include peer support hence it is difficult to establish whether a sense of being in the ‘same boat’ was generated as a result of intervention content or more generally the result of the opportunity to socialise with others with shared experiences. Although the latter may have been the case, it is unlikely as participants agreed to attend the groups, as they were fearful, conflicted or worried about disclosing a diagnosis within their social networks. Therefore the “Who to tell, how and when?” intervention may work similarly to peer-support interventions which tackle loneliness or social isolation, with some nuances that go beyond the benefits of general social contact. These nuances include matching participants to the group as a result of fear or worry about disclosure, rather than more general criteria typically used in psychosocial interventions such as being affected by dementia (Dugmore et al., 2015).

It is plausible to suggest that participants’ experiences relating to a sense of camaraderie may have been due to the peer support environment where individuals all shared the experience of living with dementia and having to face the complexities of disclosing to their social networks. Arguably, the intervention may have paved the way to generating discussions that increased the bond between participants and therefore it is difficult to discern whether the notion of

being in a group played a causal role in participant experiences, more so than the discussions generated as a result of intervention contents.

In the current study, participants with dementia and their chosen supporter were interviewed together (dyadic interviews) and this may have confounded the qualitative data presented in this Chapter. For example, each member of the dyad may have felt unable to speak honestly about the impact of the intervention or potential difference of opinion concerning disclosure decision-making. For this reason, future testing of the intervention should seek to interview members of each dyad separately; however, this decision should be grounded in further consultation with people affected by dementia to understand the benefits and drawbacks of interviewing participants separately.

### **7.4.5 Future Research**

The subtheme ‘we don’t talk about this at home’ has implications for future testing of the intervention. In Chapter 6, I listed pre- and post-intervention measures that were due to be used to evaluate the intervention. In the event, the measures were not used due to lack of recruitment to NHS sites. However, with the benefit of further time with the topic of diagnostic disclosure, it has become apparent that the planned measures would not have captured impact of novel discussions around disclosure decision-making. This has important implications for measures used for future testing of the intervention.

It was beyond the scope of this thesis to establish the mechanisms of action and health impacts of the “Who to tell, how and when?” intervention and therefore these components did not appear in the intervention logic model (see Figure 7.1).

It is possible to hypothesise the potential mechanism of action and health impacts as scope for future research that I will now discuss.

Both HOP and the “Who to tell, how and when?” intervention are designed to support participants to make autonomous decisions about disclosing stigmatised diagnoses. The “who to tell, how and when?” intervention, based on current qualitative evidence, may have the effect of empowering people to make autonomous or mutual decisions about disclosure (see Chapter 3 for decisional styles), thus promoting a positive sense of personal identity where peer support and listening to others are key. As stated in Chapter 3, an overall sense of empowerment can be maintained by people living with dementia through decision-making (Fetherstonghaugh et al., 2016; Menne & Whitlatch, 2007; Miller et al., 2017; O’Brien, Clemson & Canning, 2016). The “Who to tell, how and when?” intervention gives people living with dementia a supported space to be involved in decision-making and therefore can be thought of as an empowerment-based approach akin to HOP. As noted from the work of O’Connor and colleagues (2018), not knowing who to tell, how and when about a diagnosis of dementia can leave a lasting feeling of disempowerment contributing to social withdrawal. The “Who to tell, how and when?” intervention can be seen as a means of reducing the disempowerment of people living with dementia by supporting disclosure decision-making which has been noted to increase feelings of empowerment in other populations (Buchholz et al., 2015).

Both HOP and the “who to tell, how and when?” intervention are grounded in the value of peer support. Results from qualitative interviews spoke to the value of peer support felt by participants who attended the intervention

groups. As highlighted in Chapter 3, a key element of HOP is based on peer support being a vital component in reducing self-stigma and increasing social participation and therefore the “Who to tell, how and when?” intervention may have similar consequences for stigma reduction if self-stigma were measured before and after participation (Corrigan et al., 2013).

Due to the small sample size it is difficult to determine whether participants’ experiences of taking part in the “who to tell, how and when?” intervention matched the views expressed in the stakeholder consultation which I presented in Chapter 6. The question remains as to whether the intervention may also be beneficial for participants if the delivery format was changed to accommodate those who do not wish to attending a group-based intervention. In the online stakeholder consultation I presented in Chapter 6, face-to-face delivery was the preferred method while other options were less popular but still chosen by respondents. Future replications of this research may consider offering alternative means of delivery (e.g. a self-guided or one to one delivery), as the preferences (e.g. method of delivery) generated by the online stakeholder consultation were appropriate for the majority but not all participants.

This current study did not include an intervention fidelity measure. Future testing of this intervention should be done following the development of a fidelity measure that would, through triangulation, help to contextualise participant views on implementation, facilitator reflections and group observations.

### **7.4.6 Conclusion**

The findings of this Chapter represent an important step in understanding the experiences of people living with dementia and carers who attended the “who

to tell, how and when?” intervention. Participants found the intervention acceptable and placed significance on the group-based format and intervention content. Qualitative findings in the current study have established recommendations for future groups that can be coupled with those found in Chapter 6, to inform future testing of the intervention.

## 8 General Discussion

### 8.1 Summary of Key Findings

People living with dementia have been found to experience self-stigma yet, prior to the development of the “Who to tell, how and when” intervention, there was no existing stigma reduction interventions targeting the intrapersonal or familial level for people living with dementia. The nature of decision-making in dementia is complex with multiple influential factors including background factors (Freedom of Choice Framework; Tyrrell et al. 2006) and contextual factors (risk, resources, relationships) that determine the style of decision-making and level of involvement of a person living with dementia. Stigma influences disclosure decision-making by acting as a barrier to disclosure, resulting in psychological (isolation, rejections, low self-esteem) and social (withdrawal from social network) consequences where secrecy is used to protect against the negative reactions of others and loss of important relationships. Literature reviewed in the first section of this thesis (Chapter 2 and 3) provided an understanding of the negative influence of stigma on disclosure decision-making in dementia.

A four-stage approach presented in Chapter 4 was used to identify, adapt and test self-stigma measures (quantifying concepts of social rejection, social isolation, internalised shame, and secrecy in relation to dementia and stigma stress) in a UK population of people living with dementia. Findings from preliminary pilot testing in Chapter 4 suggests three self-stigma measures have acceptable internal consistency, test retest reliability, concurrent validity and convergent validity, with some exceptions. The burden experienced by carers of people living with dementia may be exacerbated by courtesy and affiliate stigma,



therefore in Chapter 5 of this thesis the Family Stigma Instrument was piloted to address the lack of psychometric tools for the measurement of these constructs in a UK population of carers. Preliminary pilot testing of the Family Stigma Instrument (quantifying concepts of perceived family stigma, positive aspects of caregiving and affiliate stigma) suggests the instrument is acceptable and reliable for use in a population of carers of people living with dementia in the UK. Collectively, the second section of this thesis established acceptable psychometric instruments to measure components of stigma in people living with dementia and carers.

The concept of the “Who to tell, how and when?” intervention was strongly endorsed by respondents of the stakeholder consultation (209/232 respondents) and the intervention was feasible with regards to participant attendance and attrition in community settings (N=14 participants; N=7 dyads) but not in NHS settings. A process evaluation approach using observations and facilitator reflections improved the implementation of intervention content, speaking to the value of qualitative evidence within the development process of complex interventions. Based on qualitative evidence, the “who to tell, how and when?” intervention was acceptable where participants emphasised the value of peer support and sharing experiences with others.

## **8.2 Findings in the Context of Literature and Theoretical Implications**

### ***8.2.1 The Influence of Stigma on Disclosure Decision-Making***

To the authors knowledge, two empirical papers highlight the link between stigma and disclosure decision-making in dementia, where stigma was a barrier to disclosing one’s diagnosis (O’Connor et al., 2018; Weeks et al., 2015).

Paradoxically, however, disclosure was also framed as an act of ‘stigma resistance’, that is, the notion of combating stigma. The promotion of empowerment and benefits of disclosing as an act of stigma resistance has also been found in other populations, as mentioned previously (Buchholz et al., 2015; Kalichman et al., 2003; Paxton, 2002). Findings of Chapter 7 suggest that disclosure decision-making may be grounded in the value of peer support and empowerment through decision-making rather than an act of combating stigma directly. For example, the goal of disclosure for people living with dementia may be more aligned to increasing social connectedness and maintaining an existing social network where feeling empowered and supported by peers is more influential in the disclosure decision-making process.

An associated consequence of self-stigma is the need for diagnostic secrecy; however, this has never been investigated in people living with dementia until now. Findings in Chapter 4 suggest that internalised shame and secrecy (as a means of coping with stigma) were related to increased levels of disclosure related distress in the context of telling family and friends about a diagnosis of dementia. Speaking to the influence of stigma on disclosure decision-making, it is plausible that internalised shame (one concept of self-stigma), may be a barrier to disclosing a diagnosis of dementia. This is similar to previous research that suggests internalised shame plays an integral part in shaping the experience of stigma in mental health (Rüsch et al., 2009; Wood et al., 2017). It is possible that, for people living with dementia, internalised shame may be the key component of the stigma process that influences disclosure decision-making in particular, rather than everyday experiences of stigma. The findings of Chapter 4 have to be interpreted with caution due to small sample sizes.

### 8.2.2 *A dyadic Approach to Disclosure Decision-Making*

According to the review described in Chapter 3, carers were found to perform a supportive (managed autonomy) or unsupportive (reductive) role in decision-making styles. In Chapter 3, the narrative surrounding the involvement of carers in decision-making was in relation to person living with dementia whereas the role of the carer was not explicitly included in existing disclosure decision-making models (Chaudoir & Fisher, 2010; Greene, 2009; Omarzu, 2000).

In Chapter 5, the role of caring for someone living with dementia was appraised by more than half of carers to be stigmatising, this is similar to the findings of Mitter et al. (2018). The stigma experience for carers was quantified through experiences such as being excluded from activities and being looked at differently by others. Although the core topic of this thesis was the influence of stigma on disclosure decision-making by people living with dementia, the stigma felt by carers, and the overwhelming preference by online stakeholder consultation respondents for carers to be involved in the “Who to tell, how and when?” intervention highlights the importance of support for carers.

From the analysis in Chapter 7, it can be deduced that carers were participants in the “who to tell, how and when?” intervention as well as people living with dementia. Carers felt the benefits of meeting others in a similar situation to them. There was a sense of unity amongst the carers, some of whom suggested further intervention sessions run separately for carers. Given the position of carers from the data collected in Chapter 7, framing disclosure decision-making through a dyadic lens, as seen in the “who to tell, how and

when?” intervention, promotes a mutual style of decision-making where carers are active participants as well as the person living with dementia.

### **8.3 Lessons Learned**

#### **8.3.1 Research Governance**

The first ethics application submitted for NHS REC approval encompassed a plan for all of the empirical work outlined in this thesis as well as a mixed methods pilot feasibility study where pre and post measures were due to be tested alongside the intervention. Due to an unfavourable opinion from the first NHS REC application, the research process was delayed considerably and alternative ethical approval was sought from UCL such that all of the empirical work could be carried out in non-NHS settings. Another attempt was made at NHS REC approval, which was successful however not enough participants were recruited for a group to start in the NHS, as outlined in Chapter 6. Through the NHS ethics process I have learned about the various regulatory processes and bodies, the timescale of completing an application and obtaining approval, the various requirements from the central NHS and NHS-based Research and Development departments with regards to study protocol, which places me in a good position for future engagement in the NHS ethics process.

Another challenge was the introduction of the General Data Protection Regulation (GDPR). Once I had completed the mandatory training, I ensured that participant information sheets and consent forms adhered to GDPR, which meant adding the legally required wording to the aforementioned materials, thus making them longer. The mandated wording contained language that was not accessible for the average reading age and therefore after consultation with the UCL data

protection team and other researchers, more accessible wording was agreed upon and the length of the documents reduced to contain minimal detail but importantly, still convey rights and protections under GDPR.

### **8.3.2 *Stigma and Disclosure in Dementia***

Stigma has been understudied in psychosocial dementia research and therefore no theories or frameworks of dementia-related stigma were available to draw upon when establishing the influence of stigma on disclosure decision-making in dementia. In an attempt to address this problem, I conducted a systematic review to understand the nature of decision-making in dementia. Unfortunately, however, this review did not yield any literature on decision-making relevant to disclosure. For the purposes of conceptual understanding, it was then necessary to compare and contrast disclosure decision-making models alongside systematic review findings and two studies exploring disclosure in dementia in an attempt to elucidate the influence of stigma on disclosure decision-making in dementia. By doing so, the findings of the first section of this thesis concluded that stigma may influence disclosure decision-making by exacerbating the risk associated with decision-making which includes psychological (withdrawal, internalised shame, reduced self-esteem) and social consequences (social isolation, social rejection).

The two empirical papers, which highlighted the link between stigma and disclosure, were not found in the systematic review. The O'Connor et al. (2018) paper was published after the systematic review had been completed and the Weaks et al. (2015) paper was focussed on the importance of sharing a diagnosis rather than the process through which decision-making takes place. Therefore in

order to have captured this paper, terms akin to ‘disclosure’ and synonyms such as ‘sharing’ or ‘telling’ could have been added to the original search terms.

### ***8.3.3 Quantifying Stigma in Dementia***

It became apparent that existing measures of stigma had limitations (under reporting of psychometric properties such as test retest reliability, no stakeholder involvement, not culturally appropriate). I addressed these limitations by adapting and testing existing measures as a necessary step to producing outcome measures which were sensitive to change for longitudinal evaluation of the “Who to tell, how and when?” intervention. Due to the small sample size of people living with dementia, a full validation including the analysis of factor structure was beyond the scope of this thesis for measures of self-stigma in people living with dementia and this will be addressed later in the future research section.

The preliminary findings presented in Chapter 4 are the first to highlight the relationship between secrecy, disclosure related distress, and internalised shame building a rationale to understanding disclosure decision-making in dementia through stigma. Internalised shame was specifically of importance above other concepts. This has implications for future evaluations of the “Who to tell, how and when?” intervention as internalised shame and diagnostic secrecy may be more fruitful outcomes measures of self-stigma in the context of disclosure decision-making.

### ***8.3.4 Developing a Complex Intervention for Disclosure Decision-Making in Dementia***

The successful use of the HOP programme in supporting disclosure decision-making in mental health was the rationale for adapting HOP for people

living with dementia. The problem that emerged, however, was that there was no available guidance to guide adaptation for a population of people living with dementia. To address this problem I utilised existing guidelines and constructed a methodology that involved several stages of development to inform the “Who to tell, how and when?” intervention.

### **8.4 Methodological Considerations**

#### **8.4.1 *Participants of the Research***

##### **8.4.1.1 Participant Recruitment**

Data represented in Chapters 4, 5 and 7 were from participants who were recruited through both community groups (e.g. peer support) and others through the Join Dementia Research (JDR) database. It is important to note that those participants embedded in social groups that have shared experiences of dementia may have very different narratives regarding stigma and dementia to those not embedded in such groups. Attending an established peer support group may have significant impact on wellbeing for people with dementia and the relationship between social connectedness, isolation and self-stigma, which warrants further attention in future research.

##### **8.4.1.2 Participant Ethnicity**

The barriers of disclosure decision-making may differ in Black, Asian, minority ethnic (BAME) communities. In the same way, the consequences of self-stigma may be different due to the intersectionality of stigmatised characteristics. It is known that service access in BAME communities is influenced by cultural factors, religious influences, language and literacy, attitudes and assumptions by the majority, inadequate assessments and unsuitable services. It is possible that in the same way disclosure decision-making, or attendance of an intervention to

support this, is also influenced by the aforementioned factors. As the majority of participants in the current research identified as ‘white’, it is beyond the scope of this research to imply whether the “who to tell, how and when?” intervention would benefit BAME communities. However, it can be acknowledged that BAME individuals may experience nuanced challenges in disclosure decision-making, which may require adaptations to the “who to tell, how and when?” intervention.

### **8.4.1.3 Representation of Other Characteristics**

BAME communities are one of many groups that come under the title of protected characteristics that bear the burden of intersectional stigmatising characteristics. For example, there is often a reoccurring theme in dementia literature about ‘being in the same boat’ however, this does not mean individuals living with dementia share the same number of stigmatising marks (Keyes et al., 2016; Price, 2010; Spector et al., 2011). Price et al. (2010) found that participants spoke openly about dementia whilst some chose not to identify themselves to other group members as being homosexual or heterosexual (known as passive nondisclosure). Stigmatisation in relation to disclosure can put an individual in double (or more) jeopardy where a choice may be made to disclose one aspect of a person’s identity and not another. The “who to tell, how and when?” intervention did not specifically seek to recruit individuals with protected characteristics however, the work in this thesis may be a blueprint to providing support to these individuals in the future after careful consultation with people who have protected characteristics, around content considerations that may need adaptation.



A further characteristic that was beyond the remit of the “Who to tell, how and when?” intervention was supporting people affected by dementia who are employed. The development process of the “who to tell, how and when” intervention led to content representing disclosure decision-making within one’s social network. The content of the intervention did not focus on other types of disclosures, such as those made to employers. As people are being diagnosed with dementia at younger ages, 2 to 10% of cases start before the age of 65, when many people are still in employment (World Health Organisation, 2012). Disclosure decision-making whilst in employment was absent from systematic review findings in Chapter 3 further speaking to this research gap. Two participants who engaged in the intervention groups were still in employment and therefore a rationale for more specialised support in relation to sharing a diagnosis of dementia at work is an avenue for future research that will be discussed later.

