Use of technology by persons with dementia in sharing their diagnosis

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Thesis submitted for the degree of Doctor of Philosophy

Research Department of Clinical, Educational and Health Psychology
Division of Psychology and Language Sciences
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“What we have once enjoyed deeply we can never lose. All that we love deeply becomes a part of us.” – Helen Keller

Declaration

I, Gianna Kohl, 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.

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Abstract

Background: People with dementia may want to conceal their condition for fear of consequences and stigma. However, to maximise social health, it is beneficial to tell other people about one's diagnosis. Disclosures may be made in person or, given the increasing number of people with dementia incorporating information and communication technology into their daily lives, through digital media.

Aims: This thesis explored how the face-to-face intervention 'Who to tell, how and when intervention', aimed at people with dementia who are fearful of sharing their diagnosis with others, can be adapted for digital delivery.

Methods: A systematic review and semi-structured interviews were conducted to explore disclosure and concealment of the diagnosis in person and online. Participants' use of social media and sharing of information about their dementia was explored using a cross-sectional online survey. The 'Who to tell, how and when' intervention was adapted for digital delivery through user-centred design, using focus groups. A prototype was tested using think-aloud interviews. People with dementia were involved throughout this research as participants, consultants, and collaborators.

Results: The systematic review revealed only one study that explored digital diagnosis disclosure and showed that disclosure decisions are complex and evolving, which was endorsed by participants interviewed for this thesis. 143 respondents aged 44 to 95 took part in the survey, with 77 respondents being social media users. People with dementia actively disclosed their diagnosis on social media for 'advocacy and awareness', 'peer support', and to proclaim their ‘dementia journey’. The findings were taken to adapt the intervention for digital delivery, with participants endorsing the final prototype based on feedback.

Conclusion: Technology can be a useful tool to disclose one’s diagnosis and to receive support with the dementia journey, thus enhancing social health. Collaborations with intended end users is advised to adapt face-to-face interventions for digital delivery.

Impact statement

In this thesis, I explored people with dementia disclosing their diagnosis to their social networks, and adapted the face-to-face intervention 'Who to tell, how and when', aimed at people with dementia who are fearful of sharing their diagnosis with other people, for digital delivery. This adaptation included exploring how individuals manage disclosure, which lays the foundation for identifying effective ways to provide support to people with dementia and enhance their social health. As such, this thesis generated novel insights into self-disclosure of a dementia diagnosis and describes a valuable example for researchers aiming to develop accessible interventions for people affected by the condition.

This thesis was conducted as part of my appointment as Early-Stage Researcher (ESR) in the Maria Skłodowska-Curie Innovative Training Network DISTINCT, a research network working with technology to enhance social health of people affected by dementia. I presented the work in this thesis at national and international DISTINCT training events and workshops as an invited speaker in front of fellow ESRs and international dementia researchers. The work in this thesis has informed the collaborative Best Practice Guidance (https://www.dementiainduct.eu/guidance/), which is a resource accessed by policymakers, researchers, and technology developers globally. My work has led to important guidance on enhancing the development of digital interventions and recruitment of people with dementia. As such, findings from this PhD have far-reaching implications for the dementia field.

Findings from this thesis have been and will be widely disseminated in academic circles. I have presented my work at eight national and international academic conferences as oral and poster presentations and an invited speaker, among which the annual meeting of the Gerontological Society of America, the Alzheimer's Association International Conference, and the Alzheimer Europe conference.

A version of Chapter 4 (use of social media by people with dementia) has been published as a peer-reviewed article in the International Journal of Human-Computer Interaction (IF: 4.7; Kohl et al., 2023), which was accessed over 534 times between October 2023 and December 2023. This paper was awarded the Paper of the Month award for October 2023 by INTERDEM. Manuscripts for Chapters 2 and 3 have been submitted and are under review, and a manuscript for Chapter 5 is in preparation.

I have also disseminated the work in this thesis on Twitter, in various newsletters of dementia organisations, and on the Dementia Researcher Podcast (https://www.dementiaresearcher.nihr.ac.uk/podcast-design-development-of-tech-interventions/).

Members of the dementia community have been involved in and engaged with this research, highlighting the importance of the research findings. New academic and non-academic collaborations were established, including with researchers at the University of Hertfordshire, Maastricht University, University of Galway, the University of Queensland, Alzheimer's Disease International, and Alzheimer Europe.

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List of abbreviations

AD	Alzheimer’s disease
ADI	Alzheimer’s Disease International
BCT	Behaviour change technique
BCW	Behaviour change wheel
CRIPACC	Centre for Research in Public Health and Community Care
CST	Cognitive Stimulation Therapy
DEEP	Dementia Engagement and Empowerment Project
DH	Doug Hobson
DISTINCT	Dementia: Intersectorial Strategy for Training and Innovation Network for Current Technology
DSM-5-TR	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision
ESR	Early-Stage Researcher
EWGPWD	European Working Group of People with Dementia
FC	Family carer
FTD	Frontotemporal dementia
GC	Georgina Charlesworth
GK	Gianna Kohl
HOP	Honest, Open, Proud
ICT	Information and communication technology
IF	Impact factor
INDUCT	Interdisciplinary Network for Dementia Using Current Technology

JDR	Join Dementia Research
JL	Jennifer Lynch
KS	Katrina Scior
MMU	Mauricio Molinari Ulate
NHS	National Health Service
PCA	Posterior cortical atrophy
PH	Pascale Heins
PPI	Patient and Public Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO	International prospective register of systematic reviews
PWD	People with dementia
SC	Sabrina Cardoso
SPSS	Statistical Package for the Social Sciences
UCL	University College London
UCLUS	UCL Unit for Stigma Research
UK	United Kingdom
VD	Vascular dementia
WHO	World Health Organization
WQK	Wei Qi Koh

Chapter 1: Introduction

1.1 Overview of this chapter

In this chapter, I first provide an overview of dementia in terms of its definition, epidemiology, subtypes, symptoms, and impact. I then describe two research groupings, Dementia: Intersectorial Strategy for Training and Innovation Network for Current Technology (DISTINCT) and UCL Unit for Stigma Research (UCLUS), as the context in which this research took place, influencing the conceptual drivers (stigma as a barrier to social health in dementia) and intervention selection ('Who to tell, how and when'). I then give an overview of digital technology use by older cohorts and people with dementia and describe relevant considerations for digitally adapting interventions for people with dementia. I conclude the chapter with the aims and structure of this thesis.

1.2 Dementia

1.2.1 Definition of dementia

Dementia is a collective term describing a range of diseases related to progressive neurodegenerative conditions such as Alzheimer's disease or vascular dementia. It is characterized by a decline in cognitive functioning, such as memory, language, decision-making, and planning, activities of daily living, and social participation (National Health Service [NHS], 2023). The revised Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5-TR; American Psychiatric Association, 2022) defines dementia as a major neurocognitive disorder that is characterised by substantial impairments from a previous level of performance in one or more cognitive domains. These impairments must interfere substantially with the individual’s everyday activities, that is, the person requires assistance in their daily activities such as paying bills or going shopping.

Dementia is often characterised based on the onset of symptoms. Young-onset dementia, also referred to as early-onset dementia, is defined as the occurrence of symptoms and subsequent diagnosis before an individual is 65 years old. Late-onset dementia, in contrast, refers to individuals aged 65 years and older receiving a diagnosis of dementia (van de Veen et al., 2021).