### **8.4.2 *PPI and Stakeholder Involvement***

INVOLVE guidelines seek to support researchers in delivering good quality and meaningful PPI (INVOLVE, 2012). The current research presented in this thesis, implemented guidelines and involved people living with dementia and carers in the adaptation of self-stigma measures and the development of the “who to tell, how and when?” intervention. The involvement of those with lived experiences comes with strengths and challenges. Lived experience expertise from PPI members and stakeholders has allowed for the author to not only see the research from a different perspective but also foresee potential difficulties prior to testing. This being said, there are some general challenges with the PPI culture that currently exist in research and it is these challenges that I will now summarise.

General challenges of PPI include institutional factors restricting PPI implementation and difficulties around the representativeness of the PPI process. INVOLVE guidelines give an overview of how to incorporate PPI into the research process with specific recommendations such as payment amount (INVOLVE, 2012). Yet the infrastructure within university budgets or PhD grants may not be able to accommodate this financial recommendation. Conducting PPI in line with the payment recommendations of INVOLVE (2012) is often not feasible more than once or twice in a three year project. This restricts the implementation of meaningful PPI as a result of institutional factors.

PPI has gained momentum, as have the number of people who sit on any PPI panel. In the process of creating a PPI group to support the current research, I often found that PPI members were part of a number of other groups across conditions and settings, this culture can be seen as ‘PPI professionalism’, where the same key people may sit across many groups. This is problematic as it reduces the diversity of PPI. The [Breaking Boundaries strategic review](#) of public involvement announced on March 31<sup>st</sup> 2014, called for more diversity and inclusion in the PPI process (NIHR, 2014). Diversity was identified as a future measure of success in an evaluation of National Institute for Health Research (NIHR), with the aim of framing the NIHR 2025 vision for researchers to focus on reaching and engaging communities so PPI becomes a diverse and inclusive process (Staniszewska, Denegri, Matthews, & Minogue, 2018).

There is currently a consequentialist rationale for PPI, where it is seen to be morally right as a process to improve the quality and ecological validity of research (INVOLVE, 2012). The consequentialist rationale however, is

problematic as it gives greater voice and power to a selection of individuals who are not the subjects of the research (Edelman & Barron, 2016). In addition, the PPI process itself can be seen as a complex intervention for which there is a lack of evidence on the specific benefits to PPI members, and therefore no detailed foundation from which an evaluation framework can be meaningfully created and used (Edelman & Barron, 2016). Collectively the PPI process raises moral and ethical concerns that should be considered by researchers. In the current study, the PPI and stakeholder involvement was not subject to any evaluation. It is therefore beyond the scope of this research to identify the benefits or impact of PPI on the research process and for PPI members themselves.

### **8.4.3 *Intervention Development***

#### **8.4.3.1 Preferences Generated from Stakeholder Consultations**

The current research was not able to address the benefits of other forms of delivery, for the “Who to tell, how and when?” intervention. Although face-to-face delivery was the preferred method based on the results of the online stakeholder consultation, other delivery formats were less popular, but still selected by respondents. It is plausible that alternative forms of delivery (self-guided, remote facilitation, combinations of face-to-face and self-guided) may be able to accommodate participants who do not wish to attend a group yet would benefit from engaging with the intervention content.

#### **8.4.3.2 Guidelines for Complex Interventions**

The MRC guidelines were used to adapt HOP to develop the “Who to tell, how and when?” intervention, as no pre-specified guidelines for adapting HOP were available. However, MRC guidelines may not be sensitive to community contexts and provide little detail on the operationalisation of the three

development stages (Wight et al., 2015). MRC guidelines offer no framework for adapting an existing intervention to other clinical populations. It may have been more fruitful to implement the Six Steps in Quality Intervention Development (6Squid) framework to develop the “Who to tell, how and when?” intervention (Wight et al., 2015). Some of the limitations of the MRC guidelines may have been addressed by using the 6Squid framework that focusses on public health impact, wider applicability of intervention content in community settings and providing practical development guidelines that are not limited to intervention evaluation (Wight et al., 2015). Although this is the case, the MRC guidelines and the 6Squid framework do not give specific guidance around adapting existing interventions to different clinical populations.

#### **8.4.4 *Intervention Evaluation***

A step before hypothesising the use of particular outcomes measures of stigma (presented in Chapter 4 and 5) would have been to do a qualitative exploration of disclosure decision-making in dementia to understand the psychosocial concepts that are central to the experience of telling others about one’s diagnosis. Although the intervention was developed over a series of stages with careful thought given to the previous literature and stakeholder preferences, qualitative data speaking to the potential mechanisms of action for this intervention would have provided a more solid foundation for further testing. This includes the selection of suitable outcome measures.

The evaluation of the “Who to tell, how and when?” intervention was reliant on facilitator reflection, group observations and qualitative follow up interviews. For this reason, the logic model proposed in Chapter 7 of this thesis

must be tentatively interpreted, specifically as some of the proposed mechanisms of impact of the “who to tell, how and when intervention” differed from HOP which has been more rigorously tested in RCTs across populations (Scior et al., 2019). In order for stronger conclusions to be drawn about the mechanisms of impact of the “Who to tell, how and when?” intervention, qualitative methodology should have been used alongside quantitative measures (pre and post intervention completion). Collectively, it is beyond the scope of the current research to draw out exactly which mechanisms of impact are being tackled by the “Who to tell, how and when?” intervention.

## **8.5 Future Research**

### ***8.5.1 Addressing the Impact of Intersectionality on Stigma as a Barrier to Disclosure***

The understanding and perception of dementia is different in BAME populations and therefore psychosocial research investigating the influence of stigma on disclosure decision making should accommodate for ethnic and cultural differences (La Fontaine, Ahuja, Bradbury, Phillips, & Oyebode, 2007; Parveen, Peltier, & Oyebode, 2017). The link between stigma and disclosure by individuals in BAME communities is under researched and therefore unsupported in interventional literature. It is necessary to understand how the “Who to tell, how and when?” intervention may present differing mechanisms of impact for BAME individuals and whether or how stigmatisation is included in this.

### **8.5.2 *Self-Stigma in People Living with Dementia using the Stigma Impact Scale***

Findings from Chapter 4 provided tentative psychometric properties for the SIS. The next stage is to confirm these properties in a large-scale study and conduct further psychometric analysis to validate the factor structure of stigma impact in dementia. I was invited to contribute to the World Alzheimer Report 2019 and, as a result, the data collected in people living with dementia (n = 1,446) included the SIS (Alzheimer's Disease International, 2019). As I have been invited by ADI to conduct further analysis on the data, the next step would be to test the data collected in the World Alzheimer Report 2019 to understand the factor structure of the SIS. This will help establish the prevalence of social rejection, internalised shame and social isolation as concepts relating to the self-stigma experience of people living with dementia.

### **8.5.3 *Further Testing of the “Who to tell, how and when?” Intervention***

#### **8.5.3.1 *Changing the Delivery Format***

A process evaluation using qualitative data indicates that the implementation of the “who to tell, how and when?” intervention was as expected and in scenarios that iteration was necessary, optimisation led to improvements in participant experience. Future research may be able to improve the recruitment to the intervention if a self-guided or a one to one version of the intervention was offered to potential participants who were less confident in group settings or were worried about attending a group to discuss the sensitivities of disclosure.

#### **8.5.3.2 *Understanding Mechanisms of Change***

As the “Who to tell, how and when?” intervention is the first intervention of its kind, it is necessary to field test it further to understand the universality of

the preferences generated by the stakeholder consultation and the underlying causal mechanisms of action. Future research should aim to implement controlled study designs, for example, a pilot RCT should aim to use a mixed methods approach to implement both psychometric measures as well as qualitative interviews to evaluate intervention feasibility. In Chapters 4 and 5, stigma instruments for people living with dementia and carers were tested respectively, and preliminary analysis showed that the measures were acceptable. However further psychometric testing would be necessary.

### **8.5.3.3 Understanding Intervention Impact within Dyads**

Poorer health outcomes in terms of well-being, depression and quality of life have been reported in carers of people living with dementia (Argimon, Limon, Vila, & Cabezas, 2004; Laver, Milte, Dyer, & Crotty, 2017; Spector, Orrell, Charlesworth, & Marston, 2016; Vernooij-dassen et al., 2019). Psychosocial interventions for dyads of people living with dementia and their carers have reduced depressive symptoms, decreased burden, reduced carer upset and improved quality of life (literature reviewed in Laver et al., 2017). The “Who to tell, how and when?” intervention is the first to support disclosure decision-making in dyads. However, due to lack of recruitment the intended pre and post measures were not obtained which included evaluating the impact of the intervention on relationship quality. It was beyond the scope of the current study to establish the benefits of the intervention on the dyadic relationship. Future research should use both cross sectional and longitudinal designs to ascertain the effects of the “who to tell, how and when?” intervention on decision-making outcomes for dyads (e.g. communication and conflict) as well as quality of

relationships and empathy. A full list of measures that were intended to be used for pre and post intervention testing are listed in Chapter 6.

#### **8.5.3.4 Future Intervention Recruitment**

With regards to future recruitment, researchers attending pre-existing groups in the community (e.g. peer support or voluntary sector organized activities) to build relationships with potential participants may prove more fruitful than using an online approach; further recruiting a more ethnically diverse population will help to understand the cross cultural transference of the “Who to tell, how and when?” intervention.

#### **8.5.3.5 A Version for Employees**

The development process of the “Who to tell, how and when” intervention led to content representing disclosure decision-making within one’s social network. The content of the intervention did not focus on other types of disclosures, such as those made to employers. Documented ignorance by employers to support the rights and legal position of people living with dementia may create a difficult climate for those who wish to disclose a diagnosis to employers (Egdell et al., 2019). Training for employers to support people living with dementia should be a priority as well as supporting the disclosure decision-making of people living with dementia who are still in employment. The latter can be done through careful adaptation of the “Who to tell, how and when?” intervention which would require a multi-disciplinary approach involving legal and institutional expertise. Supporting people living with dementia in making disclosure decisions to employers is beyond the scope of this thesis however future research should aim to evaluate the efficacy of delivering the “Who to tell, how and when?” intervention in this context.



## **8.6 Conclusion**

To the author's knowledge, this is the first research into the influence of stigma on disclosure decision-making in dementia. Findings suggest that stigma is a barrier to disclosure in dementia, which is compounded by existing challenges in the nature of decision-making for people living with dementia. Although disclosure decision-making has traditionally been seen to affect only the person with the stigmatised diagnosis, the work of this thesis speaks to carers as well as people living with dementia experiencing stigma and therefore may equally experience its influence on disclosure decision-making. The "Who to tell, how and when?" intervention to support disclosure decision-making was experienced as acceptable for people living with dementia and carers, who emphasised the value of peer support and sharing experiences of dementia as beneficial.

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**10 Appendices**



## 10.1 Ethics Letters and Insurance

### 10.1.1 UCL Ethical Approval 11501/002

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UCL RESEARCH ETHICS COMMITTEE  
OFFICE FOR THE VICE PROVOST RESEARCH



17<sup>th</sup> August 2018

Dr Georgina Charlesworth  
Research Department of Clinical Education and Health Psychology  
UCL

Dear Dr Charlesworth

**Notification of Ethics Approval with Provisos**

**Project ID/Title: 11501/002: Investigating the stigma experience of people living with dementia**

Further to your satisfactory responses to my comments, I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that I have ethically approved your study until 31<sup>st</sup> December 2019.

Ethical approval is subject to the following provisos:

**Notification of Amendments to the Research**

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form' <http://ethics.grad.ucl.ac.uk/responsibilities.php>

**Adverse Event Reporting – Serious and Non-Serious**

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

**Final Report**

At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

Office of the Vice Provost Research, 2 Tavilton Street  
University College London  
Tel: +44 (0)20 7679 8717  
Email: [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)  
<http://ethics.grad.ucl.ac.uk/>

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: <http://www.ucl.ac.uk/srs/governance-and-committees/resgov/code-of-conduct-research>
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely



Professor Michael Heinrich  
Joint Chair, UCL Research Ethics Committee

Cc: Jem Bhatt & Dr Katrina Scior

**10.1.2 UCL Ethical Approval 14001/001**

UCL RESEARCH ETHICS COMMITTEE  
OFFICE FOR THE VICE PROVOST RESEARCH



28<sup>th</sup> August 2018

Dr Georgina Charlesworth  
Research Department of Clinical Education and Health Psychology  
UCL

Dear Dr Charlesworth

**Notification of Ethics Approval with Provisos**

**Project ID/Title: 14001/001: The experience of attending a “talking about diagnosis” group for people living with mild dementia: a qualitative interview study.**

Further to your satisfactory responses to my comments, I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that I have ethically approved your study until **1<sup>st</sup> September 2019**.

Ethical approval is subject to the following provisos:

- The information sheet: please rephrase in such a way that you clearly spell out the aims of this study, not what people have to do formally. What we be your intervention?

**Notification of Amendments to the Research**

You must seek Chair’s approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an ‘Amendment Approval Request Form’  
<http://ethics.grad.ucl.ac.uk/responsibilities.php>

**Adverse Event Reporting – Serious and Non-Serious**

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

**Final Report**

At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research

Office of the Vice Provost Research, 2 Taviton Street  
University College London  
Tel: +44 (0)20 7679 8717  
Email: [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)  
<http://ethics.grad.ucl.ac.uk/>

## Stigma and Disclosure Decision-Making in Dementia

i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: <http://www.ucl.ac.uk/srs/governance-and-committees/resgov/code-of-conduct-research>
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely



**Professor Michael Heinrich**  
Joint Chair, UCL Research Ethics Committee

Cc: Tamatha Ruffell

**10.1.3 NHS Approval Letter**



**London - Surrey Borders Research Ethics Committee**  
Research Ethics Committee (REC) London Centre  
Ground Floor  
Skilton House  
80 London Road  
London  
SE1 6LH

**Please note:** This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

28 August 2019

Dr Georgina Charlesworth  
Research Department of Clinical, Educational and Health Psychology  
1-19 Torrington Place  
London  
WC1E 7HB

Dear Dr Charlesworth,

<b>Study title:</b>	<b>"Who to tell, how and when?" – A feasibility evaluation of an intervention to help support people living with dementia who are fearful of disclosing their diagnosis to others</b>
<b>REC reference:</b>	<b>19/LO/1163</b>
<b>Protocol number:</b>	<b>122232</b>
<b>IRAS project ID:</b>	<b>254026</b>

Thank you for your letter of 15 August 2019, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Alternate Vice-Chair.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of management permissions from host organisations*

### Registration of Clinical Trials

It is a condition of the REC favourable opinion that all clinical trials are registered on a publicly accessible database. For this purpose, clinical trials are defined as the first four project categories in IRAS project filter question 2. For clinical trials of investigational medicinal products (CTIMPs), other than adult phase I trials, registration is a legal requirement.

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee ( see here for more information on requesting a deferral: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>)

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/>

You should notify the REC of the registration details. We will audit these as part of the annual progress reporting process.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

### After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

### Ethical review of research sites

#### NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Advertisement_254026_V1.0_14-01-2019.docx]	V2.0	30 July 2019
Covering letter on headed paper [ResponsetoRevisions_IRAS254026_V1.0_11082019]	V1.0	11 August 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UCL Insurance Certificate_254026]		12 June 2019
GP/consultant information sheets or letters [GPNotificationLetter_254026_V1.0_14-01-2019.docx]	V1.0	14 January 2019
Interview schedules or topic guides for participants [InterviewGuide_254026_V1.0_14-01-2019.docx]	V1.0	14 January 2019
IRAS Application Form [IRAS_Form_13062019]		13 June 2019
IRAS Application Form XML file [IRAS_Form_13062019]		13 June 2019
IRAS Checklist XML [Checklist_13062019]		13 June 2019
Letter from funder [FundingLetterAlzheimer'sSociety_JemBhatt_232901_06-12-2016]		06 December 2016
Letters of invitation to participant [Letterofinvitation_254026_V1.0_14-01-2019.docx]	V2.0	30 July 2019
Other [CapacityToConsentForm_254026_V1.0_14-01-2019]	V1.0	14 January 2019
Other [ClinicalDementiaRatingScale_254026_V1.0_17-09-2018.pdf]	V1.0	17 September 2018
Other [ParticipantQuestionnaires_254026_V1.0_14-01-2019.docx]	V1.0	14 January 2019
Other [UCLRiskAssessmentSigned_254026_V1.0_12-06-2019.pdf]	V1.0	12 June 2019
Other [Screening Questionnaire_254026_V1.0_14-01-2019.docx]	V1.0	14 January 2019
Other [ConsentToContactForm_254026_V1.0_14-01-2019.docx]	V2.0	30 July 2019
Other [ParticipantDebriefDocument_254026_V1.0_14-01-2019]	V2.0	30 July 2019

Participant consent form [ConsentForm_254026_V1.1_07-05-2019.doc]	V1.1	07 May 2019
Participant information sheet (PIS) [ParticipantInformationBooklet_AdditionalInformation_254026_V1.1_14-01-2019.docx]	V2.0	30 July 2019
Participant information sheet (PIS) [ParticipantInformationBooklet_EssentialInformation_254026_V1.1_14-01-2019]	V2.0	30 July 2019
Referee's report or other scientific critique report [ResearchGrantPeerReview_232901_30-03-2018]		30 March 2018
Research protocol or project proposal [ResearchProtocol_V1.1_254026_14-01-2019_Final.docx]	V1.1	14 January 2019
Summary CV for Chief Investigator (CI) [ResearchCV_GeorginaCharlesworth.docx]		10 March 2018
Summary CV for student [ResearchCV_JemBhatt.pdf]		10 April 2018
Summary CV for supervisor (student research) [ ResearchCV_KatrinScior.pdf]		10 April 2018

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:  
<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

#### HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities— see details at:  
<https://www.hra.nhs.uk/planning-and-improving-research/learning/>

19/LO/1163	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely,



Mr. Tobias Davis  
Alternate Vice Chair

Email: nrescommittee.london-surreyborders@nhs.net



## Stigma and Disclosure Decision-Making in Dementia

*Enclosures:* "After ethical review – guidance for researchers"

*Copy to:* Mr Pushpsen Joshi

### 10.1.4 HRA Approval Letter



Dr Georgina Charlesworth  
Research Department of Clinical, Educational and  
Health Psychology  
1-19 Torrington Place  
London  
WC1E 7HB

28 August 2019

Dear Dr Charlesworth,

**HRA and Health and Care  
Research Wales (HCRW)  
Approval Letter**



Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)  
[HCRW.approvals@wales.nhs.uk](mailto:HCRW.approvals@wales.nhs.uk)

**Study title:** "Who to tell, how and when?" – A feasibility evaluation of an intervention to help support people living with dementia who are fearful of disclosing their diagnosis to others

**IRAS project ID:** 254026

**Protocol number:** 122232

**REC reference:** 19/LO/1163

**Sponsor:** University College London

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, [in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.](#)

**How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?**

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report

## Stigma and Disclosure Decision-Making in Dementia

(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

### **How should I work with participating non-NHS organisations?**

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

### **What are my notification responsibilities during the study?**

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

### **Who should I contact for further information?**

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **254026**. Please quote this on all correspondence.

Yours sincerely,

Emma Stoica  
Approvals Manager

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to: *Mr Pushpsen Joshi*

## Stigma and Disclosure Decision-Making in Dementia

### List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Advertisement_254026_V1.0_14-01-2019.docx]	V2.0	30 July 2019
Covering letter on headed paper [ResponsetoRevisions_IRAS254026_V1.0_11082019]	V1.0	11 August 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UCL Insurance Certificate_254026]		12 June 2019
GP/consultant information sheets or letters [GPNotificationLetter_254026_V1.0_14-01-2019.docx]	V1.0	14 January 2019
HRA Schedule of Events	HRA V1.0	23 July 2019
Interview schedules or topic guides for participants [InterviewGuide_254026_V1.0_14-01-2019.docx]	V1.0	14 January 2019
IRAS Application Form [IRAS_Form_13062019]		13 June 2019
Letter from funder [FundingLetterAlzheimer'sSociety_JemBhatt_232901_06-12-2016]		06 December 2016
Letters of invitation to participant [Letterofinvitation_254026_V1.0_14-01-2019.docx]	V2.0	30 July 2019
Organisation Information Document	1.0	25 July 2019
Other [ ConsentToContactForm_254026_V1.0_14-01-2019.docx]	V2.0	30 July 2019
Other [ParticipantDebriefDocument_254026_V1.0_14-01-2019]	V2.0	30 July 2019
Other [CapacityToConsentForm_254026_V1.0_14-01-2019]	V1.0	14 January 2019
Other [ ClinicalDementiaRatingScale_254026_V1.0_17-09-2018.pdf]	V1.0	17 September 2018
Other [ ParticipantQuestionnaires_254026_V1.0_14-01-2019.docx]	V1.0	14 January 2019
Other [UCLRiskAssessmentSigned_254026_V1.0_12-06-2019.pdf]	V1.0	12 June 2019
Other [ Screening Questionnaire_254026_V1.0_14-01-2019.docx]	V1.0	14 January 2019
Participant consent form [ConsentForm_254026_V1.1_07-05-2019.doc]	V1.1	07 May 2019
Participant information sheet (PIS) [ParticipantInformationBooklet_AdditionalInformation_254026_V1.1_14-01-2019.docx]	V2.0	30 July 2019
Participant information sheet (PIS) [ParticipantInformationBooklet_EssentialInformation_254026_V1.1_14-01-2019]	V2.0	30 July 2019
Referee's report or other scientific critique report [ResearchGrantPeerReview_232901_30-03-2018]		30 March 2018
Research protocol or project proposal [ResearchProtocol_V1.1_254026_14-01-2019_Final.docx]	V1.1	14 January 2019
Summary CV for Chief Investigator (CI) [ResearchCV_GeorginaCharlesworth.docx]		10 March 2018
Summary CV for student [ResearchCV_JemBhatt.pdf]		10 April 2018
Summary CV for supervisor (student research) [ ResearchCV_KatrinScior.pdf]		10 April 2018

## 10.2 Psychometrics Study Participant Materials

### 10.2.1 Participant Information Sheet for People living with Dementia and Carers

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Research Department of Clinical,  
Educational and Health Psychology  
UNIVERSITY COLLEGE LONDON



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Investigating the impact of stigma on people living with dementia and carers: A questionnaire study

#### PARTICIPANT INFORMATION SHEET

My Name is Jem Bhatt and I am a researcher from University College London. I would like to invite you to take part in this study.



You are being invited to take part in a research study as part of a PhD project sponsored by University College London. Please read the below information carefully and discuss it with others if you wish. Please ask us if you need more information. Thank you for reading this information sheet.

#### Why have I been chosen?

We are inviting those who have a primary diagnosis of dementia or are a carer of someone living with dementia and have the capacity to provide informed consent, to take part in this questionnaire study.

You will not be eligible to take part if you:

- Do not have the capacity to provide informed consent for the study
- Have any significant health problems that require care from others such as a chronic illness in which you are in the later stages
- Experience sensory impairments to the extent that you would not be able to participate or engage in answering the questionnaires of this study.

We are only able to invite participants who have the capacity to provide informed consent.

#### Who is running this study?

This study is being organised by Jem Bhatt, a PhD student at University College London who are sponsoring this research. The research has been funded by the Economic Social Research Council and Alzheimer's Society.

## Why is this study being done?

People often talk about the "stigma of dementia" but it is hard to pin down what this means. At the moment, there are no measures of stigma for people living with dementia or their carers. This study is designed to test whether "stigma questionnaires" are relevant to people living with dementia and their carers.

## Do I have to take part?

You do not have to take part. Participation is entirely voluntary. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. You can withdraw at any time without giving a reason and without it affecting any benefits that you are entitled to. If you decide to take part, but then change your mind, you will be asked what you wish to happen to any information that you have already provided up to that point. Up to 1<sup>st</sup> August 2019 you can choose to have all your information withdrawn from the study.

## What does this study involve?

We will ask you to complete a short questionnaire about you (e.g. age, ethnicity); you will only have to do this once. You will also be asked to complete a set of questionnaires (measuring negative attitudes and self-esteem), once at the beginning of the research following consent, and then again one week later. The questionnaires should take around 45 minutes to complete each time.

## How will taking part impact me?

We do not think that taking part will involve any disadvantages or specific risks that would cause you any harm. Some questions may carry the risk of emotional distress, as they are personal questions in relation to your dementia. The research team will make every effort to be supportive in the unlikely event that participation in this study causes you harm. It is also important to remember that participating is voluntary and you can change your mind at any time. We hope that you will find the study interesting.

## Where will this study take place?

If you agree to take part, a researcher will contact you to discuss how you would like to complete the questionnaires. This can be done face to face with a researcher or on an online form.

## What happens to my information?

All personal information about you during the study will be kept strictly confidential and destroyed at the end of the study. Data that we collect from you will be totally anonymised and be presented at conferences and published in scientific journals. We will follow the guidance from the General Data Protection Regulation (GDPR). You can ask for any data collected about you to be deleted at any time before the start of analysis.

## Data Protection Privacy Notice

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk). UCL's Data Protection can also be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

## Stigma and Disclosure Decision-Making in Dementia

Your personal data will be processed for the purposes outlined in this notice.

The legal basis that would be used to process your *personal data* will performance of a task in the public interest. The legal basis used to process *special category personal data* will be for scientific and historical research or statistical purposes/explicit consent.

*Your personal data will be processed so long as it is required for the research project.* We are able to anonymise the personal data you provide and will endeavour to minimise the processing of personal data wherever possible. All personal data will be destroyed following the completion of this study.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk). If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

### Who is organising and funding the research?

The study is being organised by Jem Bhatt; a PhD student at University College London (UCL) who are also sponsoring this research and is funded by Economic Social Research Council and Alzheimer's Society.

### Who has reviewed this study?

University College London Research Ethics Committee (UCL REC)

### Whom can I contact for further information?

Jem Bhatt - Research Department of Clinical Educational and Health Psychology  
1-19 Torrington Place, London WC1E 7HB  
Email: [jemini.bhatt.15@ucl.ac.uk](mailto:jemini.bhatt.15@ucl.ac.uk)  
Telephone: 020 7679 8275

### If you have any concerns or complaints about anything to do with this study, please contact:

Academic Supervisor: Dr Georgina Charlesworth ClinPsyD PhD CPsychol  
Senior Lecturer  
Research Department of Clinical Educational and Health Psychology  
1-19 Torrington Place, London WC1E 7HB  
Email: [g.charlesworth@ucl.ac.uk](mailto:g.charlesworth@ucl.ac.uk)

**10.2.2 Consent Form for People living with Dementia and Carers**

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Educational and Health Psychology  
UNIVERSITY COLLEGE LONDON



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**CONSENT FORM**

Please complete this form after you have read the information sheet and/or listened to an explanation about the research

**Title of Study:** Investigating the impact of stigma on people living with dementia and carers: A questionnaire study

**Department:** Research Department of Clinical Educational and Health Psychology, University College London

**Name and Contact Details of the Researcher:** Jem Bhatt  
1-19 Torrington Place, London WC1E 7HB  
Email: jemini.bhatt.15@ucl.ac.uk

**Name and Contact Details of the Principal Researcher:** Dr Georgina Charlesworth  
ClinPsyD PhD CPsychol  
1-19 Torrington Place, London WC1E 7HB  
Email: g.charlesworth@ucl.ac.uk

**Name and Contact Details of the UCL Data Protection Officer:** Lee Shailer  
Email: l.shailer@ucl.ac.uk

This study has been approved by the UCL Research Ethics Committee:  
Project ID number: 11501002

**Summary of Study:**

This study is designed to test whether "stigma questionnaires" are relevant to people living with dementia and carers. It is important to note that you are only eligible for this study if you have a primary diagnosis of dementia or are a carer of someone living with dementia and have the capacity to provide informed consent.

We will ask you to complete a short questionnaire about you (e.g. age, ethnicity); you will only have to do this once. You will also be asked to complete a set of questionnaires (measuring negative attitudes and self-esteem), once at



## Stigma and Disclosure Decision-Making in Dementia

the beginning of the research following consent, and then again one week later. The questionnaires should take around 45 minutes to complete each time. It is important to note that participation is voluntary and you are free to withdraw from the study at any time without this causing any negative consequences for you.

Thank you for considering taking part in this research. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Please complete this form after you have read the information sheet and/or listened to an explanation about the research

I confirm that I understand that by initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Initial Box
1.	I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction and would like to take part in this questionnaire study	
2.	I understand that I will be able to withdraw my data up to 01/08/2019	
3.	I consent to the processing of my personal information (gender, age, type of dementia, length of time since diagnosis, ethnicity, marital status, living situation, education level, employment status and first language) for the purposes explained to me. I understand that such information will be handled in accordance with all applicable data protection legislation.	
4.	I understand that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.	
5.	I understand that my personal or anonymized information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	

## Stigma and Disclosure Decision-Making in Dementia

6.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. I understand that if I decide to withdraw, any identifiable data I have provided up to that point will be deleted unless I agree otherwise.	
7.	I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	
8.	I understand the direct/indirect benefits of participating.	
9.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
10.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	
11.	I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.	
12.	a) I hereby confirm that I understand the exclusion criteria as detailed in the Information Sheet and explained to me by the researcher; and b) I do not fall under the exclusion criteria.	
13.	I am aware of who I should contact if I wish to lodge a complaint.	
14.	I voluntarily agree to take part in this study.	
15.	I would be happy for the anonymised data I provide to be archived at UCL for 10 years following the completion of this study.	

**TO BE COMPLETED BY THE PARTICIPANT**

Name of participant: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**TO BE COMPLETED BY THE RESEARCHER:**

Name of researcher: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

### 10.2.3 Debrief Form for People living with dementia and Carers

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UNIVERSITY COLLEGE LONDON



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#### PARTICIPANT DEBRIEF

**Investigating the stigma experience of people living with dementia: a questionnaire study**

Thank you for completing this study.

All information collected about you from this study will be kept strictly confidential. Any personal details are kept separate from all other information to ensure that no-one outside of the research team will be able to identify you personally from these records. All identifiable data about you will be destroyed following the completion of this study.

If you have any questions please contact:

**PhD Student (study organiser): Jem Bhatt**  
Research Department of Clinical Educational and Health Psychology  
1-19 Torrington Place, London WC1E 7HB  
Email: [jemini.bhatt.15@ucl.ac.uk](mailto:jemini.bhatt.15@ucl.ac.uk)

**Academic Supervisor: Dr Georgina Charlesworth ClinPsyD PhD CPsychol**  
Senior Lecturer  
Research Department of Clinical Educational and Health Psychology  
1-19 Torrington Place, London WC1E 7HB  
Email: [g.charlesworth@ucl.ac.uk](mailto:g.charlesworth@ucl.ac.uk)

Where can I find out about the results of the study?

Please visit the University College London Unit for Stigma research (UCLUS) website page to be kept up to date about the results of this study

Website: [www.ucl.ac.uk/stigma-research](http://www.ucl.ac.uk/stigma-research)

Where to find support?

Below are a list of organisations that provide support for people living with dementia and their supporters:

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## Stigma and Disclosure Decision-Making in Dementia

Alzheimer's Society (local services and information provision)	Email: <a href="mailto:enquiries@alzheimers.org.uk">enquiries@alzheimers.org.uk</a> Telephone: 0300 222 11 22 Website: <a href="http://www.alzheimers.org.uk">www.alzheimers.org.uk</a>
Pathways Through Dementia (legal support and information provision)	Email: <a href="mailto:swilcox@pathwaysthroughdementia.org">swilcox@pathwaysthroughdementia.org</a> Telephone: 0203 405 5940 Website: <a href="http://www.pathwaysthroughdementia.org">www.pathwaysthroughdementia.org</a>
AgeUK (local services and information provision)	Email: <a href="mailto:contact@ageuk.org.uk">contact@ageuk.org.uk</a> Telephone: 0800 055 6112 Website: <a href="http://www.ageuk.org.uk">www.ageuk.org.uk</a>
CarePlace (care and community services, information and guidance)	Telephone (The Silver Line): 0800 4 70 80 90 Website: <a href="http://www.careplace.org.uk">www.careplace.org.uk</a>

**10.2.4 Demographics Questionnaire for People with Dementia**

Participant Number:

T:

The purpose of the short questionnaire is to get baseline information about you. The answers you give are completely confidential and will not be shared with anyone outside the research team. All data will be kept anonymously. All personally identifiable data collected about you will be destroyed at the end of this study.

Please try and answer all questions to the best of your ability. You do not have to answer anything you do not wish to.

Question	Answer Categories (please circle, unless text is necessary)		
1. Please select your gender	Male	Female	Other
2. How old are you?	___ ___ Years Old		
3. How long have you had a diagnosis of dementia? An approximate time is fine	_____ Months _____ Years		
4. Please specify what type of dementia you have been diagnosed with, if known?			
5. Choose one option that best describes your ethnic group or background	White Mixed/Multiple Ethnic groups Asian/Asian British Black/African/Caribbean/Black British Other Ethnic Group		
6. Do you live alone?	Yes	No	
7. What is your current employment status	Employed (Self/part time/ full time)	Retired	Other
8. Do you have normal or correct vision?	Yes	No	
9. Is English your first language?	Yes	No	

*10.2.5 Stigma Stress Scale*

	Strongly disagree	Disagree	Somewhat disagree	Neither agree or disagree	Somewhat agree	Agree	Strongly agree
Stigma against people living with dementia will have a negative impact on my future							
Stigma against people living with dementia will have harmful or bad consequences for me							
Stigma against people living with dementia will affect many areas of my life.							
Stigma against people living with dementia will have a severe impact on my life.							

Stigma is defined as negative attitudes people may hold towards a person. Please read through the following statements and rate each statement using the scale below.