1.2.2 Epidemiology of dementia

Dementia is considered a global health concern. According to the World Health Organization (WHO, 2023) more than 55 million people worldwide are living with a diagnosis of dementia. It is estimated that 3.9 million people have young-onset dementia, which accounts for approximately 5-10 percent of the global dementia population (Hendriks et al., 2021). In the United Kingdom (UK), approximately 900,000 people have a diagnosis of dementia (Wittenberg et al., 2019) of which around 7.5% have young-onset dementia (Carter et al., 2022).

Dementia is rising more in low and middle-income countries due to population ageing and changing lifestyles and risk factors (Prince et al., 2015). Evidence has been found for several modifiable risk factors including medical conditions (e.g., depression, hearing loss, hypertension, diabetes, obesity), lifestyle choices (smoking, excessive alcohol consumption, physical inactivity), social isolation, air pollution, and lower education levels (Livingston et al., 2020). While often incorrectly assumed, dementia is not a normal part of ageing. Ageing is, however, the biggest risk factor for developing the condition (Gauthier et al., 2021).

1.2.3 Types and symptoms of dementia

There are several conditions that can cause dementia. Alzheimer’s disease is the most common one, accounting for approximately 60-70% of global cases of dementia (WHO, 2023) or around 50-75% of cases in the UK (Alzheimer’s Society, 2020). Early symptoms of Alzheimer’s disease typically include memory problems, problems with planning and language, confusion with time or place, and changes in mood and behaviour (Gauthier et al., 2021).

The second and third most common types are vascular dementia and dementia with Lewy bodies, respectively (Livingston et al., 2017). In the UK, vascular dementia accounts for approximately 20% of the cases while dementia with Lewy bodies is estimated to account for 10-15%. Common early signs of vascular dementia are mood changes, difficulties with concentration and planning, and slowness of thought, while dementia with Lewy bodies is characterised by recurrent visual hallucinations, problems with attention and alertness, and a decline in cognitive abilities (Gauthier et al., 2021).

Frontotemporal dementia (FTD) is more often diagnosed in people under the age of 65 than in people who are 65 years and older (Hogan et al., 2016). Early signs include changes in personality, behaviour, and impulse control (Gauthier et al., 2021). It can be challenging to distinguish between the various types of dementia since they often share similar clinical features, and mixed dementia, that is, having more than one type of dementia, is not uncommon (Karantzoulis & Galvin, 2011).

1.2.4 Socioeconomic impact

The current economic cost of dementia in the UK is substantial. A report commissioned by the Alzheimer's Society estimated that £34.7 billion are spent on dementia care annually (Wittenberg et al., 2019). These costs consist of health care, social care, and unpaid care. The largest proportion with around £15.7 billion is social care, that is, the cost associated with care provided at home. Approximately £13.9 billion is unpaid care provided by informal carers (e.g., partners or other family members), and £4.9 billion is care provided by the NHS. With the number of people with dementia in the UK set to increase, the expected cost for dementia care is estimated to almost triple and reach approximately £94.1 billion by the year 2040 (Wittenberg et al., 2019).

This report only takes the costs associated with late-onset dementia into consideration; research on the socioeconomic impact of young-onset dementia is limited. In contrast to people with late-onset dementia, people with young-onset dementia are of working age and usually have significant financial and work-related obligations. Though UK data on the societal economic impact of young-onset dementia is lacking, a recent survey explored the financial impact of the diagnosis on individuals and families. Mayrhofer et al. (2021) found that individuals reported notable financial strains due to premature retirement, reduced pensions, and ongoing financial insecurities, with partners or family members often having to give up their jobs as well to provide full-time care. These financial losses are likely to further contribute to the established cost of dementia care in the UK.

1.2.5 Emotional, social, and practical consequences of dementia

The cognitive and functional changes in ability that are, by definition, characteristic of dementia have emotional, social, and practical consequences for the person with dementia and their families.

On a practical level, the dementia symptoms can affect an individual's ability to manage daily tasks and activities independently. A review of qualitative research highlighted that individuals may experience disengagement from activities due to a loss of skills, among other things, which in turn can lead to a decreased confidence or loss of motivation (Górska et al., 2018). For people with young-onset dementia, the loss of independence can be particularly challenging given their typically more active lifestyle or work responsibilities (Rostad et al., 2013).

On an emotional level, both people with dementia and their families must adjust to the progressive cognitive and behavioural changes. Socially, changes in cognitive abilities can alter or disrupt relationships with family and friends. Reduced cognitive abilities, such as communication difficulties, can limit engagement in social activities (Lough et al., 2006). Family members who provide support and care for someone with dementia may experience a high caregiving burden (K. Lee et al., 2019).

1.2.6 Impact of diagnosis on identity

In the UK, the Prime Minister's Challenge on Dementia 2020 was introduced in 2015 to improve the quality of life and care for people with dementia. One key focus outlined in the Challenge was the improvement of dementia diagnosis rates (Department of Health, 2015), based on the biomedical model where diagnosis is regarded as a vital precursor to appropriate treatment. An increasing number and proportion of individuals have been receiving a dementia diagnosis in the UK since 2005, a longitudinal study showed (Donegan et al., 2017). Despite the ongoing lack of clarity on the pathophysiology of dementia, the absence of a ‘cure’ (Malik et al., 2022), or even disease-modifying treatments, the potential advantages of receiving a diagnosis are often emphasised, including, for example: an end to uncertainty, access to available symptomatic treatments and resources, ability to plan for the future, the chance to develop positive coping strategies, and an increased understanding of the causes of difficulties (Bamford et al., 2004; Dubois et al., 2016; Robinson et al., 2011).

However, receiving a diagnosis of dementia can be life-altering for individuals and their families due to the impact on perceived *identity*. The shift in identity from ‘a person’ to ‘a person with dementia’ is associated with significant emotional and social consequences, over and above the inherent impact of the dementia itself.

Changes to identity, include, for example a loss of status linked to loss of role and changing perceptions of their place in the world and independence (Read et al., 2017). This can lead to feelings of shock, sadness, depression and fear (Aminzadeh et al., 2007; Xanthopoulou et al., 2019), perhaps unsurprising for a condition described in the British press as the nation’s “biggest killer” (Brookes et al., 2018).

People with dementia may experience reduced social interactions due to others’ stereotyped expectations, prejudiced views and discriminatory actions, leading to increased social isolation (Hackett et al., 2019; Singleton et al., 2017). A global survey undertaken by Alzheimer's Disease International (ADI) found that among people with dementia in high-income countries, 38% reported having been treated unfairly in their social life (e.g., being excluded from social gatherings), 41% reported having been laughed about, and 55% reported having been told to not do things they still could do because of their diagnosis. According to the survey, experiences of discrimination were commonly higher in low- and middle-income countries than high-income countries.

People with young-onset dementia may additionally grapple with disbelief in themselves and others due to the unexpected nature of dementia at a younger age (Clemerson et al., 2014) and the common misconception that people with dementia are necessarily 'old' (Cahill et al., 2015; Low & Purwaningrum, 2020).

1.2.7 Dementia as a stigmatised condition

Social devaluation and associated discrimination have been referred to as consequences of 'stigma'. The negative attitudes and fear surrounding dementia mean that it is often regarded as a 'stigmatised condition' (Herrmann et al., 2018; T. Nguyen & Li, 2020; Werner, 2014). The term 'stigma' was used by Goffman (1963) to refer to an "attribute that is deeply discrediting" (p. 3). The 'internalisation' of the negative connotations of a stigmatised condition by an individual has been termed self-stigma (Corrigan & Watson, 2002). Self-stigma has been observed in people with dementia, for example Gajardo et al. (2022) conducted interviews with eleven people with dementia and found that participants felt ashamed and 'labelled' by their diagnosis, which had a "deeply negative meaning for them" (p. 2484).