	Strongly disagree	Disagree	Somewhat disagree	Neither agree or disagree	Somewhat agree	Agree	Strongly agree
I am prepared to deal with stigma against people living with dementia.							
I have the resources I need to handle problems posed by stigma against people living with dementia.							
I will do the best I can to deal with stigma against people living with dementia.							
I am able to rise up and meet the challenges posed by stigma against people living with dementia.							

*10.2.6 Disclosure Related Distress Scale*

Please answer the below questions by circling the answer that suits you the best.

1. In general, how comfortable would you feel talking to a friend about dementia, for example, telling them you have a dementia diagnosis and how it affects you?

Not at all	A little	Somewhat	Moderately	Considerably	A great deal	Very much
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2. In general, how comfortable would you feel talking to a family member about dementia, for example, telling them you have a dementia diagnosis and how it affects you?

Not at all	A little	Somewhat	Moderately	Considerably	A great deal	Very much
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*10.2.7 Stigma Impact Scale*

	Not Applicable	Strongly Disagree	Disagree	Agree	Agree Strongly
My employer/co-workers have discriminated against me.					
Some people act as though I am less competent than usual.					
I feel I have been treated with less respect than usual by others.					
I feel set apart from others who are well.					
I feel others are concerned they could "catch" my impairment through contact like a handshake or eating food I prepare.					
I feel others avoid me because of my impairment					
Some family members have rejected me because of my impairment					
I feel others think I am to blame for my impairment.					
I do not feel I can be open with others about my impairment.					
I fear someone telling others about my impairment without my permission.					

	Not Applicable	Strongly Disagree	Disagree	Agree	Agree Strongly
I feel a need to keep my impairment a secret.					
I feel some friends have rejected me because of my impairment.					
I have a greater need than usual for reassurance that others care about me					
I feel lonely more often than usual.					
Due to my impairment I have a sense of being unequal in my relationship with others.					
I feel I am at least partially to blame for my impairment.					
I feel less competent than I did before my impairment.					
I encounter embarrassing situations as a result of my impairment.					
Due to my impairment others seem to feel awkward and tense when they are around me.					
Due to my impairment I sometimes feel useless.					
Changes in my appearance have affected my social life.					

**10.2.8 Rosenberg Self-Esteem Scale**

Please record the appropriate answer for each item.

	Strongly disagree	Disagree	Agree	Strongly agree
On the whole, I am satisfied with myself.				
At times I think I am no good at all.				
I feel that I have a number of good qualities.				
I am able to do things as well as most other people.				
I feel I do not have much to be proud of.				
I certainly feel useless at times.				
I feel that I'm a person of worth.				
I wish I could have more respect for myself.				
All in all, I am inclined to think that I am a failure.				
I take a positive attitude toward myself.				

**10.2.9 Secrecy Scale**

For each question, please mark whether you strongly disagree (1), disagree (2), agree (3), or strongly agree (4).

	Strongly disagree 1	Disagree 2	Agree 3	Strongly agree 4
If you had a close relative who had dementia, you would advise him or her not to tell anyone about it.				
If you were in treatment for dementia you would worry about certain people finding out about your treatment.				
If you have ever been treated for dementia the best thing to do is to keep it a secret.				
There is no reason for a person to hide the fact they have dementia.				
In view of society's negative attitudes towards people living with dementia, you would advise people with dementia to keep it a secret.				
You encourage other members of your family to keep your dementia a secret.				
When you meet people for the first time, you make a special effort to keep the fact that you have dementia a secret.				

**10.2.10 Demographics Questionnaires for Carers**

The purpose of the short questionnaire is to get baseline information about you. The answers you give are completely confidential and will not be shared with anyone outside the research team. All data will be kept anonymously. All personally identifiable data collected about you will be destroyed at the end of this study.

Please try and answer all questions to the best of your ability. You do not have to answer anything you do not wish to.

Question	Answer Categories (please circle, unless text is necessary)		
1. Please select your gender	Male	Female	Other
2. How old are you?	___ ___ Years Old		
3. How old is the <u>person you are a carer for</u> in years?	___ ___ Years Old		
4. Approximately how long has the <u>person you are a carer for</u> had a diagnosis of dementia?	_____ Months _____ Years		
5. What type of dementia does the <u>person you are a carer for</u> have?			
6. Please complete this sentence. The person living with dementia that I am a carer for is my...	Spouse Parent/Parent in Law Other (optional please specify: _____)		
7. Choose one option that best describes your ethnic group or background	White Mixed/Multiple Ethnic groups Asian/Asian British Black/African/Caribbean/Black British Other Ethnic Group		
8. Do you live alone?	Yes	No	

9. What is your current employment status	Employed (Self/part time/ full time)	Retired	Other
10. Do you have normal or correct vision?	Yes	No	
11. Is English your first language?	Yes	No	

**10.2.11 Family Stigma Instrument**

**Family Stigma Instrument**

To what extent do you agree that some people might respond in the following ways towards a family member of someone living with dementia? (Note: here we are not necessarily asking about your personal experiences but rather what you may have seen or heard regarding how some people respond to the family members of people living with dementia). The questions are framed as such: Some people might..., where "them" or "their" refers to the family of someone living with dementia

(A1) Some people might...

	Strongly Disagree	Somewhat Disagree	Neither agree nor disagree	Somewhat Agree	Strongly Agree
1) ...feel embarrassed about associating with them.					
2) ...feel uncomfortable about going to their house.					
3) Treat them more negatively.					
4) ...think that the family has done something wrong because of them.					
5) ...behave negatively towards them when they are with the person living with dementia in public					
6) ...avoid making friends with them.					
7) ...not want to hear about any of their problems					
8) ...not invite the family to social events					

## Stigma and Disclosure Decision-Making in Dementia

To what extent do you agree that caring for your family member living with dementia has changed you in the following aspects?

(A2) Caring for my family member living with dementia has...

	Strongly Disagree	Somewhat Disagree	Neither agree nor disagree	Somewhat Agree	Strongly Agree
9) ...enabled me to develop a more positive attitude toward life.					
10) ...made me feel needed.					
11) ...strengthened my spirituality and faith					
12) ...allowed me to form friendships with others in a similar situation					
13) ...made me feel that I make a positive contribution to society.					
14) ...strengthened some of my relationships with family/friends.					

## Stigma and Disclosure Decision-Making in Dementia

To what extent do you experience the following responses towards your family member with Dementia? The questions are framed as such: I feel/am/avoid..., where "them" or "their" refers to your family member living with dementia

(A3) I feel...

	Strongly Disagree	Somewhat Disagree	Neither agree nor disagree	Somewhat Agree	Strongly Agree
15) ...embarrassed about them (my family member living with dementia)					
16) ...distressed about being associated with them.					
17) ...guilty about having them in the family.					
18) ...uncomfortable when I have friends about because of them					

(A4) I am...

	Strongly Disagree	Somewhat Disagree	Neither agree nor disagree	Somewhat Agree	Strongly Agree
19) ...treated differently by some people when I am with them.					
20) ...excluded from activities when other people find out about their dementia					
21) ...aware of how some people look at me when I am out with them.					



## Stigma and Disclosure Decision-Making in Dementia

22) ...treated differently by some people because of them					
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(A5) I avoid...

	Strongly Disagree	Somewhat Disagree	Neither agree nor disagree	Somewhat Agree	Strongly Agree
23) ...introducing my friends to them (my family member living with dementia)					
24) ...telling people that I am related to them.					
25) ... making new friends because of them					
26) ... being seen with them					

## 10.3 Qualitative Study Documentation

### 10.3.1 Participant Information Sheet

Research Department of Clinical,  
Educational and Health Psychology  
UNIVERSITY COLLEGE LONDON



#### PARTICIPANT INFORMATION SHEET for

The experience of attending a "talking about diagnosis" group for people living with mild dementia: a qualitative interview study

UCL Research Ethics Committee Approval ID number: 14001\_001

#### We are the research team



Tamatha Ruffell;  
Researcher



Jem Bhatt;  
Researcher



Dr Georgina Charlesworth;  
Principal Researcher and  
Project Supervisor



Dr Katrina Scior;  
Project Supervisor



from the Research Department of Clinical, Educational and Health Psychology  
University College London (UCL)

We would like to invite you to take part in our study

Please continue reading for more information

## YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

**Title of Study:** The experience of attending a "talking about diagnosis" group for people living with mild dementia: a qualitative interview study

**Department:** Research Department of Clinical, Educational and Health Psychology  
University College London (UCL)

**Name and Contact Details of the Researchers:** Tamatha Ruffell  
([tamatha.ruffell.16@ucl.ac.uk](mailto:tamatha.ruffell.16@ucl.ac.uk)), Jem Bhatt ([jemini.bhatt.15@ucl.ac.uk](mailto:jemini.bhatt.15@ucl.ac.uk)), Dr Georgina Charlesworth ([g.charlesworth@ucl.ac.uk](mailto:g.charlesworth@ucl.ac.uk)), and Dr Katrina Scior ([k.scior@ucl.ac.uk](mailto:k.scior@ucl.ac.uk)), Research Department of Clinical Educational and Health Psychology, University College London, 1-19 Torrington Place, London, WC1E 7HB. Telephone: 020 7679 1897

**Name and Contact Details of the Principal Researcher:** Dr Georgina Charlesworth ([g.charlesworth@ucl.ac.uk](mailto:g.charlesworth@ucl.ac.uk)) Research Department of Clinical Education and Health Psychology, University College London, 1-19 Torrington Place, London, WC1E 7HB. Telephone: 020 7679 1897

### **Invitation to participate in a research study**

You are being invited to take part in a "one off" interview as part of an evaluation of the "Who to tell, how and when?" groups for people living with dementia. Before you decide to take part, it is important you understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Thank you for reading this information sheet.

### **What is the aim of the study**

The aim of this study is to explore and understand the views and experiences of participants who have been invited to attend a "Who to tell, how and when?" group for people living with dementia. This will be done through a "one-off" audio-recorded interview with a University researcher where participants will be asked questions that explore how acceptable they found the group and whether it was felt to have had an impact on their lives.

### **Why have I been invited?**

We are inviting everybody who was invited to take part in the "Who to tell, how and when?" groups. We hope to interview 20 people.

**You will not be eligible to take part if you do not have the capacity to provide informed consent for the study, have any significant mental or physical health problems that require care from others or experience sensory impairments to the extent that you would not be able to participate or engage in the interview.**

### **Do I have to take part?**

You do not have to take part. Participation is entirely voluntary. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. You can withdraw at any time without giving a reason and without it affecting any benefits that you are entitled to. If you decide to take part, but then change your mind, you will be asked what you wish to happen to any information that you have already provided up to that point. Up to 31<sup>st</sup> March 2019 you can choose to have all your information withdrawn from the study.

### **What does taking part involve?**

- Reading this information sheet.
  
- Signing a consent form. A signed copy will be given to you to keep for your records. You will also be given a participant identification number so that your participation in the study is anonymous.
  
- Answering some questions about you; name, address, age, gender, type of dementia and length of time since diagnosis, if applicable, ethnicity, marital status, living situation, education level, employment status and first language.
  
- Taking part in an audio-recorded interview with a University researcher. This can take place either in your home or at your local Alzheimer's Society, Age Concern or Tapestry office where the groups have been held, dependent on your choice. During this interview you will be asked questions about your experience of the group, or your reasons for not wanting to take part. You will also be asked about your views of telling others about your diagnosis. The interview will take approximately 30 to 60 minutes. If you start to feel tired, you can choose to stop and continue on another day.

Those who attend the interview will be reimbursed with a £7.50 shopping voucher for their time.

### **How will the recording be used?**

The audio recording of the interview made during this research will be used only for analysis and for illustration in conference presentations and lectures. No other use will be made of it without your written permission, and no one outside the project will be allowed access to the original recordings.

### **What are the possible disadvantages of taking part?**

We do not think that taking part will involve any disadvantages. Some questions are about your dementia experience, and you might feel upset about this. The research team will make every effort to be supportive and signpost you to sources of support where needed. It is also important to remember that participation is voluntary and you can change your mind at any time.

### **What are the possible benefits of taking part?**

We hope that you will find taking part in the study interesting and enjoy talking to the researcher during the interview. Participating in this research will deliver wider benefits to others living with dementia. It is hoped that this work will determine the helpfulness of the "Who to tell, how and when?" groups for people living with dementia.

### **What if something goes wrong?**

If you are unhappy or dissatisfied with any aspect of your participation or if you wish to make a complaint you should contact either Tamatha Ruffell (researcher), or Dr Georgina Charlesworth, (project supervisor) and we will do our best to address your concerns and

find a solution. If you feel your complaint has not been handled to your satisfaction then you can contact the Chair of the UCL Research Ethics Committee – [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk).

### **Will my taking part in this study be kept confidential?**

All information collected about you during the course of the study will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications. Any personal details will be kept separate from the information recorded about you during the course of the study to ensure that no-one outside of the research team will be able to identify you personally from these records.

### **Limits to confidentiality**

The only situation in which we might need to share information about you with other professionals would be if the researchers observe or hear anything that causes very serious concern about your health, safety or wellbeing. This could include possible risk to yourself, risk to others, criminal behaviour or professional misconduct. If this happens the researchers have a duty of care to report to the relevant authorities possible harm or danger to participants or others. We would make every effort to explain to you why we need to share this information before doing so.

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

Personal data will be stored at UCL in a locked cupboard in a locked room. The audio recording from the interview will be stored on an encrypted memory stick for transport back to UCL and transferred to the UCL network after which time the recording will be deleted from the memory stick. After transcription the anonymised recording will be destroyed. You can ask for your information to be withdrawn and destroyed at any time up to 31<sup>st</sup> March 2019.

The findings from this study will be presented within a doctoral thesis and used to inform the further development of the "Who to tell, how and when?" groups. Information about the development of "Who to tell, how and when?" will be presented at conferences and published in peer reviewed journals. Findings will also be summarised in an article for an Alzheimer's Society newsletter, within a blog on the UCLUS website and distributed to the Alzheimer's Society staff / branches and / or other voluntary sector organisations, where the 'Who to tell, how and when?' groups took place.

### Data Protection Privacy Notice

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk). UCL's Data Protection Officer can also be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

Further information on how UCL uses participant information can be found here:

[www.ucl.ac.uk/lego-services/privacy/participants-health-and-care-research-privacy-notice](http://www.ucl.ac.uk/lego-services/privacy/participants-health-and-care-research-privacy-notice)

Your personal data will be used for the purposes outlined in this notice. The category of personal data used will be as follows: name, address, age, gender, type of dementia and length of time since diagnosis, if applicable, ethnicity, marital status, living situation, education level, employment status and first language.

The legal basis that would be used to process your personal data will be performance of a task in the public interest. The legal basis used to process special category personal data will be for scientific and historical research or statistical purposes/explicit consent.

Your personal data will be processed and the anonymised recordings will be stored electronically in data archives provided by University College London for 10 years. If we are



able to anonymise or pseudonymise the personal data you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible.

You have certain rights under data protection legislation in relation to the personal information that we hold about you. These rights apply only in particular circumstances and are subject to certain exemptions such as public interest (for example the prevention of crime). They include:

- The right to access your personal information
- The right to rectification of your personal information
- The right to erasure of your personal data
- The right to restrict or object to the processing of your personal data
- The right to object to the use of your data for direct marketing purposes
- The right to data portability
- Where the justification for processing is based on your consent, the right to withdraw such consent at anytime and
- The right to complain to the Information Commissioner's Office (ICO) about the use of your personal data.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact Spencer Crouch at UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk). If you remain unsatisfied, you may wish to contact the ICO. Contact details and further details of data subject rights are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

### Who is organising the research?

The study is being organised by Tamatha Ruffell, a trainee Clinical Psychologist, Jem Bhatt, a PhD student, Dr Georgina Charlesworth and Dr Katrina Scior, Senior Lecturers, from

## Stigma and Disclosure Decision-Making in Dementia

University College London (UCL). UCL is sponsoring this study. It is funded by Economic Social Research Council and Alzheimer's Society.

**Who can I contact for further information or if I have any concerns or complaints about this study?**

Tamatha Ruffell

Research Department of Clinical Educational and Health Psychology, University College London

1-19 Torrington Place

London

WC1E 7HB

Email: [tamatha.ruffell.16@ucl.ac.uk](mailto:tamatha.ruffell.16@ucl.ac.uk)

**Who can I contact if I have any concerns or complaints about this study?**

Dr Georgina Charlesworth, Research Department of Clinical Educational and Health Psychology, University College London, University College London

1-19 Torrington Place

London

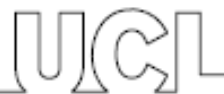
WC1E 7HB

Email: [g.charlesworth@ucl.ac.uk](mailto:g.charlesworth@ucl.ac.uk)

**Thank you for reading this information sheet and for considering taking part in this research study.**

### 10.3.2 Consent Form

Research Department of Clinical,  
Educational and Health Psychology  
UNIVERSITY COLLEGE LONDON



---

**CONSENT FORM for**

**The experience of attending a “talking about diagnosis” group for people living with mild dementia: a qualitative interview study**

UCL Research Ethics Committee Approval ID number: 14001\_001

**Title of Study:** The experience of attending a “talking about diagnosis” group for people with mild dementia: a qualitative interview study

**Study summary:** This study is evaluating the “Who to tell, how and when?” groups for people living with dementia. You are being invited to take part in a one-off interview because you were invited to take part in these groups. The interview will take approximately 30 to 60 minutes and can take place either in your home or at your local Alzheimer’s Society, Age Concern or Tapestry office where the groups have been held, dependent on your choice. During this interview you will be asked questions about your experience of the group, or your reasons for not wanting to take part. You will also be asked about your views of telling others about your diagnosis. It is important to note that participation is voluntary and you are free to withdraw from the study at any time without this causing any negative consequences for you.