Higher levels of self-stigma in people with dementia have been found to correlate positively with depression and anxiety, and negatively with self-esteem, perceived social support, and physical health (Bhatt et al., 2023; Burgener, Buckwalter, Perkhounkova, & Liu, 2015). Self-stigma can create a range of barriers for people with dementia, such as a lack of confidence, reduced activity participation, delayed help-seeking or social withdrawal (T. Nguyen & Li, 2020; Parker et al., 2020).

The self-stigma observed in people with dementia can be reinforced by *enacted stigma*, that is, actual unfair treatment or discrimination, which may subsequently affect dementia symptoms and quality of life (Ballard et al., 2018). The social withdrawal which might follow enacted stigma is also associated with increased risk of cognitive decline (Lara et al., 2019). A further stigma concept of relevance to dementia is 'concealability'. Given the recent emphasis on early detection and diagnosis of dementia (Alzheimer Europe, 2018; WHO, 2017), more people with dementia are being diagnosed in the early stages when changes may not be obvious to the casual observer, which can make concealing a diagnosis easier (Gove et al., 2016). Therefore, mild dementia can be considered a concealable stigmatised condition, also referred to as a *concealable stigmatised identity* (Pachankis, 2007). It has been found that a quarter of people with dementia report concealing or hiding their diagnosis because of the stigma associated with the condition (ADI, 2019).

In summary, dementia presents a significant challenge to the wellbeing of both the individual and their families, not only due to the cognitive and functional changes associated with dementia, but also due to psychological and social processes of stereotyping, prejudice and discrimination, leading to 'self-stigma' in the person with dementia even when changes are concealable, and 'enacted stigma' in social networks and society when the diagnosis is known or suspected.

1.3 Stigma and wellbeing in dementia: DISTINCT and UCLUS

The research presented in this thesis has been influenced by the conceptual positioning of two networks, both of which are concerned with enhancing wellbeing through the reduction of stigma. These networks are DISTINCT (see https://www.dementiadistinct.com/) and UCLUS (see https://www.ucl.ac.uk/pals/research/clinical-educational-and-health-psychology/research-groups/ucl-unit-stigma-research-uclus). I now describe DISTINCT and UCLUS in turn, with particular emphasis on conceptualisation of the relationships between stigma and wellbeing, and technologies to enhance wellbeing through reduction of self-stigma. I then describe the 'Who to tell, how and when' intervention that forms parts of this thesis.

1.3.1 DISTINCT: Enhancing social health through use of technology

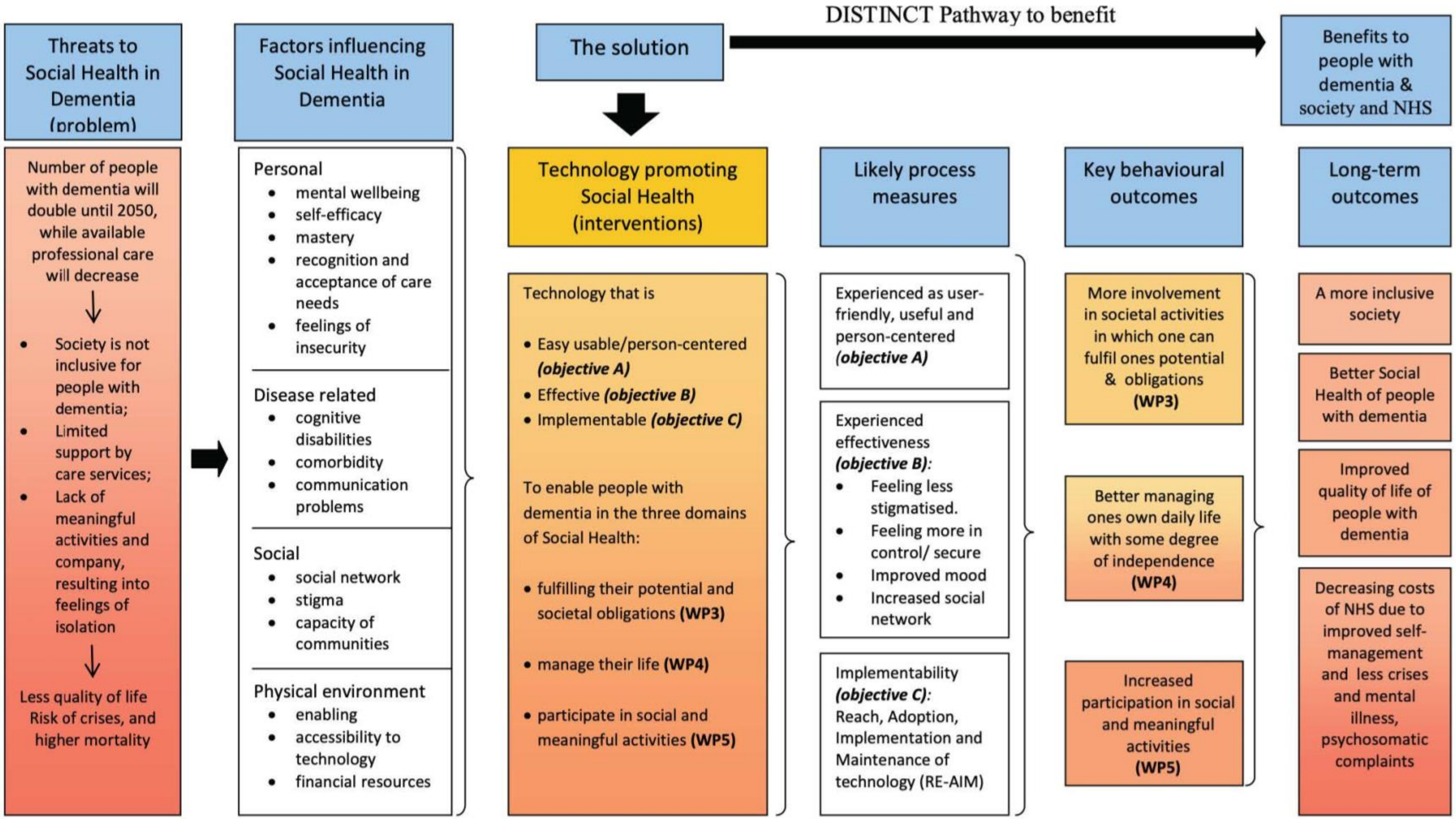
The DISTINCT training network has involved 15 Early-Stage Researchers (ESRs) across seven European countries supervised by members of INTERDEM (a pan-European network comprising leading dementia researchers, see https://www.interdem.org). The primary aim of DISTINCT is to demonstrate how technology can improve the wellbeing of people affected by dementia. Use of technology in the dementia field is not new. Indeed, it has been growing since the early 2000s (Topo, 2009), and a wide range of interventions or support utilising technology are now being used by people with dementia living at home. These include technologies specifically developed for this population, termed ‘assistive technologies’, and ‘off-the-shelf’ technologies such as mobile phones (Meiland et al., 2017).