**Department:** Research Department of Clinical, Educational and Health Psychology  
University College London (UCL)

**Name and Contact Details of the Researchers:** Tamatha Ruffell (tamatha.ruffell.16@ucl.ac.uk), Jem Bhatt (jemini.bhatt.15@ucl.ac.uk), Dr Georgina Charlesworth ([g.charlesworth@ucl.ac.uk](mailto:g.charlesworth@ucl.ac.uk)), and Dr Katrina Scior (k.scior@ucl.ac.uk), Research Department of Clinical Educational and Health Psychology, University College London, 1-19 Torrington Place, London, WC1E 7HB. Telephone: 020 7679 1897

## Stigma and Disclosure Decision-Making in Dementia

Name and Contact Details of the Principal Researcher: Dr Georgina Charlesworth  
([g.charlesworth@ucl.ac.uk](mailto:g.charlesworth@ucl.ac.uk)) Research Department of Clinical Education and Health  
Psychology, University College London, 1-19 Torrington Place, London, WC1E 7HB.  
Telephone: 020 7679 1897

This study has been approved by the UCL Research Ethics Committee: Project ID number:

Thank you for considering taking part in this research. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by initialling each box below I am consenting to this element of the study. I understand that it will be assumed that un-initialled boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

Please initial box

1. I confirm that I have read the information sheet dated \_\_ / \_\_ / \_\_\_\_ for the above study. I have had the opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions and have had these answered satisfactorily and would like to take part in:

an audio-recorded interview that will take place after being invited to or attending a "talking about diagnosis" group

2. I understand that I will be able to withdraw my data up to the 31<sup>st</sup> March 2019

3. I consent to the processing of my personal information (name, address, gender, age, type of dementia and length of time since diagnosis if applicable, ethnicity, marital status, living situation, education level, employment status and first language) for the purposes explained to me. I understand that such

information will be handled in accordance with all applicable data protection legislation

4. Use of the information for this project

- a. I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified. I understand that confidentiality may be limited and conditional given that you have a duty of care to report to the relevant authorities possible harm/danger to participants or others.
- b. I understand that the interview recording will be stored anonymously and securely. It will not be possible to identify me in any publications.
- 5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason without the care I receive or my legal rights being affected. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.
- 6. I understand that the interview will include discussion of my dementia diagnosis, and that discussing issues about dementia might be upsetting.
- 7. I understand the direct and indirect benefits of participating.
- 8. I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researchers undertaking this study
- 9. I understand that I will not benefit financially from any possible outcome of this study that may result in the future
- 10. I understand that I will be compensated for the portion of time spent in the study if I choose to withdraw
- 11. I understand that the anonymised information I have submitted will be presented within a doctoral thesis and used to inform further "Who to tell, how and when?" groups. Information about the development of "Who to tell, how and when?" will be presented at conferences and published in peer reviewed journals. Findings will also be summarised in an article for an Alzheimer's Society newsletter, within a blog on the UCLUS website and distributed to the Alzheimer's Society staff and branches, and/or other voluntary sector organisations, where the "Who to tell, how and when?" groups took place.

## Stigma and Disclosure Decision-Making in Dementia

12. I consent to my interview being audio recorded and understand that the recordings will be destroyed immediately following transcription.
13. I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher i.e. an invitation to the "Who to tell, how and when?" groups.
14. I hereby confirm that
- a. I understand the exclusion criteria as detailed in the Information Sheet under "Why I have been invited to take part?" where it talks about why you would not be eligible to take part in the study and explained to me by the researcher
  - b. I do not fall under the exclusion criteria
15. I am aware of who I should contact if I wish to lodge a complaint
16. Use of information for this project and beyond
- a. I would be happy for the data I provide to be archived at UCL for 10 years
  - b. I understand that other authenticated researchers (Jem Bhatt, Dr Georgina Charlesworth and Dr Katrina Scior) will have access to my anonymised data
17. I voluntarily agree to take part in this study

### TO BE COMPLETED BY THE PARTICIPANT:

Name of participant: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

### TO BE COMPLETED BY THE RESEARCHER:

Researcher's Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

10.3.3 Interview Schedule

Research Department of Clinical,  
Educational and Health Psychology

UNIVERSITY COLLEGE LONDON



The experience of attending a “talking about diagnosis” group for people living with mild dementia: a qualitative interview study

UCL Research Ethics Committee Approval ID number: 14001\_001

Interview Guide

Below is the interview guide that outlines the domains to be covered.

*Subject Question(s) for participant*

<i>General</i>	How are you? Complete demographics questionnaire
<i>Decision Making</i>	What was it like making decisions about who to tell, how and when about your diagnosis {before/after this programme}? How do you feel about making decisions to disclose your diagnosis? How conflicted are you about disclosing your diagnosis?
<i>Stigma/Fear/Distress</i>	How have the sessions made a difference to your thoughts, feelings and behaviours? How do you feel about telling others about your diagnosis? [fear/distress] What is your attitude towards your dementia diagnosis? Have your attitudes towards your diagnosis changed? [stigma]
<i>Self-Identification</i>	What does being diagnosed with dementia mean to you? Do you identify with your diagnosis?
<i>Programme</i>	Overall how did you find the programme? What aspects did you like/dislike? What sticks in your mind about them? Do you have any suggestions for how the sessions could be changed (materials, session content)? Would you recommend this programme to someone else living with dementia/friends and family?

## 10.4 Online Stakeholder Consultation Survey

### A public consultation: who to tell, how and when?

We want to create a programme to help support people with dementia in talking to others about their diagnosis.

By participating in this consultation, you guide the direction of our research. The survey will take 5-15 minutes to complete.

We want this survey to gather your thoughts and views. Only answer questions if you want to. If you would like to stop at any point just close the browser. This survey is anonymous.

If you have any questions about this public consultation or study please feel free to contact: Jem Bhatt Research Department of Clinical, Educational and Health Psychology University College London  
Direct Telephone: 020 7679 8275. Email: jemini.bhatt.15@ucl.ac.uk

- I have read the above information and wish to continue
- I do not wish to continue

*Skip To: End of Survey If = I do not wish to continue*



## Stigma and Disclosure Decision-Making in Dementia

1. Which of the below best describes you:  
(you can select more than one if you wish)

- Person living with dementia
  - Health/Social care worker
  - Carer/Relative of a person living with dementia
  - Member of the public
  - Other (please specify)
- 

2. What do you think may stop people from telling others that they have dementia? You can select more than one

- Worry that others will view them differently (example, less able)
- Shame
- Unsure of what to say or what language to use
- Not wanting to use the word "dementia"
- Not knowing who to tell
- Scared of what might be ahead
- Talking about it makes it more real
- Not accepting or denying the diagnosis
- Worry about losing relationships
- Worry that others may avoid or exclude them
- Not wanting to burden or upset others

Carer or family not wanting them to tell others

Other (please specify)

---

3. Nowadays most people are directly told by their doctors that they have dementia. Currently, there is no advice given to people on how they can tell others about their dementia.

Do you think people who are newly diagnosed with dementia, and unsure whether or how to talk to others about their diagnosis, might benefit from support with this?

Yes

Not Sure

No

Other (please specify)

---

4. We want to create a programme to support individuals newly diagnosed with dementia to talk about their diagnosis should they wish to. This will be the first programme of its kind in dementia care. We are planning to adapt an existing programme that was developed to support people with other 'difficult to discuss' diagnoses. The programme was originally delivered

over 3 weekly sessions lasting 1h30mins each. The existing programme has the below topics:

Contents

**Who am I going to tell about my diagnosis?**

*What are hurtful and helpful attitudes towards my diagnosis?*

*What does my diagnosis mean to me?*

*What problems will I face telling others and how can they hurt me?*

*What are the pros and cons of telling others and should I tell them or not?*

**How and when to tell others**

*What are the different ways to tell others and what are the pros and cons of these ways?*

*Who do I select to tell?*

*What language do I use?*

*How will others respond to me and how will this make me feel?*

**My own story**

*Combining everything I have learnt so far.*

*Deciding whether telling others is right for me.*

Do you think the above programme is suited to people with dementia?

- Yes - this programme seems suited for people living with dementia as it is
- No - the programme needs adaptation to be more dementia specific
- Other (please specify)

---

You have answered "no", please use this box to explain why this programme is not suited to people with dementia

---

5. Do you have any suggestions about what this programme should be called?

---

6. What do you think is the best way of delivering this programme? (you may select multiple answers)

Face to face with a trained facilitator

Guided self-help (e.g. individuals complete a workbook with regular contact from trained facilitators)

Other (please specify)

---

7. From the below which face-to-face method would be best?

*Please use the text boxes beside each answer if you have further comments*

Small group of people with dementia and a trained programme facilitator \_\_\_\_\_

One to one with a person living with dementia and a trained program facilitator \_\_\_\_\_

Person living with dementia, a supporter of their choice (e.g. family member, friend) and a trained programme leader \_\_\_\_\_

Other (please specify)

---

---

If this programme is delivered in small groups of people with dementia, how long should it last?

- 3 weekly sessions lasting 1-1h30mins each
  - One whole day with breaks and lunch
  - Other (please specify)
- 

If this programme is delivered one to one, how long should it last?

- 3 weekly sessions lasting 1-1h30mins each
  - One whole day with breaks and lunch
  - Other (please specify)
- 

8. From the below what is your most preferred "guided self-help" method of delivering this programme?

*Please use the text boxes beside each answer if you have further comments*

A printed workbook

---

An online workbook

---

Other (please specify)

---

---

Do you think the printed workbook should be completed alongside regular telephone or email contact with a trained facilitator?

- Yes
- No

---

Do you think the online workbook should be completed alongside regular telephone or email contact with a trained facilitator?

- Yes
- No

9. What do you think would help people with dementia take part in this programme? (you may select multiple answers)

- Previous knowledge about dementia
  - Support from their family or friends
  - Trained facilitator with personal experience of dementia
  - More information to help them decide if it is for them
  - Group delivery to take place outside clinical settings (e.g. community centre)
  - Built-in involvement of primary supporter
  - Other (please specify)
-

10. What do you think would stop people with dementia taking part in this programme? (you may select multiple answers)

- Not knowing enough about dementia
  - Embarrassment
  - Wanting to "keep it in the family"
  - Not wanting "outside help"
  - Fear of diagnosis
  - Wanting to keep the diagnosis to themselves
  - May have other ways of deciding who to tell, how and when
  - Not knowing the programme exists
  - Worrying about travelling (if it is a group programme)
  - Not wanting to be in a group with other people who have dementia
  - Other (please specify)
- 

11. Would you like to hear more about developing this programme?

- Yes
- No

*Skip To: End of Survey If = No*

---

## Stigma and Disclosure Decision-Making in Dementia

Thank you for your interest in developing this programme.  
Please contact Jem Bhatt for more information.

**Direct Telephone:** 020 7679 8275 **Email:** jemini.bhatt.15@ucl.ac.uk

**Postal Address:**

Jem Bhatt Research Department of Clinical, Educational and Health  
Psychology, University College London 4th Floor, 1-19 Torrington  
Place, WC1E 7HB

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Thank you for completing the questionnaire. If you have any further  
comments please write them in the space provided below

---



## 10.5 The “Who to tell, how and when?” Intervention

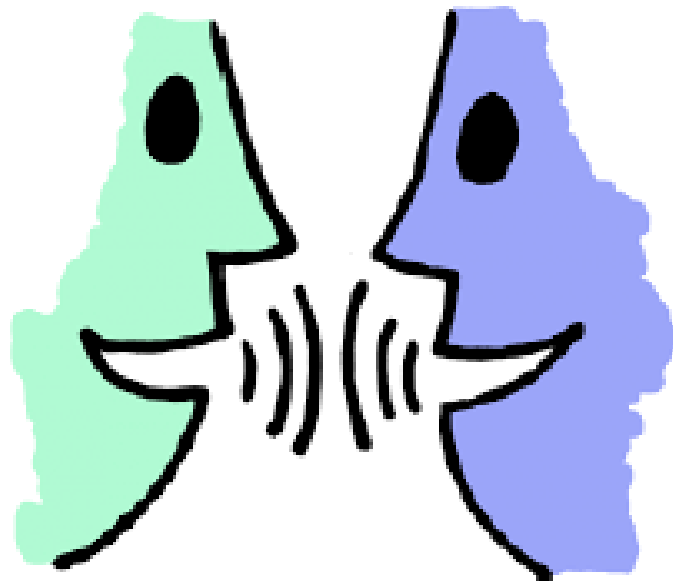
### 10.5.1 Participant Workbook

Participant Booklet

# “Who to tell, how and when?”

A HOP Programme

## Participant booklet



Participant Booklet

## Programme development

This programme has been adapted from the original Honest, Open, Proud programme written by Pat Corrigan and Jon Larson. It has been developed by Tamatha Ruffell, Jemini Bhatt, Dr Georgina Charlesworth and Dr Katrina Scior at UCL in consultation with the PPI group and the Promoting Independence in Dementia, PRIDE, programme WP2/3.

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Participant Booklet

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Participant Booklet

## Introduction

---

The “Who to tell, how and when?” programme is designed to support people living with dementia<sup>1</sup> who are worried about telling others about the diagnosis.

Throughout the programme you will find quotes from people living with dementia. These have been taken from interviews carried out as part of research studies. Quotes are used to illustrate the different views and experiences that people living with dementia may have and their lived experience. You may relate to some quote more than others. This is to be expected as there is no “one size fits all” for who to tell, how or when to share the diagnosis.

## Overview

---

The programme is split into three sessions. Each session is about different aspects of sharing a dementia diagnosis:

**Session 1: Talking about dementia**

**Session 2: Who, how and when to tell?**

**Session 3: Support for me, for you, for us**

Each session will include a discussion of the issues we cover. The aim of these discussions is to give you time and space to think about whether or not to share the diagnosis, and to

---

<sup>1</sup> A “person living with dementia” is someone who may have received a diagnosis or someone who is supporting a person with dementia.

## Participant Booklet

consider, how you might do this with family, friends, neighbours or acquaintances.

In this booklet there is a notes section at the end of each session. Please feel free to use this to write down anything that you found helpful in the session.

The course is not designed to give individually tailored advice or legal guidance. For support on how to tell employers, and the issues that may surround this, please contact the organisations listed on the last page.

## **Guidelines for each session**

---

Please be aware that during sessions attendees may wish to talk about their own personal experiences.

### **We ask that you:**

- Talk about your thoughts and reactions to sessions with others outside the programme if you wish **but** do not repeat the things you hear from other people. Keep others' information confidential.
- Be mindful that everyone's opinion counts
- Respect each other

Participant Booklet

## **Session 1: Talking about dementia**

---

Dementia can be difficult to talk about.

For many years, doctors have received training on how to tell a person they have dementia, but this is not the case for people living with dementia. People living with dementia sometimes feel fearful of telling others, not knowing what to say, or how to say it.

**This session looks at:**

- How dementia is talked about and the effect of receiving the diagnosis
- The advantages and disadvantages of telling or not telling others

## Talking about dementia; what's in a name?

---

The word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language.

Many people find it difficult to talk about a diagnosis of dementia.

Part of the difficulty can be around not wishing to use the word, dementia. It is not unusual for people to use other terms rather than dementia.

*"I couldn't even say the word. Since I got my diagnosis I feel as though I don't know where to turn or who to talk to about it."*

*Jim*



## The effect of a diagnosis

---

Most forms of dementia do not directly affect a person's personality<sup>2</sup>. However, being given a diagnosis of dementia can affect a person's sense of 'who they are' and their 'outlook' on life.

*"I used to be a confident person but since the diagnosis my confidence has been shaken. Now I find it difficult to talk to people and start discussions. I just don't feel like the person I used to be"*

**Leila**

*"I was shocked. Then I thought about all the plans I'd made for my retirement with my wife. I realised it would no longer be possible. Now, much later, I'm enjoying life with my wife but it's different and sometimes I feel bitter about it."*

**George**

A person's thoughts and feelings about dementia and the diagnosis may also affect whether they feel able to talk to others.

For some it might feel easier to accept the diagnosis and reach out, like Anisha below.

*"I finally had a name for what was happening. It was a bit of a relief. It meant I could finally talk to others and get help with the things I was struggling with"*

**Anisha**

---

<sup>2</sup> If certain frontal areas of the brain, or connections to them, are damaged, this can cause personality change such as disinhibition, or, at the other end of the scale, extreme apathy.

**DISCUSSION:**

- What words have you noticed being used instead of the word "dementia"?
- What might the diagnosis mean for a person's sense of "who they are" and their outlook on life?

**Why tell others?**

---

There can be advantages and disadvantages to telling or not telling others. Below Samira, Raj and Philip talk about the advantages they have experienced as a result of sharing the diagnosis.

*"When I get muddled with change at my local shop, the shop keeper reaches over to help me. He usually says, "yes that one and that one", and I say, "thank you very much". It relaxes me that he knows."*

**Samira**

*"I play golf with the lads regularly. I have told them about my dementia in case I forget something, just to remind them I am not doing it on purpose and I won't be offended if they remind me. They understand. It means I can carry on doing something I love."*

**Raj**

*"I've told very close friends I have a memory problem so they make allowances and understand."*

**Philip**

Some people do not find it helpful to tell others. Here Sarah and William talk about their experiences of losing friends and not feeling listened to.

*"I have lost a couple of friends who do not want to see me anymore. I think that is very hurtful. I am not sure why this is the case. One of them in particular used to be a close friend who I used to see almost every week. It just means that I don't want to tell other people about it."*

**Sarah**

*"After telling my family, I have been feeling that people have put me down. They don't listen to my opinion. I don't want other people to think I don't have anything to say because of the dementia."*

**William**

For some, like Jane and Nicki, it might feel like there are advantages to not sharing a diagnosis.

*"I'm not telling anyone because it's nice just to be part of a group, as a person and not as someone with dementia."*

**Jane**

*"I am worried that other people will look at me differently. I don't want people to exclude me or think that I am a burden to them"*

**Nicki**

However, not telling others might not be so helpful. For Inge it meant that she did not feel able to continue doing the things that she loved.

*"I used to have lots of different hobbies that I loved, like knitting and sewing, but now I find it difficult to understand and remember instructions and keep making mistakes. No one offers to help so I've just stopped doing these hobbies. I feel really disheartened."*

**Inge**

**DISCUSSION:**

- Having heard about the experiences of others are there any advantages or disadvantages that you identify with?
- Are there any advantages or disadvantages anyone has not considered before?

### **Session summary**

---

#### **In this session we talked about:**

- The words that are sometimes used instead of the word dementia
- The effect of receiving the diagnosis on sense of self and outlook
- The advantages and disadvantages of sharing and not sharing the diagnosis

### **Next time**

---

We are going to consider who to tell, how and when, and think about how others might react.



## Session 2: Who to tell, how and when?

---

**This session looks at;**

- Who to tell?
- How and when to tell?
- How others might react

## Who to tell?

---

There are a range of options available to you from ....



Here is what Malika, Sarah, Atul and Jeremy say about the approach they took.

*"I haven't told anyone...I don't want anyone else to know right now."*  
**Malika**

*"I was having coffee with an old work colleague, a really good friend of mine. We've been friends for years and all of a sudden I just came out and said it. I didn't want to keep it from her."*  
**Sarah**

*"If it doesn't concern them they don't need to know, that is the policy my wife and I use when deciding who to tell about my dementia. We decided that we would just tell the children and that's it."*  
**Atul**

*"I wanted to show people that you can live with dementia and there's support out there. So I arranged to go on the local radio to talk about my dementia."*  
**Jeremy**

**DISCUSSION:** What might the consequences be of telling no one, to telling everyone?



## Stigma and Disclosure Decision-Making in Dementia

For some telling others may give you access to sources of support. Feeling supported can make a difference for a person's well-being and help you to live well with dementia. It may be that others already know about the diagnosis.

Take a moment now to **note down the people that you have already told or may already know about the diagnosis.**

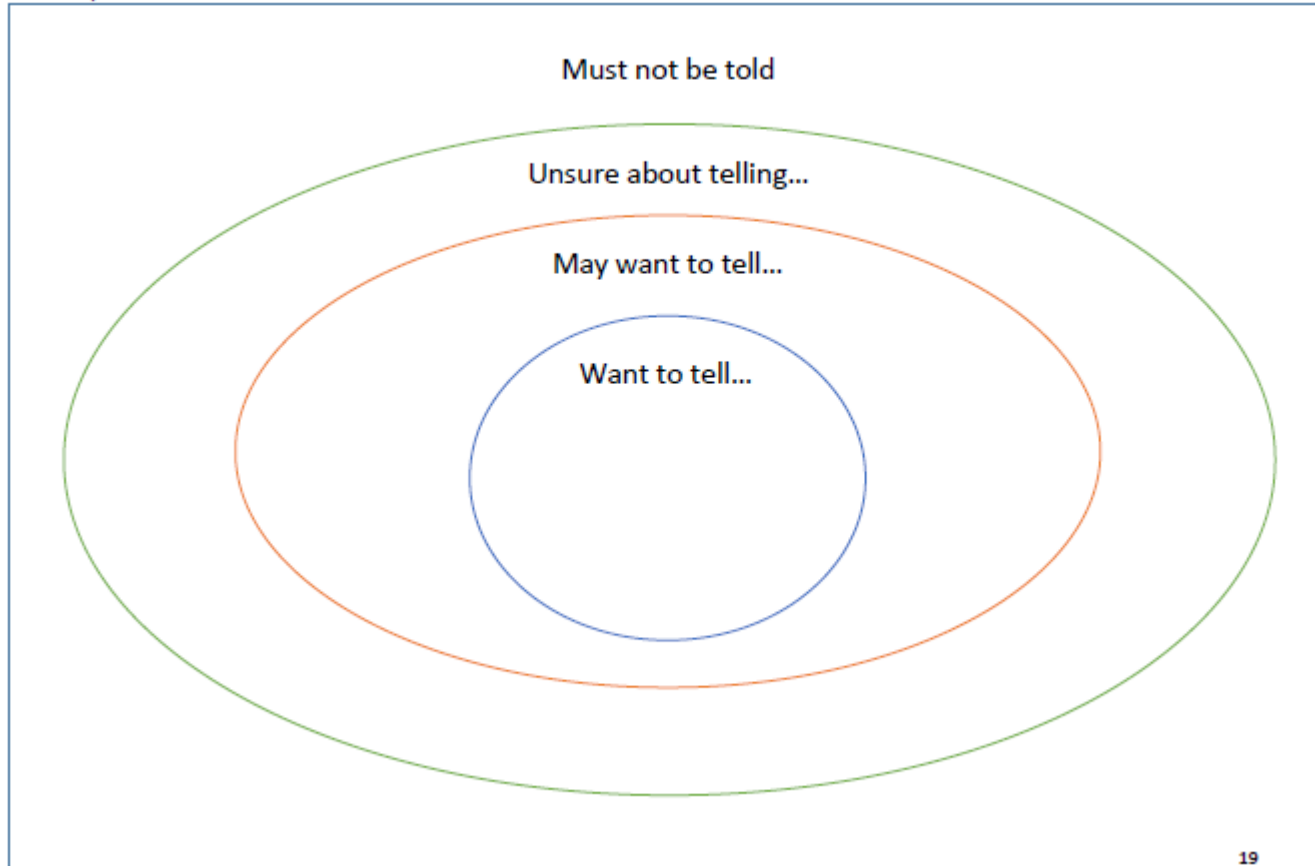
Who have I already told? Who do I think already knows?

Now we are going to spend some time thinking about the people you may want to tell about a diagnosis. We are not going to share this with the group but we will refer to it later on when considering who you want to tell.

Using the circles on the next page start in the middle and work outwards:

- Put the people who you **want to tell the most** in the **centre**.
- In the **second circle** put those people you **may want to tell**.
- The **third circle** is for those **people in your life you are unsure about**.
- The **outer area** is for **those who you may feel must not be told**.

Participant Booklet





### How and when to tell?

---

There are different ways that people tell others about a diagnosis of dementia. Here Tobias talks about how he went about it.

*"My neighbour is one of the first people I told. My wife passed a few years back and I have grown closer to him recently. We were talking about our health generally and I just said that I am having some memory problems. I didn't really think about it."*

**Tobias**

**DISCUSSION:** What do you think about how Tobias told his neighbour?

Maria took a different approach. Below she talks about her experience.

*"My husband and I decided to tell my friend Jessica together. All three of us have known one another a long time. We told her that we had something important to tell her and invited her over for dinner. Before she came over we talked about what we would say and told her over coffee at the end of the night. I said, Jess, I've been forgetting things recently so I went to the Doctor because I was worried. I had some tests and they've told me I have Alzheimer's. I just want you to know just in case I do things I wouldn't normally do"*

**Maria**

**DISCUSSION:** What do you think about how Maria told her friend?

## How others might react

---

Often people living with dementia worry that others might guess. Choosing to tell others can help people feel more in control of the situation than living with the uncertainty of whether others can guess.

Not everyone reacts well to hearing that a friend or relative has dementia but there are many 'dementia friends'<sup>3</sup> in all parts of the country. Everyone will react in their own unique way.

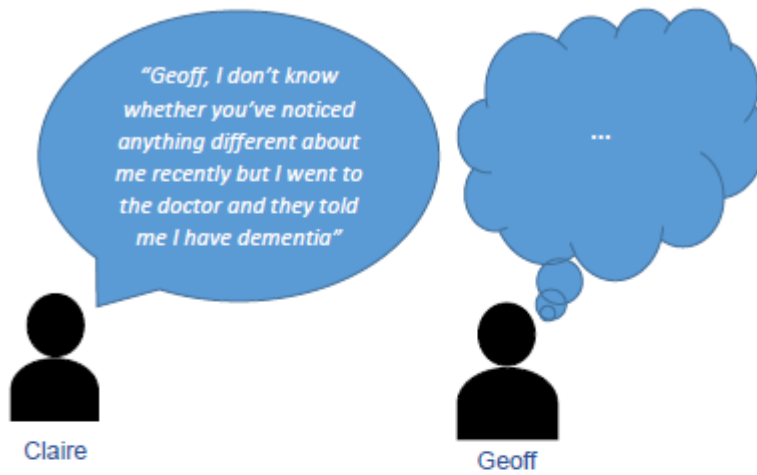
Here is an example where Claire tells her friend Geoff about the diagnosis.

Claire and Geoff have known each other for years, they had worked together for many years and saw each other regularly for coffee. One afternoon over coffee Claire decides to tell Geoff about her diagnosis.

---

<sup>3</sup> Increasing numbers of people are signing up to be a "Dementia Friend"; <https://www.dementiafriends.org.uk/>. Being a "Dementia Friend" means finding out more about how dementia affects a person – and then, armed with this understanding, doing small everyday things that help. For example, being patient in a shop queue, or spending time with someone you know who's living with dementia.

Participant Booklet



There was a pause...

**DISCUSSION:** What do you think is going through Geoff's mind?  
What do you think is going through Claire's mind?

## Session summary

---

### In this session we have covered:

- Who to tell
- How and when to tell
- How others might react

### Something to try

Between now and the next session we invite you to think about;

- Who you would tell; no one, someone, everyone?
- How and when you would tell them; plan it or be spontaneous, face to face, over the phone or in a letter?
- The words that you would use; would you talk about memory problems or dementia?

We will come back to this at the beginning of next week's session.



## Next time

---

- We will discuss our thoughts from last week's session on who to tell, how and when.
- Support for me, for you, for us; we will consider the issues that arise when others do the telling and think about how to access the sources of support that are out there.



### **Session 3: Support for me, for you, for us**

---

#### **A summary so far**

- In session one we discussed the language used around dementia and the advantages and disadvantages of telling others.
- In session two we discussed who to tell, how and when. We also thought about the reactions of others.

#### **This session looks at;**

- Who to tell, how and when – a discussion of your thoughts from last week's session
- When others do the telling
- Sources of support

## Who to tell, how and when: a review

---

At the end of the last session we invited you to think about;

- Who you would tell
- How and when you would tell them
- The words that you would use

**DISCUSSION:** Has anyone taken the step of telling someone about the diagnosis? If so, how did this go?

### Whose diagnosis is it?

---

For some of you in this room today the diagnosis may have been delivered to you and your supporter at the same time. Deciding how this information is shared can be challenging.

**DISCUSSION:** What reasons do you think others may have for sharing this information?

### When others do the telling

---

Sometimes people may tell others about the diagnosis. There may be times when you agree with this but other times when you may not.

Below Jacinda talks about her experience.

*"I had told a friend who attends the same Church. I thought he would keep the information to himself as I hadn't wanted anyone else to know. Anyway, when I was at Church one day another parishioner came up to me and said they were so sorry to hear about my diagnosis. I felt really taken aback and I didn't know what to say"*

*Jacinda*

**DISCUSSION:** Who do you think is "allowed" to share the diagnosis?

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Thinking about this issue when telling others can be helpful.  
There are no right or wrong approaches to this.

Here is just one example of how Anoushka went about it.

*"We sat down as a family and talked about who else should know. We all agreed that my family can share the information about the diagnosis with their close friends and our wider family as long as they make sure the people they tell do not tell anyone else. I was happy for this to happen as telling others was really difficult for me."*

*Anoushka*

**DISCUSSION:** How would you deal with differences of opinion with the people that you tell?

## Sources of support

---

There is wide ranging support available that values and respects people living with dementia and supports them to live well.

**DISCUSSION:** What groups, activities or sources of support have you heard of in your area and who would you consider approaching?

## Session summary

---

**In this session we have considered:**

- Our current thoughts about who to tell, how and when
- When others are doing the telling
- Sources of support

## Programme Summary

---

Over the course of the programme's 3 sessions we have talked about:

- the diagnosis and the way it can affect lives
- the advantages and disadvantages of telling or not telling others
- who, how and when you might tell others and how they might react
- when others do the telling
- sources of support



NOTES

Lined area for notes with horizontal lines.

Participant Booklet

### **What happens now?**

---

This workbook is yours to keep. You can refer to it whenever you wish to.

The next page has important details of organisations who can provide support for those living with dementia and their supporters.

**For more information about this research please contact Tamatha Ruffell or Jemini Bhatt at;**

**Address:** 1-19 Torrington Place, University College London, WC1E 7HB

**Telephone:** 020 7679 8275

**Email:** [tamatha.ruffell.16@ucl.ac.uk](mailto:tamatha.ruffell.16@ucl.ac.uk) or [jemini.bhatt@ucl.ac.uk](mailto:jemini.bhatt@ucl.ac.uk) or [tamatha.ruffell.16@ucl.ac.uk](mailto:tamatha.ruffell.16@ucl.ac.uk)

## Acknowledgements

We are indebted to the original authors, Pat Corrigan and Jon Larson, and other members of the HOP “community” for their support in developing this workbook.

**Where to find support?**

<p><b>Alzheimer's Society</b> (local services and information provision)</p> 	<p><b>Email:</b> <a href="mailto:enquiries@alzheimers.org.uk">enquiries@alzheimers.org.uk</a>  <b>Telephone:</b> 0300 222 11 22  <b>Website:</b> <a href="http://www.alzheimers.org.uk">www.alzheimers.org.uk</a></p>
<p><b>Pathways Through Dementia</b> (legal support and information provision)</p> 	<p><b>Email:</b> <a href="mailto:swilcox@pathwaysthroughdementia.org">swilcox@pathwaysthroughdementia.org</a>  <b>Telephone:</b> 0203 405 5940  <b>Website:</b> <a href="http://www.pathwaysthroughdementia.org">www.pathwaysthroughdementia.org</a></p>
<p><b>AgeUK</b> (local services and information provision)</p> 	<p><b>Email:</b> <a href="mailto:contact@ageuk.org.uk">contact@ageuk.org.uk</a>  <b>Telephone:</b> 0800 055 6112  <b>Website:</b> <a href="http://www.ageuk.org.uk">www.ageuk.org.uk</a></p>
<p><b>CarePlace</b> (care and community services, information and guidance)</p> 	<p><b>Telephone (The Silver Line):</b> 0800 4 70 80 90  <b>Website:</b> <a href="http://www.careplace.org.uk">www.careplace.org.uk</a></p>

*10.5.2 Facilitator Manual*

Facilitator Booklet

**“Who to tell, how and when?”**

A HOP Programme

**Facilitator booklet**



Facilitator Booklet

## Programme development

This programme has been adapted from the original Honest, Open, Proud programme written by Pat Corrigan and Jon Larson. It has been developed by Tamatha Ruffell, Jemini Bhatt, Dr Georgina Charlesworth and Dr Katrina Sclor at UCL in consultation with the PPI group and the Promoting Independence In Dementia, PRIDE, programme WP2/3.

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## Facilitator Booklet

### General guidelines for facilitators

---

Before starting each session ensure you have;

- 2 A3 boards with stands
  - Board 1 = a reality orientation board with the day, date, season, year, programme name ("Who to tell, how and when?") start and end time of session, session number and time of breaks.
  - Board 2 = a board with lots of blank A3 paper the facilitators can use to write down the outcomes of the discussion.
- lots of A3 paper to put on the boards
- markers
- a large clock
- stickers for name tags
- pens for attendees to use
- chairs for all attendees, have these placed in a circle in the room
- bluetac to display the outcomes of the discussions around the room during the session
- refreshments for the break and cups/mugs for the refreshments
- reminder cards for attendees of the next day, date, time, location of the next session.

Facilitator notes throughout this booklet are in black. At the end of each discussion point is a list of possible answers that may arise in the discussion. These are for your general information to aid facilitation and are not designed as a check list to follow.

A list of local groups, activities and sources of support available in the area that you can share with attendees throughout the course but specifically in session 3.

Ensure you keep a register recording attendance and attrition.