Within INTERDEM, ‘wellbeing’ is considered “the ability to adapt and self manage”, as described within Huber’s definition of social heath (Huber et al., 2011, p. 3). Huber et al. (2011) created the concept of ‘social health’ to address the perceived limitations of the WHO’s 1946 definition of health as “a state of complete physical, mental, and social wellbeing” (WHO, 2020). The social health framework was adopted by INTERDEM as a ‘capability-led’ approach that both acknowledges the negative experiences of dementia and the potential for an adaptive response to the inherent changes (de Vugt & Dröes, 2017; Vernooij-Dassen & Jeon, 2016). The social health framework consists of three domains: (1) the capacity to fulfil one’s potential and obligations; (2) the ability to manage life with some degree of independence; and (3) the ability to actively participate in social activities (Dröes et al., 2017). All domains have influencing factors on a personal, disease-related, social, and physical level. Applied to the person with dementia, the first domain comprises the ability to function in society according to one’s talents and competencies (‘potential’) and social demands (‘obligations’), with influencing factors being a person’s mental wellbeing, level of resilience, or the severity of cognitive symptoms. The second domain can be operationalised as a person’s ability to keep their autonomy, to solve daily-life problems, and to adapt and cope to emotional and practical consequences of their dementia symptomatology. Influencing factors are a person’s pre-morbid personality, their life values and a felt sense of usefulness, or dementia-related disabilities in the subsequent stages of their condition. The third and final domain refers to being active and partaking in meaningful activities as well as engaging in social interactions and relationships. Influencing factors include feeling insecure participating in social activities due to (communication) difficulties or cognitive/physical abilities to attend social gatherings (Dröes et al., 2017). Utilising the social health framework, researchers are enabled and encouraged to support people with dementia in maintaining or enhancing their social health, which can include the development and use of psychosocial interventions, including those utilising digital technologies (Moniz-Cook et al., 2011).

The social health framework guided the research conducted in the DISTINCT network, with each of the 15 ESRs focusing on a project within one of the three domains. Figure 1.1 shows the logic model for DISTINCT, illustrating the way in which technology interventions can benefit people with dementia, society and healthcare systems by developing useable, effective and implementable technology to mitigate threats to social health. My task as DISTINCT ESR10 was to develop a user-friendly, useful, person-centred technology (see logic model, objective A) aimed at increasing participation in social and meaningful activities (see logic model, work package 5).

As shown in the second column of the model, factors influencing social health in dementia include personal, disease-related, and environmental factors, comprising both social and physical environments. Notably, stigma is an important social factor impacting people with dementia and their social health. As disclosing one's diagnosis is a social undertaking that includes a person disclosing and a disclosure recipient, this PhD project is rooted in the third domain ‘the ability to actively participate in social activities’. It is understood that supporting people with dementia in their disclosure process can help address the stigma associated with the condition. This, in turn, can enhance their ability to take part in meaningful activities and to form or maintain relationships. The third column of the model underscores that achieving this participation relies on the development of usable and person-centered technology. Such technology is essential for enabling individuals with dementia to fulfil their potential and societal obligations, manage their daily lives, and engage socially, thereby fostering a more inclusive and supportive environment.

Figure 1.1. Promoting social health in dementia with usable, effective and implementable technology - Logic model for DISTINCT



1.3.2 UCLUS: Stigma and wellbeing

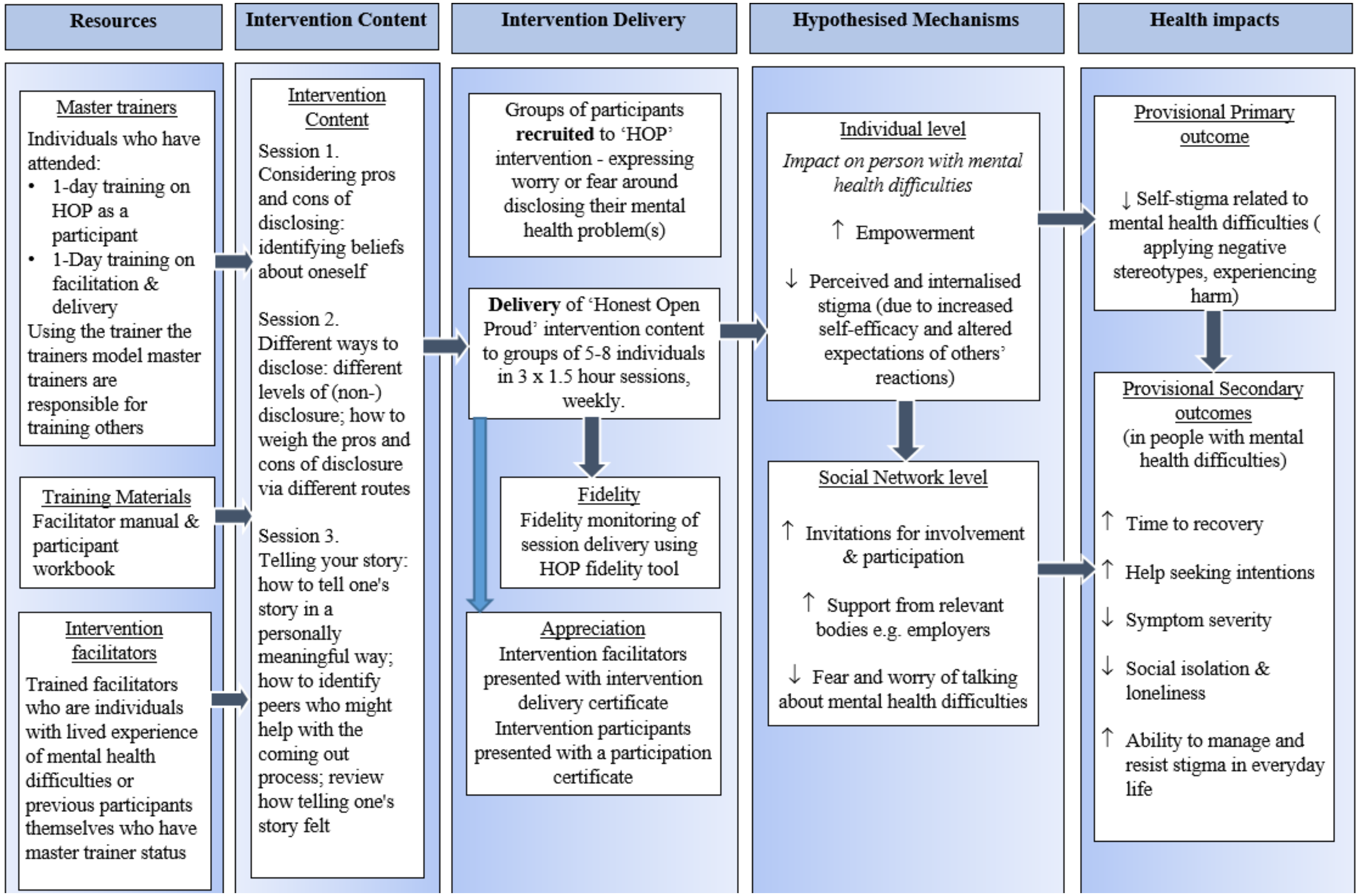
In addition to me being embedded in DISTINCT, I have also been a member of UCLUS, founded by my secondary supervisor Katrina Scior. UCLUS is a hub for innovation in research and theory production in the stigma field, which gave me the opportunity to consider in more detail the relationship between stigma and wellbeing in dementia, and also to consider the use of stigma-reduction interventions.