## Facilitator Booklet

### Begin the session by...

- introducing yourself and thank everyone for coming
- provide information relating to toilets, fire exits and break times. Draw attendees' attention to the reality orientation board in the room
- inform all attendees that they can take a break or leave the session at any point if needed/as necessary
- invite attendees to write their names on the stickers provided and wear these

Now read out the introduction, programme development, overview and guidelines out loud.

Facilitator Booklet

## Introduction

---

The "Who to tell, how and when?" programme is designed to support people living with dementia<sup>1</sup> who are worried about telling others about the diagnosis.

Throughout the programme you will find quotes from people living with dementia. These have been taken from interviews carried out as part of research studies and are used to illustrate the different views and experiences of people living with dementia may have and their lived experience. You may relate to some quotes more than others. This is to be expected as there is no "no size fits all" for who to tell, how or when to share the diagnosis.

## Overview

---

The programme is split into three sessions. Each session is about different aspects of sharing a dementia diagnosis:

**Session 1: Talking about dementia**

**Session 2: Who, how and when to tell?**

**Session 3: Support for me, for you, for us**

Each session will include a discussion of the issues. The aim of these discussions is to give you time and space to think about whether or not to share the diagnosis, and to consider, how you might do this with family, friends, neighbours or acquaintances.

In this booklet there is a notes section at the end of each session. Please feel free to use this to write down anything that you found helpful in the session.

The course is not designed to give individually tailored advice or legal guidance. For support on how to tell employers, and the issues that may surround this, please contact the organisations listed on the last page.

## Guidelines for each session

---

Please be aware that during sessions attendees may wish to talk about their own personal experiences.

**We ask that you:**

- Talk about your thoughts and reactions to sessions with others outside the programme if you wish but do not repeat the things you hear from other people. Keep others' information confidential.

---

<sup>1</sup> A "person living with dementia" is someone who may have received a diagnosis or someone who is supporting a person with dementia.

## Facilitator Booklet

- Be mindful that everyone's opinion counts
- Respect each other

**FACILITATOR:** "Now could each person introduce themselves and say "one thing" they would like to get out of the sessions". Note down these points and return to them at the end of the programme.

"Does anyone have any questions at this point?". Answer them to the best of your ability. If you are unable to answer an attendee's question, note it down and let them know that you will look into this and that you will do your best to answer the question at the beginning of the next session.

Now read aloud from the text underneath the title "Session 1: Talking about dementia" through to the discussion after Anisha's vignette.

## Session 1: Talking about dementia

---

Dementia can be difficult to talk about. For many years, doctors have received training on how to tell a person they have dementia, but this is not the case for people living with dementia. People living with dementia sometimes feel fearful of telling others, not knowing what to say, or how to say it.

This session looks at:

- How dementia is talked about and the effect of receiving the diagnosis
- The advantages and disadvantages of telling or not telling others

## Talking about dementia; what's in a name?

---

The word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. Many people find it difficult to talk about a diagnosis of dementia. Part of the difficulty can be around not wishing to use the word, dementia. It is not unusual for people to use other terms rather than dementia.

*"I couldn't even say the word. Since I got my diagnosis I feel as though I don't know where to turn or who to talk to about it."*

*Jim*

## The effect of a diagnosis

---

Most forms of dementia do not directly affect a person's personality<sup>2</sup>. However, being given a diagnosis of dementia can affect a person's sense of 'who they are' and their 'outlook' on life.

*"I used to be a confident person but since the diagnosis my confidence has been shaken. Now I find it difficult to talk to people and start discussions. I just don't feel like the person I used to be"*

**Leila**

*"I was shocked. Then I thought about all the plans I'd made for my retirement with my wife. I realised it would no longer be possible. Now, much later, I'm enjoying life with my wife but it's different and sometimes I feel bitter about it."*

**George**

A person's thoughts and feelings about dementia and the diagnosis may also affect whether they feel able to talk to others. For some it might feel easier to accept the diagnosis and reach out, like Anisha below.

*"I finally had a name for what was happening. It was a bit of a relief. It meant I could finally talk to others and get help with the things I was struggling with"*

**Anisha**

## DISCUSSION: Dementia and language, dementia and outlook

**FACILITATOR:** Throughout the discussion note down attendees' thoughts.

**Q:** "What words have you noticed being used instead of the word, dementia?"

**A1:** many different words are used. Acknowledge the confusion 'out there' as to whether dementia is the same or different to specific illnesses such as Alzheimer's

---

<sup>2</sup> if certain frontal areas of the brain, or connections to them, are damaged, this can cause personality change such as disinhibition, or, at the other end of the scale, extreme apathy.

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Disease, Vascular disease etc; and the euphemisms used, such as, 'memory problems' and 'having senior moments'.

A2: acknowledge and normalise the struggle that some people will be having to even use the word let alone use it when talking to others.

**Q: What might the diagnosis mean for a person's sense of "who they are" and their outlook on life?**

A1: there will be a range of emotional responses that may come up: denial, anger, anxiety, shame, fear, depression, despair, suicidal ideation, relief, acceptance.

A2: receiving the diagnosis might mean

- a loss of personal identity/sense of self
- grief and fear for the future loss of the self
- struggle to accept the new identity as a person living with dementia

**At the end of this discussion summarise the points raised and read out the key takeaway points below. Bluetac these somewhere where attendees can see them.**

### KEY TAKEAWAY POINTS:

- lots of different words are used when describing dementia
- people sometimes find it hard to use these words
- a diagnosis can impact a person's sense of "who they are" and their outlook on life
- everyone will react differently, it is normal to spend time adjusting

Offer 10 minute refreshment break here.

## Why tell others?

---

**Facilitator: Now read out the advantages and disadvantages of telling or not telling others.**

There can be advantages and disadvantages to telling or not telling others. Below Samira, Raj and Philip talk about the advantages they have experienced as a result of sharing the diagnosis.

*"When I get muddled with change at my local shop, the shop keeper reaches over to help me. He usually says, "yes that one and that one", and I say, "thank you very much". It relaxes me that he knows."*

*Samira*

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*"I play golf with the lads regularly. I have told them about my dementia in case I forget something, just to remind them I am not doing it on purpose and I won't be offended if they remind me. They understand. It means I can carry on doing something I love."*

**Raj**

*"I've told very close friends I have a memory problem so they make allowances and understand."*

**Philip**

Some people do not find it helpful to tell others. Here Sarah and William talk about their experiences of losing friends and not feeling listened to.

*"I have lost a couple of friends who do not want to see me anymore. I think that is very hurtful. I am not sure why this is the case. One of them in particular used to be a close friend who I used to see almost every week. It just means that I don't want to tell other people about it."*

**Sarah**

*"After telling my family, I have been feeling that people have put me down. They don't listen to my opinion. I don't want other people to think I don't have anything to say because of the dementia."*

**William**

For some it might feel like there are advantages to not sharing a diagnosis.

*"I'm not telling anyone because it's nice just to be part of a group, as a person and not as someone with dementia."*

**Jane**

*"I am worried that other people will look at me differently. I don't want people to exclude me or think that I am a burden to them"*

**Nicki**

However, not telling others might not be so helpful. For Inge it meant that she did not feel able to continue doing the things that she loved.

*"I used to have lots of different hobbies that I loved, like knitting and sewing, but now I find it difficult to understand and remember instructions and keep making mistakes. No one offers to help so I've just stopped doing these hobbies. I feel really disheartened."*

**Inge**

Facilitator Booklet

## **DISCUSSION: Your own advantages and disadvantages, other advantages and disadvantages not considered before**

Facilitator: throughout the discussion note down attendees' thoughts.

**Q2: Are there any advantages or disadvantages anyone hasn't considered before?**

**A1:** Potential advantages to telling others: "living well with dementia" - accessing support, being able to make informed decisions about your future, emotional processing, taking on valued goals (being a spokes-person).

**A2:** Potential disadvantages to telling others: loss of friends, stigma, shame, "being seen differently".

**A3:** Potential advantages to not telling others, "keeping" your identity, avoid discrimination, loss of friends.

**A4:** Potential disadvantages to not telling others: social isolation stigma/shame, fear of being "found out", lots of effort spent on "covering up" the symptoms which could be spent elsewhere.

**A5:** Potential barriers to telling others (this might come up in the discussion so below are some potential answers)

- thoughts: individual - perception that help is not needed, family discourses ("never washing our linen in public"), socio cultural discourses (stigma/shame), anxiety based thoughts "my friends will reject me"
- feelings: ambivalence – what help will it do, fears upsetting others, being rejected/treated differently
- behaviours: avoidance of feared outcomes

**At the end of this discussion summarise the points raised and read out the key takeaway points below. Bluetac the key takeaway points onto the wall for attendees to see.**

### **KEY TAKEAWAY POINTS:**

- there are advantages and disadvantages to telling/not telling others about the diagnosis
- the advantages and disadvantages will be personal
- it is important to spend time thinking them through and deciding what is most helpful for you

it may help to consider barriers to telling others the diagnosis.

**Now read session 1 summary.**



Facilitator Booklet

## Session summary

---

In this session we talked about:

- The words that are sometimes used instead of the word dementia
- The effect of receiving the diagnosis on sense of self and outlook
- The advantages and disadvantages of sharing and not sharing the diagnosis

**FACILITATOR:** “Does anyone have any questions or comments about today’s session?”

Answer these as best you can. Any questions you are unable to answer note down and tell the attendee you will find out the answer and get back to them in the next session.

End of session feedback:

1. “How has everyone found today’s session in terms of its
  - what we talked about
  - length
2. What have you found most helpful about the session?
3. What would you have liked to have changed?”

Now read out what will happen in next week’s session.

## Next time

---

We are going to consider who to tell, how and when, and think about how others might react.

**FACILITATOR:** Thank everyone for coming and say goodbye.

Facilitator Booklet

## Session 2: Who to tell, how and when?

---

**FACILITATOR:** Before the session ensure last week's session summary is visible on a sheet.

Begin the session by...

- introducing yourself and thank everyone for coming again
- provide information relating to toilets, fire exits and break times. Draw attendees' attention to the reality orientation board in the room
- inform all attendees that they can take a break or leave the session at any point if needed/as necessary
- invite attendees to write their names on the stickers provided and wear these
- "As always we ask that you talk about your thoughts and reactions to sessions with others outside the programme but keep confidential the things you hear from other people. Be mindful that everyone's opinion counts and respect each other."

Once attendees have written their names down on the stickers say,

"Last week we talked about the language used around dementia and the advantages and disadvantages of telling others. Has anyone had any thoughts or questions about last week's session?"

Now read out what this session will look at, who to tell up to the discussion at the end of this section.

This session looks at;

- Who to tell?
- How and when to tell?
- How others might react



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**A1:** telling no one may mean that the person feels they are protecting their identity but it may mean the person has to make extensive changes to their lives avoiding situations or persons.

**A2:** a lot of energy might be spent on "hiding" the symptoms. It may also be hard to access support and "live well with dementia".

**A3:** telling some TRUSTED people may mean you get access to support and can continue to "live well with dementia".

**A4:** telling everyone may mean that you become a spokesperson and develop a new valued empowered identity where you "live well with dementia" and provide others with hope and support.

**At the end of this discussion summarise the points raised. Now read out the key takeaway points below. Bluetac the key takeaway points where attendees can see them.**

**KEY TAKEAWAY POINTS**

- Consequences are personal
- Telling no one may seem "safe" but it may also be exhausting, there may be "hidden" consequences.

**Now read about support systems and instructions for the network circles exercise. Give attendees approximately 10 minutes to complete the exercise.**

For some telling others may give you access to sources of support. Feeling supported can make a difference for a person's well-being and help you to live well with dementia. It may be that others already know about the diagnosis. Take a moment now to note down the people that you have already told or who may already know about your dementia:

Who have I already told? Who do I think already knows?

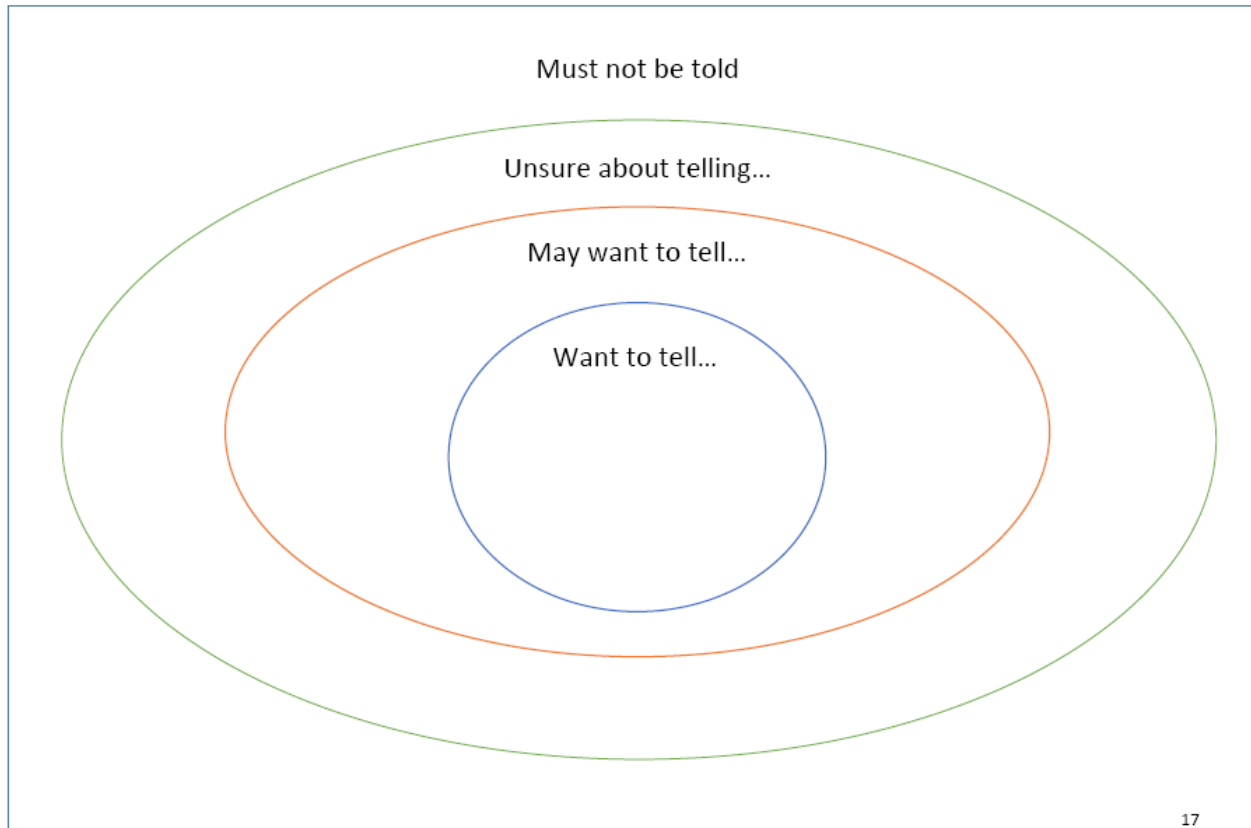
Now we would like you to spend time thinking about the people you may want to tell about a diagnosis. We are not going to share this with the group but we will refer to it later on when considering who you want to tell.

Using the circles on the next page start in the middle and work outwards:

- Put the people who you want to tell the most in the centre.
- In the second circle put those people you may want to tell.
- The third circle is for those people in your life you are unsure about.
- The outer area is for those who you may feel must not be told.



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FACILITATOR: "How did you find completing that exercise? Please feel free to edit the circles as we progress through these sessions and beyond if this is helpful"

Offer 10 minute refreshment break here.

Now read out the "How and when to tell?" section with Tobias' vignette.

### How and when to tell?

There are different ways that people tell others about a diagnosis of dementia. Here Tobias talks about how he went about it.

*"My neighbour is one of the first people I told. My wife passed a few years back and I have grown closer to him recently. We were talking about our health generally and I just said that I am having some memory problems. I didn't really think about it."*

**Tobias**

### DISCUSSION: How Tobias told his neighbour

FACILITATOR: throughout the discussion note down attendees' thoughts.

Q: "What do you think about how Tobias told his neighbour"

A1: It was unplanned but in the context of a chat about health in general so this could be seen as an appropriate time to bring it up, "spotting opportunities to tell".

A2: It was to a neighbour Tobias was close to so potentially someone trustworthy and who could be of some support in the future.

Now read out Maria's vignette.

Maria took a different approach. Below she talks about her experience.

*"My husband and I decided to tell my friend Jessica together. All three of us have known one another a long time. We told her that we had something important to tell her and invited her over for dinner. Before she came over we talked about what we would say and told her over coffee at the end of the night. I said, Jess, I've been forgetting things recently so I went to the Doctor because I was worried. I had some tests and they've told me I have Alzheimer's. I just want you to know just in case I do things I wouldn't normally do"*

**Maria**

## DISCUSSION: How Maria told her friend

**Q:** What do you think about how Maria told her friend?

**A1:** A "safer" approach? Thought about and planned. Maria told a trusted friend so reduced the risks and used it as a way of giving her friend an explanation for her symptoms. May address her need to "live well WITH dementia".

At the end of this discussion summarise the points raised and read out the key takeaway points. Bluetac the key takeaway points where attendees can see them.