UCLUS is part of a wider network of organisations developing and evaluating the 'Honest, Open Proud' (HOP) intervention to support individuals who have been diagnosed with stigmatised conditions (https://hopprogram.org/). People with a stigmatised condition are faced with decisions regarding if and to whom they want to disclose their diagnosis, how much they want to disclose, and at what point in time. They may choose to conceal their diagnosis due to worries about or experiences with prejudice, discrimination, and rejection by others (Camacho et al., 2020; Corrigan, 2005), or to avoid social exclusion and negative evaluations (Pachankis, 2007). Whilst concealing one's stigmatised condition may protect individuals from further stigmatisation (Camacho et al., 2020), studies have shown that concealment can have negative effects on individuals. For example, a cross-sectional survey study by Quinn et al. (2017) conducted with 288 individuals with mental health problems, chronic illness or minority sexual orientation found that actively concealing one's identity was predictive of worse quality of life. Another cross-sectional study by Hagger and Riley (2019) exploring the consequences of concealing acquired brain injury found that active concealment was associated with higher social anxiety, social avoidance, loneliness and lower self-esteem.

Concealment is also associated with social withdrawal (Camacho et al., 2020). In short, people with stigmatised conditions may hesitate to tell others about their diagnosis due to concerns that ‘coming out’ may lead to prejudice or negative treatment from others. However, disclosure can be beneficial as it can alleviate the stress associated with concealment, increase the likelihood of receiving social support, and improve social connections and interactions (Camacho et al., 2020; Chaudoir & Fisher, 2010). Disclosure can also enable access to valuable resources and increase levels of self-esteem and empowerment (Beals et al., 2009).

The HOP intervention, a three-session, in-person, peer-led, group-based intervention (Corrigan et al., 2013; Scior et al., 2019), was originally devised on the premise that supporting disclosure decisions can reduce stress associated with stigma and a fear of being found out, reduce self-stigma, and empower individuals by increasing their self-efficacy in coping with stigma, thus ultimately supporting the journey toward increased wellbeing (Scior et al., 2019). The HOP logic model is shown in Figure 1.2, outlining intervention resources, content, and delivery, as well as its hypothesised mechanisms and health impact.

Figure 1.2. Logic model for HOP



Note. The figure was adapted from 'Supporting mental health disclosure decisions: The Honest, Open, Proud programme,' by K. Scior, N. Rüsch, C. White, and P. Corrigan, 2019, *The British Journal of Psychiatry*, pp. 1-3 (https://doi.org/10.1192/bjp.2019.256)

The HOP intervention has been evaluated with adolescents and adults with mental health problems, including suicide attempt survivors, and is currently being adapted for and tested with people with Tourette syndrome, psychosis, substance use disorders, and urinary incontinence (Rüsch & Kösters, 2021). A recent meta-analysis examining the efficacy of HOP found that it reduced perceptions of stigma-related stress and positively affected self-stigma but had less consistent effects on depressive symptoms (Rüsch & Kösters, 2021).

A dementia-specific HOP-intervention has also been developed within UCLUS, namely the 'Who to tell, how and when' intervention (Bhatt et al., 2020). It was the adaptation and testing of this intervention for digital delivery that was written into the programme of work for ESR 10 of DISTINCT as an intervention with potential to enhance participation in social activities and thus improve social health. Therefore, in the next section, I summarise the early development of the 'Who to tell, how and when' intervention, as carried out by Jem Bhatt and Tamatha Ruffell (Bhatt et al., 2020).

1.3.3 The 'Who to tell, how and when' intervention

Similar to HOP, 'Who to tell, how and when' is a three-session, group-based intervention guided by a trained facilitator. The process of adapting HOP into 'Who to tell, how and when', was described in three stages by Bhatt and colleagues (2020): 1) identifying the existing evidence base and theory of HOP, 2) modifying the language and content from 'mental health' to 'dementia', ensuring relevance and accessibility through consultation with researchers and people with lived experience, and 3) pilot testing with people affected by dementia.

Intervention participants consist of people with dementia and their carers, as research has established the beneficial effects of dyadic psychosocial interventions on participants (van't Leven et al., 2013). The group facilitators for the 'Who to tell, how and when' intervention guided participants through a paper-based manual that comprises information, exercises, vignettes, and quotes by people affected by dementia. During the sessions, participants were invited to reflect on the content and discuss their thoughts and experiences with each other. Table 1.1 provides an overview of the content of the sessions, the functions applied in each session, and the techniques used to convey the functions. The latter two are based on the Behavior Change Wheel (BCW; Michie et al., 2011) and BCT (Behavior Change Techniques) taxonomy (Michie et al., 2013), which were used to describe the intervention functions and content in more detail.

The aim of the intervention is not to persuade individuals to always disclose their diagnosis, but to provide the space to reach a decision regarding disclosure that feels right for the person. Preliminary testing of the face-to-face intervention with two groups (seven dyads) showed that the intervention was well-received, with participants valuing a shared space to discuss their experiences and reflect on disclosure decisions (Bhatt et al., 2020).

Table 1.1. Content and main features of 'Who to tell, how and when'

Session	Session details	Intervention functions based on BCW	BCTs
1. Talking about dementia	• Vignette on the meaning of getting the diagnosis • Information on the emotional effect of the diagnosis • Vignettes on the emotional effect of the diagnosis • Group discussion on meaning of 'dementia' and the emotional effects of a diagnosis • Vignettes on pros and cons of disclosing or concealing one's diagnosis • Group discussion on the pros and cons of disclosing or concealing	• Education • Modelling • Training	• Social support (unspecified) • Information about social and environmental consequences • Information about emotional consequences • Demonstration of the behaviour • Credible source • Pros and cons • Verbal persuasion about capability
2. Who to tell, how and when?	• Vignettes on the range of telling • Group discussion about the consequences of telling no one to telling everyone • Information about support systems • Individual exercise on who a person has told and who should or should not be told • Vignettes on how and when to tell followed by group discussion	• Education • Modelling • Training	• Social support (unspecified) • Demonstration of the behaviour • Credible source • Verbal persuasion about capability • Focus on past success

	• Information on possible reactions from others • Vignette on possible reactions followed by group discussion • Homework on who, how and when to tell		
3. Support for me, for you, for us	• Group discussion on homework • Information on who ‘owns’ the diagnosis followed by group discussion • Vignette on when others disclose the diagnosis followed by group discussion • Group discussion on navigating differences in opinion • Information on sources of support	• Education • Modelling • Training	• Social support (unspecified) • Demonstration of the behaviour • Credible source • 1Verbal persuasion about capability

Note. BCT = Behaviour change techniques, based on Michie et al. (2013); BCW = Behaviour change wheel, based on Michie et al. (2011).

However, there were a number of limitations in the adaptation of the ‘Honest, Open, Proud’ intervention to create the ‘Who to Tell, How and When’ intervention for people with dementia. Firstly, the adaptation was undertaken in the absence of any literature review on self-disclosure by people with dementia. This seemingly notable absence was due to the early adapters of HOP for dementia, Jem Bhatt and Tamatha Ruffell, focusing on other important points of consideration during their reviews of the literature. Tamatha Ruffell focused on the involvement of supportive others in interventions for people with dementia (Ruffell, 2019) and Jem Bhatt focused on the nature of decision-making in people with dementia (Bhatt et al, 2020). These were important points of consideration for the ‘Who to Tell, How and When’ intervention, given the involvement of supportive others, the decision-making elements of the intervention, the cognitive demands of decision making, and the cognitive impairments inherent in dementia, but nonetheless left a significant gap in the developmental literature for the intervention. Another limitation was that the vignettes included in ‘Who to tell, how and when’ were generated from the ‘Promoting Independence in Dementia’ (PRIDE) programme (Csipke et al., 2021; Yates et al., 2019), which focused on remaining physically, cognitively, and socially active rather than specifically addressing experiences with self-disclosure of a diagnosis. While these vignettes were valuable for ‘Who to tell, how and when’ and its feasibility testing (Bhatt et al., 2020), it is unclear if they cover all relevant aspects of self-disclosure.

1.4 Dementia and digital technology

Information and Communication Technology (ICT) has become ubiquitous in our society, changing how people communicate, shifting from primarily in-person *offline* communication to technology-mediated *online* communication. Exploring ways in which individuals with dementia engage with and utilise technology is therefore important.

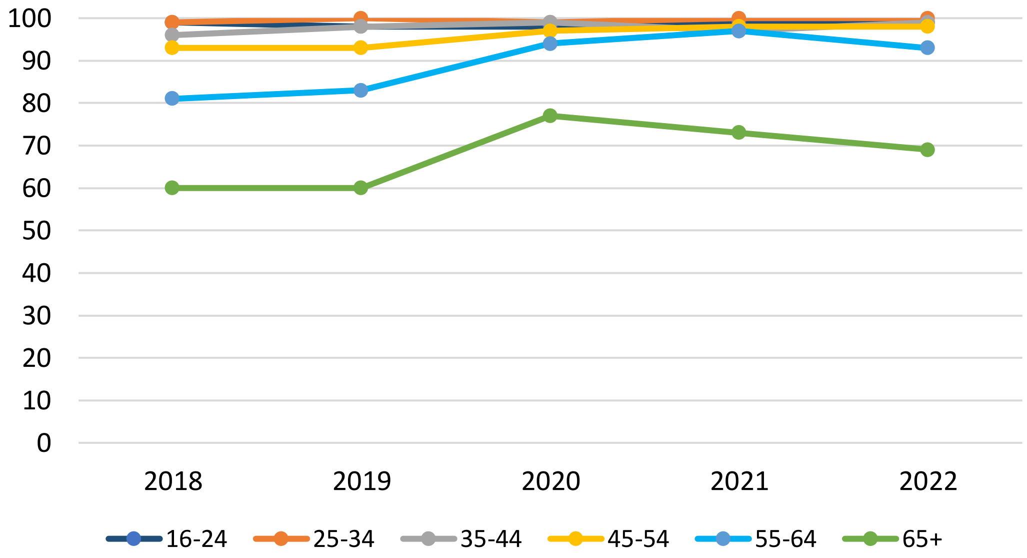
In this thesis, I focus on everyday, off-the-shelf technologies as these are readily available and frequently used by people with and without dementia (Fairburn & Patel, 2017). More specifically, I focus on 'digital technologies', by which I am referring to screen-based devices, systems or applications that utilise the internet to view, create, share or store information or data. Examples include smartphones, laptops, tablet computers (tablets) and mobile applications (apps). A similar definition has previously been used to explore the use of digital technology to provide meaningful activities to people with dementia (Goodall et al., 2021). In the following paragraphs, I provide an overview of internet and digital technology use by people above the age of 55 and people with dementia, followed by describing barriers and advantages to using ICT among these populations as a pre-cursor for considering the adaptation of psychosocial interventions for people with dementia for online delivery.

1.4.1 Internet and digital technology use by older cohorts

Digital technologies and the internet have been increasingly adopted by the general population, including people aged 55 years and older. According to a recent report by Ofcom (2023) based on data collected in 2022 in the UK, 88% of people aged 55 to 64, and 69% of people aged 65 and older use the internet at home, increases of 10% and 27%, respectively, compared to 2013 (Ofcom, 2014). Figure 1.3 provides an overview of the percentage of people in the UK who have had access to the internet at home over the past five years by age. Though people aged 55 years and older are still less likely to have internet access compared to their younger counterparts, this population has seen the largest increases over the years. Based on these increases and a 'tech-savvy' population that is aging, it is likely that the number of people aged 55 years and older with internet access at home will increase in the future.

As can be seen in Figure 1.3, there is a slight decrease in the number of people aged 55 and older with internet access between the years 2020 to 2022. This decline may be due to changes in the way data were collected by Ofcom due to the COVID-19 pandemic.

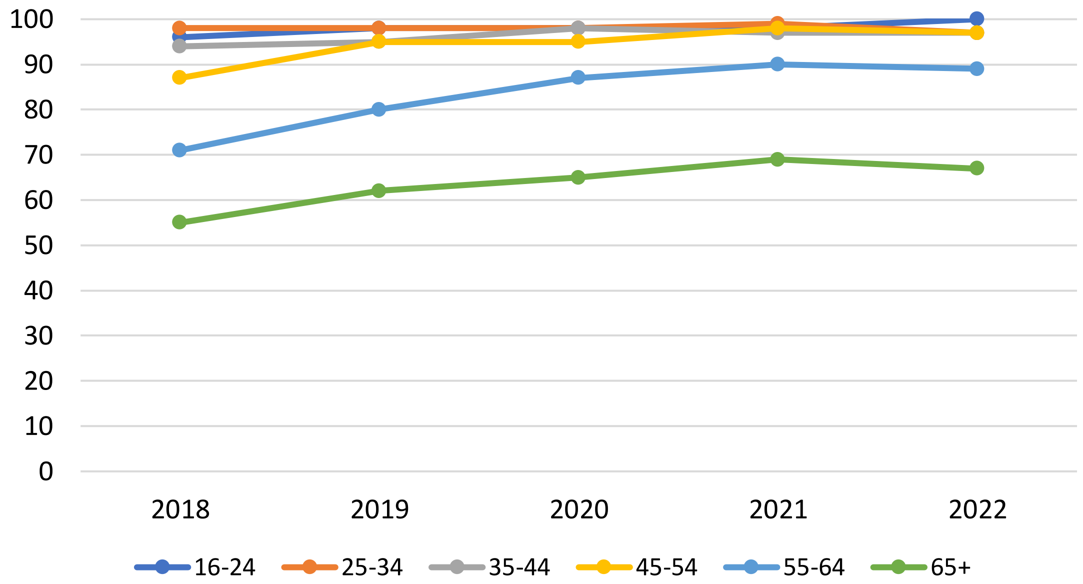
Figure 1.3. Internet access in the UK by age group, 2018-2022



Note. Based on data taken from the annual *Adults' media use and attitudes reports,* OfCom (2023).

Similarly, the number of adults in the UK who own a smartphone has increased over the years. In 2022, 89% of adults aged 55 to 64 and 67% of adults aged 65 and older owned a smartphone, increases of 17% and 12%, respectively, compared to 2018 (Ofcom, 2019). Figure 1.4 provides an overview of smartphone ownership in the UK by age for the years 2018 to 2022.

Figure 1.4. Smartphone ownership in the UK by age group, 2018-2022



Note. Based on data from the annual *Adults' media use and attitudes reports,* OfCom (2023)

As our society has increasingly become digital, individuals who do not engage with or do not have access to digital technology are at risk of being left behind. This has become especially evident during the COVID-19 pandemic in which older adults had to adopt technology they had not used before to stay socially connected (Haase et al., 2021). The disparity between people who use and those who do not use ICT is called the ‘digital divide’. This digital divide is especially prevalent for individuals aged 65 and older (Lythreatis et al., 2022).