### KEY TAKEAWAY POINTS:

- Who and how people tell others about their diagnosis will depend on their knowledge, values, needs and support system which are constantly changing.
- The method and timing that people do this will be based on what they feel most comfortable with. There is no right or wrong. You can do this spontaneously or plan it. You could write a letter, or an email, talk on the telephone or face to face.

Now read the section below, including "how others might react" and stop at the discussion points related to Claire and Geoff's vignette.

### How others might react

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Often people living with dementia worry that others might guess. Choosing to tell others can help people feel more in control of the situation than living with the uncertainty of whether others can guess.

Not everyone reacts well to hearing that a friend or relative has dementia but there are also many 'dementia friends'<sup>3</sup> in all parts of the country. Everyone will react in their own unique way. Below is an example where Claire is telling her friend Geoff

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<sup>3</sup>Increasing numbers of people are signing up to be a "Dementia Friend"; <https://www.dementiafriends.org.uk/>. Being a "Dementia Friend" means finding out more about how dementia affects a person – and then, armed with this understanding, doing small everyday things that help. For example, being patient in a shop queue, or spending time with someone you know who's living with dementia.



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about the diagnosis. Claire and Geoff have known each other for years, they had worked together and saw each other regularly for coffee. One afternoon over coffee Claire decides to tell Geoff about her diagnosis.



There was a pause...

### DISCUSSION: The reactions of others, the Claire and Geoff vignette

**FACILITATOR:** throughout the discussion note down attendees' thoughts.

**Q1:** “What do you think is going through Geoff's mind”

**A1:** How awful for Claire, I want to be supportive, let me think about the best way to express my concern, sympathy and support. Maybe I can offer her help if it feels appropriate.

**A2:** That's taken me by surprise, I'm not sure quite how to respond. I'm going to need to think for a moment.

**A3:** I thought something was up. It's reminded me of my other friend's experience of living with dementia. Now let me think what they found helpful, maybe Claire might want to know.

**A4:** Oh no, I feel really awkward. I don't know what to say.

**Q2:** “What do you think is going through Claire's mind”

**A1:** Worries related to negative reactions; “he's not going to want to be my friend anymore”, “he's only going to see they dementia”, “he's going to treat me differently now”, “oh no I've upset him.”

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A2: Thoughts that the pause might indicate a positive and supportive reaction from Geoff, "maybe he's taking some time to process what I've just told him and is thinking about what to say, that's really sensitive and supportive".

At the end of this discussion summarise the points raised and read out the key takeaway points. Bluetac the key takeaway points where attendees can see them.

### KEY TAKEAWAY POINTS:

- There is no way we can know somebody else's thoughts or opinions unless we ask.
- Often the fear of what might happen is much worse than what actually happens.
- There are many ways that people can react and a lot of them are supportive.

Now read the session summary.

## Session summary

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In this session we have covered:

- Who to tell
- How and when to tell
- How others might react

**FACILITATOR:** "Does anyone have any questions or comments about today's session?"

Answer these as best you can. Any questions you are unable to answer note down and tell the attendee you will find out the answer and get back to them in the next session. Now read out "something to try"

## Something to try

Between now and the next session we invite you to think about;

- Who you would tell; no one, someone, everyone?
- How and when you would tell them; plan it or be spontaneous, face to face, over the phone or in a letter?
- The words that you would use; would you talk about memory problems or dementia?

We will come back to this at the beginning of next week's session.

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**FACILITATOR:** Now ask attendees for their end of session feedback.

1. How has everyone found today's session in terms of its
  - what we talked about
  - length
2. What have you found most helpful about the session?
3. What would you have liked to have changed?

Now read out what will happen in next week's session.

### **Next time**

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- We will discuss our thoughts from last week's session on who to tell, how and when.
- Support for me, for you, for us; we will consider the issues that arise when others do the telling and think about how to access the sources of support that are out there.

**FACILITATOR:** Thank everyone for coming and say goodbye.

## **Session 3: Support for me, for you, for us**

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Before the session ensure the session summaries for the last 2 weeks are visible in the room and can be seen by all attendees.

Begin the session by...

- introducing yourself and thank everyone for coming again
- provide information relating to toilets, fire exits and break times. Draw attendees' attention to the reality orientation board in the room
- inform all attendees that they can take a break or leave the session at any point if needed/as necessary
- invite attendees to write their names on the stickers provided and wear these
- "As always we ask that you talk about your thoughts and reactions to sessions with others outside the programme but keep confidential the things you hear from other people. Be mindful that everyone's opinion counts and respect each other."

Once attendees have written their names down on the stickers provided go around the room read out "A summary so far".

**A summary so far**

- In session one we discussed the language used around dementia and the advantages and disadvantages of telling others.
- In session two we discussed who to tell, how and when. We also thought about the reactions of others.

**FACILITATOR:** "has anyone had any thoughts or questions from the last 2 sessions?"

- Note down these points on board 2 and address the questions as best you can. If they are going to be covered in this session tell the attendee that.
- Some attendees might talk about the between session exercise. Thank them and tell them that you are going to cover this in more detail in a moment.

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Now read out what “this session looks at”

This final session looks at;

- Who to tell, how and when – a discussion of your thoughts from last week’s session
- When others do the telling
- Sources of support

Now read out “who to tell, how and when: a review”

### **Who to tell, how and when: a review**

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At the end of the last session we invited you to think about;

- Who you would tell
- How and when you would tell them
- The words that you would use

**DISCUSSION: Exploring disclosure: Has anyone taken the step of telling someone about the diagnosis? If so, how did this go?**

**FACILITATOR:** throughout the discussion note down attendees’ thoughts. This exercise is an invitation for group members to share their experiences.

For those that have told others the diagnosis invite them to share how they went about it and ask them how they felt it went, what they found helpful or not so helpful about it, and what the consequences have been.

Read out key takeaway point.

**KEY TAKEAWAY POINT:**

- thinking or doing this may change your thoughts about telling others the diagnosis and how you live your life.

Now read “whose diagnosis is it?”

### **Whose diagnosis is it?**

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For some of you in this room today the diagnosis may have been delivered to you and your supporter at the same time. Deciding how this information is shared can be challenging.

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## **DISCUSSION: Whose diagnosis is it? Reasons others may share the diagnosis**

**FACILITATOR:** throughout the discussion note down attendees' thoughts.

**Q:** "What reasons do you think others may have for sharing this information"

**A1:** To get access to support and services for themselves if they are also affected by the diagnosis.

**A2:** To share their experience and knowledge with others who are "living with dementia" as a way of supporting others and to help them feel less alone.

**At the end of this discussion summarise the points raised and read out key takeaway points. Bluetac these somewhere where attendees can see them.**

### **KEY TAKEAWAY POINTS**

- It is important to be aware that anyone you share the diagnosis with may share this information with others.
- This might be something to consider before sharing.

**FACILITATOR:** Offer 10 minute refreshment break here.

Now read "When others do the telling" and Jacinda's vignette.

### **When others do the telling**

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Sometimes people may tell others about the diagnosis. There may be times when you agree with this but other times when you may not. Below Jacinda talks about her experience.

*"I had told a friend who attends the same Church. I thought he would keep the information to himself as I hadn't wanted anyone else to know. Anyway, when I was at Church one day another parishioner came up to me and said they were so sorry to hear about my diagnosis. I felt really taken aback and I didn't know what to say"*

**Jacinda**

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## DISCUSSION: Who is “allowed to share the diagnosis?”

FACILITATOR: throughout the discussion note down attendees’ thoughts.

Q: “Who do you think is “allowed” to share the diagnosis?”

A1: Only me

A2: Only me and my friends/family with trusted others

A3: Anyone I tell

At the end of this discussion summarise the points raised and read out key takeaway points. Bluetac the key takeaway points where all attendees can see them.

### KEY TAKEAWAY POINTS:

- Once you have told someone the diagnosis it may be hard to “control” who they then go on to tell.
- Thinking and talking about this issue before telling others the diagnosis can be helpful.
- There are no right or wrong approaches to this.

Now read Anoushka’s vignette.

Here is just one example of how Anoushka went about it.

*“We sat down as a family and talked about who else should know. We all agreed that my family can share the information about the diagnosis with their close friends and our wider family as long as they make sure the people they tell do not tell anyone else. I was happy for this to happen as telling others was really difficult for me.”*

*Anoushka*

## DISCUSSION: Navigating differences of opinion with the people you tell

FACILITATOR: throughout the discussion note down attendees’ thoughts.

Q: “How would you deal with differences of opinion with the people that you tell?”

A1: Put the boundaries in place before sharing the information.

A2: Discussing each other’s points of view and trying to see it from the other person’s position.

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**A3:** Both parties coming from a position where they are open to being flexible in their position and willing to potentially compromise.

**At the end of this discussion summarise the points raised and read the key takeaway points. Bluetac these somewhere where attendees can see them.**

### KEY TAKEAWAY POINTS

- It may be helpful to be clear about your boundaries about information sharing when telling others the diagnosis.
- It may be helpful to have a discussion with others when differences of opinion arise.
- Being flexible in the opinions you hold about information sharing may be helpful when considering how you and those closest to you can "live well with dementia".

Now read sources of support

## Sources of support

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There is wide ranging support available that values and respects people living with dementia and supports them to live well.

**DISCUSSION: What groups, activities or sources of support have you heard of in your area and who would you consider approaching?**

**FACILITATOR:** Have to hand a list of local groups, activities and sources of support available in the area that you can share with attendees. This exercise is aimed at getting group members to share information with each other and highlight the resources available to them.

At the end of this discussion summarise the points raised. Give each attendee a copy of the list of local groups/activities and sources of support available in your area.



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Now read the session and programme summary.

### Session summary

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In this session we have considered:

- Our current thoughts about who to tell, how and when
- When others are doing the telling
- Sources of support

### Programme Summary

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Over the course of the programme's 3 sessions we have talked about:

- the diagnosis and the way it can affect lives
- the advantages and disadvantages of telling or not telling others
- who, how and when you might tell others and how they might react
- when others do the telling
- sources of support

**FACILITATOR:** "In session 1 we hoped that we would (read out attendees hopes from session 1)."

Go through each point and evaluate how well these have been addressed by the group.

"Does anyone have any questions from today's session or any of the previous sessions?"

Answer them to the best of your ability. If you are unable to answer a attendee's question, note it down and let them know that you will look into this and that you will get their details so that you can send them the answer in the next day.

End of session feedback:

1. How has everyone found today's session in terms of
  - what we talked about
  - its length
2. What have you found most helpful about the session?
3. What would you have liked to have changed?

Now read out "what happens now?"

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## What happens now?

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This workbook is yours to keep. You can refer to it whenever you wish to. The next page has important details of organisations who can provide support for those living with dementia and their supporters.

**FACILITATOR:** "As this is a new group UCL is undertaking an evaluation. You are all invited to take part in an audio recorded interview that will ask you about your experience of the group and help with the group's further development. The interview will take place either here or in your home and will last around an hour. If you are interested in taking part please speak to Tamatha Ruffell, trainee Clinical Psychologist from UCL, before leaving today. Thank you very much for attending these groups. We hope they have been helpful and informative. It has been a pleasure delivering them. Thank you and goodbye."

For more information about this research please contact Tamatha Ruffell or Jemini Bhatt at;

Address: 1-19 Torrington Place, University College London, WC1E 7HB

Telephone: 020 7679 8275




Email: [tamatha.ruffell.16@ucl.ac.uk](mailto:tamatha.ruffell.16@ucl.ac.uk) or [jemini.bhatt@ucl.ac.uk](mailto:jemini.bhatt@ucl.ac.uk) or [tamatha.ruffell.16@ucl.ac.uk](mailto:tamatha.ruffell.16@ucl.ac.uk)

## Acknowledgements

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## Where to find support?

<p>Alzheimer's Society (local services and information provision)</p> 	<p>Email: <a href="mailto:enquiries@alzheimers.org.uk">enquiries@alzheimers.org.uk</a>                  Telephone: 0300 222 11 22                  Website: <a href="http://www.alzheimers.org.uk">www.alzheimers.org.uk</a></p>
<p>Pathways Through Dementia (legal support and information provision)</p> 	<p>Email: <a href="mailto:swilcox@pathwaysthroughdementia.org">swilcox@pathwaysthroughdementia.org</a>                  Telephone: 0203 405 5940                  Website: <a href="http://www.pathwaysthroughdementia.org">www.pathwaysthroughdementia.org</a></p>
<p>AgeUK (local services and information provision)</p> 	<p>Email: <a href="mailto:contact@ageuk.org.uk">contact@ageuk.org.uk</a>                  Telephone: 0800 055 6112                  Website: <a href="http://www.ageuk.org.uk">www.ageuk.org.uk</a></p>
<p>CarePlace (care and community services, information and guidance)</p> 	<p>Telephone (The Silver Line): 0800 4 70 80 90                  Website: <a href="http://www.careplace.org.uk">www.careplace.org.uk</a></p>

## 10.6 List of Conference Outputs

**Bhatt, J.,** Scior, K., Higgs, P., & Charlesworth, G. (2017). An intervention to support people living with dementia who are fearful of disclosing their diagnosis to others. Oral presentation at Honest Open Proud Meeting, Together Against Stigma Conference, Copenhagen, Denmark.

**Bhatt, J.,** Scior, K., Higgs, P., & Charlesworth, G. (2017). The ‘Who to tell, how and when’ intervention: A public consultation to inform development. Poster (2<sup>nd</sup> Prize) presented at North East London Foundation Trust Research and Development Open Day, London, UK

**Bhatt, J.,** Scior, K., Higgs, P., & Charlesworth, G. (2018). The ‘Who to tell, how and when’ intervention. Poster presented at Alzheimer’s Society Annual Research Conference, London, UK.

**Bhatt, J.,** Scior, K., Higgs, P., & Charlesworth, G. (2018). The ‘Who to tell, how and when’ intervention. Oral Presentation at Faculty of the Psychology of Older People Annual Conference, British Psychological Society, Cambridge, UK.

**Bhatt, J.,** Scior, K., Higgs, P., & Charlesworth, G. (2018). The ‘Who to tell, how and when’ intervention: supporting disclosure decision-making in dementia. Oral Presentation at Alzheimer’s Europe Conference, Barcelona, Spain.

**Bhatt, J.,** Scior, K., Higgs, P., & Charlesworth, G. (2019). Honest Open Proud for people living with dementia. Oral Presentation at Citizenship, Recovery & Inclusive Society Partnership (CRISP) – Illinois Institute of Technology, Chicago, USA.

**Bhatt, J.,** Scior, K., Higgs, P., & Charlesworth, G. (2019). The ‘Who to tell, how and when’ intervention: supporting disclosure decision-making in dementia.

Oral Presentation Stigma Conference, Indiana University, Purdue University  
Indianapolis, Indiana, USA.

**Bhatt, J.,** Scior, K., Higgs, P., & Charlesworth, G. (2019). The ‘Who to tell, how and when’ intervention: supporting disclosure decision-making in dementia. Oral Presentation Stigma Conference, Indiana University, Purdue University Indianapolis, Indiana, USA.

**Bhatt, J.,** Scior, K., & Charlesworth, G. (2019). Defining and quantifying the Stigma Experience of People Living with Dementia. Poster presented at Alzheimer’s Society Annual Research Conference, London, UK.

**Bhatt, J.,** Vermeer, P., Higgs, P., & Charlesworth, G. (2019). Creating a PPI group of carers and people living with dementia: barriers of professionalism and exclusivity. Oral presentation at British Society of Gerontology Conference, Liverpool, UK.

**Bhatt, J.,** Scior, K., Higgs, P., & Charlesworth, G. (2019). Self-stigma and disclosure decision-making in dementia. Oral presentation at Together Against Stigma, Singapore.

**Bhatt, J.,** Scior, K., Higgs, P., & Charlesworth, G. (2019). Quantifying dementia related stigma. Oral presentation at Together Against Stigma, Singapore.

**Bhatt, J.,** (2019). Stigma and Dementia. Oral Presentation at Alzheimer’s Society Research Network Volunteer Conference, London, UK

**Bhatt, J.,** Scior, K., Higgs, P., & Charlesworth, G. (2019). The ‘Who to tell, how and when’ intervention: supporting disclosure decision-making in dementia. Oral Presentation at INTERDEM Meeting, The Hague, The Netherlands.

## 10.7 List of Publications

**Bhatt, J.,** Walton, H., Stoner, C. R., Scior, K., & Charlesworth, G. (2018). The nature of decision-making in people living with dementia: a systematic review. *Aging & Mental Health*, 24:3, 363-373.

<https://doi.org/10.1080/13607863.2018.1544212>

Alzheimer's Disease International. 2019. World Alzheimer Report 2019:

Attitudes to dementia. London: Alzheimer's Disease International

**Bhatt, J.,** Ruffell, T., Scior, K., & Charlesworth, G. (accepted). "Who to tell, how and when?": development and preliminary feasibility of an empowerment intervention for people living with dementia who are fearful of disclosing their diagnosis. *Clinical Interventions in Aging*

**Bhatt, J.,** Stoner, C. R., Scior, K., & Charlesworth, G. (under review). Adaptation and preliminary psychometric properties of three self-stigma outcome measures for people living with dementia. *BMC Geriatrics*