1.4.2 Internet and digital technology use by people with dementia

Research has identified people with dementia as users of the internet and digital technology devices. In a recent cross-sectional study exploring the use of digital technologies by people with dementia, it was found that 89% of the participants reported daily or almost daily internet use (A. R. Lee, McDermott, et al., 2023). Another study conducted with 221 people with cognitive impairments found that the majority used mobile phones (91%), computers (86%), and smartphones (53%), with some participants using multiple devices (LaMonica et al., 2017).

Two reviews have explored the literature on the use of digital technologies by people with dementia and cognitive impairments. In a systematic review conducted by Wilson et al. (2022), which focused on tablet and smartphone use, it was found that, overall, people with cognitive impairments not only successfully used smartphones and tablets but also enjoyed using them. Another review by Joddrell and Astell (2016) found that people with dementia were able to use tablets independently, including individuals who did not feel confident using digital technologies. They also found that touchscreen devices, due to their lack of a keyboard, are intuitive and easy to use for this population. However, those not familiar with digital technologies often need support using them. For example, a systematic review by Goodall et al. (2021) on the use of digital technologies in creating meaningful activities for people with dementia found that in the majority of the studies, support by another person was needed. However, the authors did not state if the participants had prior knowledge of using digital technologies.

1.4.3 Barriers to digital technology use

Studies have identified barriers to using digital technologies for older adults with and without dementia. Barriers for individuals aged 65 years and older without cognitive impairments include costs, inappropriate design, lack of experience or awareness, lack of guidance, lack of interest, and lack of self-efficacy and confidence (Delello & McWhorter, 2017; Vaportzis et al., 2017). Research suggests several ways to tackle these barriers. A cross-sectional survey study exploring digital technology adoption with 1,204 community-dwelling adults, of which 461 were adults aged 60 and older, found providing clear instructions and step-by-step guidance on how to use a computer boosted participants' confidence in using ICT (Czaja et al., 2006). Similar results were found in a qualitative study conducted with 53 community-dwelling adults aged 68 to 95, stating that providing age-appropriate support and advice can address a lack of experience (Peek et al., 2016).

Despite the growing development and adoption of digital technologies for people with dementia, it is essential to acknowledge that the cognitive impairments associated with dementia can pose challenges to effective digital technology use. Memory deficits, attention problems, and difficulties with abstract thinking may lead to challenges in learning how to use (new) technological devices (Gibson et al., 2015; Jekel et al., 2015). Timing can also be important, as people in the early stages of dementia might more easily learn how to use technologies than those in moderate stages (Riikonen et al., 2013). It is therefore important to consider an individual’s abilities and tailor the design and development of these technologies accordingly. Support with learning how to use digital technology and providing instructions and ongoing support can help mitigate these barriers and promote successful technology use in people with dementia (Astell et al., 2019; Lim et al., 2013).

1.4.4 Advantages to digital technology use

Research has also identified advantages to using digital technologies for older adults with and without dementia. Two important ones are maintaining social connections and maintaining cognitive functioning. In terms of social connections, a mixed-methods study, comprising 19 adults aged 61 and older without dementia, who had not used tablets before, found that regular iPad use over a six-week period enabled participants to renew or enhance social connections, thereby reducing social isolation (Delello & McWhorter, 2017). A review encompassing 23 articles found that internet use positively affected the quality of life of people aged 50 years and older by enabling them to maintain social connections, access information, and engage in leisure activities (Aggarwal et al., 2020). Regarding cognitive benefits, a recent cohort study which followed 18,154 adults aged 50 to 65 without dementia for up to 17 years found that regular internet use was associated with approximately half of the risk of developing dementia compared to non-regular use (Cho et al., 2023).

Digital technologies can have several advantages for people with dementia. For example, Astell et al. (2019) provided an overview of different technologies and identified digital ones as crucial assets to support people with dementia with pursuing social and leisure activities. Examples include smartphones with GPS and map functions to aid wayfinding (Kwan et al., 2020) and apps aimed at enhancing self-management (A. R. Lee, Csipke, et al., 2023; Øksnebjerg et al., 2019). Social media have been found to support people with dementia to stay socially connected (D. Craig & Strivens, 2016; Talbot et al., 2020). The same applies to video call platforms, for example, to stay connected with peer support groups (Gerritzen et al., 2023). The use of these platforms by people with dementia has increased in recent years, particularly in response to the COVID-19 pandemic (Cooper et al., 2021; Talbot & Briggs, 2022).

1.4.5 Digitally adapting psychosocial interventions for people with dementia

Lockdowns and in-person restrictions due to the COVID-19 pandemic accelerated the transition of various human behaviours to an online environment (Vargo et al., 2021). This has included interventions intended to enhance health and wellbeing. Adapting interventions for digital delivery can enhance their cost-effectiveness by eliminating the need for appointments or wait lists (Holmes et al., 2018). Digital delivery also offers increased accessibility, flexibility, and engagement as it removes the need to travel, ensures confidentiality, and allows for integration into everyday life (Griffiths et al., 2006; Holmes et al., 2018).

It is common practice in implementation science to adapt, i.e., modify, existing evidence-based interventions with regard to their overall context, with context referring to “a set of characteristics and circumstances that consist of active and unique factors, within which the implementation is embedded” (Pfadenhauer et al., 2017, p. 6). Several manualised interventions for people with dementia have been adapted for a different context, including for online delivery. Perkins et al. (2022) adapted Cognitive Stimulation Therapy (CST) as a result of services moving online during the COVID-19 pandemic. CST is an established psychological intervention for people with dementia that is delivered by trained facilitators. The researchers adapted the existing group manual following an established framework (P. Craig et al., 2019) and consulted people with dementia, informal carers, service managers, and previous groups facilitators in the process. The intervention was then trialled and delivered using Zoom. Rai, Schneider et al. (2020) adapted individual CST for online delivery and developed an app that was well received by people with dementia and carers. A. R. Lee, Csipke et al. (2023) adapted the 'Promoting Independence in Dementia' (PRIDE) manual, which aims to improve the self-management, independence, and quality of life of people with dementia, into an app. Both the CST and PRIDE adaptation studies utilised a user-centred design, which is an iterative approach to product or intervention design that consists of several phases and focusses on the needs and wishes of end users in the development (Courage & Baxter, 2005). In their development of the PRIDE app, A. R. Lee, Csipke et al. (2023) followed guidelines on designing accessible online content for people with dementia, which includes the use of dementia-friendly language and engaging images (Schnelli et al., 2021; Williams, 2017). They also applied the think-aloud method to test the intervention's acceptability and usability. Think-aloud methods are frequently used in the development of internet- or computer-based interventions (Jaspers, 2009). While Perkins et al. (2022) adapted CST for digital delivery themselves, Rai, Schneider et al. (2020) and A. R. Lee, Csipke et al. (2023) commissioned two software companies with the adaptations of their interventions. Overall, the adaptation of face-to-face interventions for digital delivery not only positively influences their accessibility, flexibility, and engagement but also contributes to the broader landscape of interventions available for people with dementia. By providing alternatives to traditional in-person approaches, these adapted interventions offer people with dementia and their carers valuable resources for managing their condition and improving their social health.

1.5 Rationale for this thesis

1.5.1 Use of digital technologies to support disclosure

Disclosing a stigmatised condition can be done in face-to-face or ‘real-life’ interactions but also online. This seems especially relevant considering that the overall number of internet and digital technology users, which includes people with dementia, is increasing. As such, the combination of disclosure and digital technologies (e.g., on social media) offers individuals additional avenues for sharing their stigmatised condition with diverse audiences, which can serve various purposes such as obtaining support (Coulson, 2005). As digital technologies have become ubiquitous in our society, research has been exploring what individuals with stigmatised health conditions disclose about their identity or diagnosis online. Examples include research on social media disclosure in people with mental health difficulties (Andalibi et al., 2017), inflammatory bowel syndrome (O’Leary et al., 2020), epilepsy (McKinlay & Ridsdale, 2018), or a diverse range of chronic illnesses (Sannon et al., 2019). For example, in their cross-sectional qualitative interview study, McKinlay and Ridsdale (2018) explored social media disclosure among 14 people with epilepsy. The researchers found that participants perceived social media valuable for learning about epilepsy, facilitating the exchange of social support, and advocating for greater awareness regarding epilepsy and stigma. Similar findings were reported in studies on other stigmatised health conditions (Andalibi et al., 2017; O'Leary et al., 2020; Sannon et al., 2019). Social media can also serve as a preliminary avenue for individuals to disclose their health conditions, offering the option of initially selecting private platforms or groups if they are reluctant to share their diagnosis publicly. They may then become more comfortable with disclosing their diagnosis over time (Sannon et al., 2019). While these findings indicate that social media can be useful for individuals with stigmatised health conditions, research on social media disclosure in people with dementia is lacking. Research on this topic with people with dementia may also indicate how disclosure online facilitate optimal social health in this population.

1.5.2 Involvement of people with dementia

In contrast to previous practices, current research recognises and values the contribution of people with dementia to their studies, a shift strongly influenced by a 'nothing about us without us' maxim promoted by dementia activists and groups like the European Working Group of People with Dementia (EWGPWD) and the Dementia Engagement and Empowerment Project (DEEP; Morbey et al., 2019). Therefore, the involvement of people with dementia as Patient and Public Involvement (PPI) contributors (Gove et al., 2018), defined as research being carried out 'with' or 'by' members of the public, as opposed to 'for' or 'about' them (National Institute for Health and Care Research, 2021) is crucial. The reason for including people with dementia is to gain as much insight into their personal experiences (Murphy et al., 2015) to maximise the likelihood of achieving a useable technology.

1.6 Chapter summary and thesis aim

Concerns about stigma can prompt people with dementia, especially those with young-onset dementia or those in the early stages, to conceal their diagnosis. This can lead to increased social withdrawal and limited social health. The growing use of the internet and digital technologies, along with social media’s role in disclosing stigmatised conditions, suggests that creating a digital version of ‘Who to tell, how and when’ could be beneficial for people affected by dementia. However, the specific factors influencing the decision of people with dementia to disclose their diagnosis were not systematically investigated during the initial development of ‘Who to tell, how and when’. Consequently, this thesis will first systematically explore factors associated with disclosure of a diagnosis by people with. The findings from this systematic review serve as the foundation for further studies which aid the adaptation of ‘Who to tell, how and when’ for digital delivery. Specifically, the empirical work conducted in this thesis is guided by the following research question:

- How can the ‘Who to tell, how and when’ intervention be adapted for digital delivery?

1.7 Structure of thesis

To answer the research question guiding this thesis, I conducted four distinct but related studies. An overview of these studies can be found in Table 1.2. This table provides information on the studies' methodologies and the people involved, and shows their relationship to each other, which I will elaborate on in the following. The first study I conducted is described in Chapter 2. In this chapter, I present the systematic review on factors related to people with dementia disclosing their diagnosis, both online and offline. Findings from Chapter 2 influenced the research aims of the studies in Chapters 3 and 4, which were conducted simultaneously. Chapter 3 presents a qualitative study in which I conducted semi-structured interviews with people with dementia that I analysed narratively to gain a more in-depth understanding of disclosure, including disclosure changes over time as well as the use of social media for disclosure. To gain a more comprehensive understanding of the use of social media for disclosure, Chapter 4 describes a convergent mixed-methods study exploring how people with dementia use social media, including differences in use between those with young-onset and late-onset dementia, and how they share their diagnosis on social media. Findings from Chapters 2, 3, and 4 have influenced the study I conducted in Chapter 5. In this final study, I use an iterative user-centred design approach to adapt the 'Who to tell, how and when' intervention for digital delivery. I conclude this thesis with an overarching discussion of key findings presented in relation to the thesis's research question, a reflection, and implications for future research, which is presented in Chapter 6.

Table 1.2. Overview of studies conducted for this thesis

Chapter 2

Objective:
To explore factors associated with disclosing a diagnosis of dementia by people with dementia

Study design:
Systematic review of qualitative studies

Data collection and analysis:
Systematic search of databases; details of included studies were extracted; thematic synthesis

Involvement of other researchers:
Support from MMU with study selection and data extraction, and JB with quality appraisal

Involvement of people with dementia:
People affected by dementia as PPI contributors to corroborate findings from included studies

Chapter 3

Objective:
- To explore how people with dementia experience disclosing their condition to other people
- To explore how disclosure changes over time

Study design:
Qualitative exploratory study using a narrative approach

Data collection and analysis:
Interview transcripts based on semi-structured interviews; narrative analysis

Involvement of other researchers:
- Support from WQK with data analysis
- Collaboration with DH on ethics application and topic guide

Involvement of people with dementia:
People with dementia as study participants

Chapter 4

Objective:
- To describe how people with dementia use social media and establish cohort differences
- To describe motivations for people with dementia posting dementia-related content

Study design:
Convergent mixed-methods study

Data collection and analysis:
- Numerical scores based on questions designed for this study; statistical analysis
- Qualitative data collected through open-ended questions; qualitative content analysis

Involvement of other researchers:
- Support from WQK with data analysis

Involvement of people with dementia:
- People with dementia as study participants
- Members of EWGPWD as PPI contributors to provide feedback on survey design

Chapter 5

Objective:
- To describe preferences for a digital adaptation of ‘Who to tell, how and when’
- To develop, and undertake preliminary evaluation, of prototypes

Study design:
Qualitative, applying an iterative (3-step) user-centred design approach

Data collection and analysis:
Transcripts from focus groups and think-aloud interviews; qualitative content analysis

Involvement of other researchers:
- Support from SC with data analysis for 1st round of focus groups (step 1)
- Support from SC and PH with notetaking in focus groups (steps 1 and 2)

Involvement of people with dementia:
People affected by dementia as study participants

Chapter 2: People with dementia disclosing their diagnosis to others: A systematic review

2.1 Chapter overview

As highlighted in Chapter 1, people with dementia may hesitate to disclose their diagnosis to other people, creating a barrier to participation in social activities and preventing the optimisation of social health. Despite the important role that disclosure plays in facilitating subsequent access to support, no review of self-disclosure studies was carried out in the course of the development of the 'Who to Tell, How and When' intervention, and there is no existing review on self-disclosure of dementia by people with the diagnosis using social media or digital technologies. In this chapter I address this deficit by presenting a systematic review on factors associated with people with dementia disclosing their diagnosis to other people both online and offline and consider the implications for future research, and for the further development of the 'Who to Tell, How and When' intervention.

2.2 Introduction

Self-disclosure, or disclosure, can be defined as the process of intentionally communicating or revealing personal information about oneself to others (Chaudoir & Fisher, 2010). Disclosing personal information can give an individual the opportunity to express personal thoughts, needs and feelings, and build relationships with others (Masur, 2019). Individuals often decide to not disclose personal information, that is, to conceal parts of themselves and their identity, when they are concerned about the potential consequences of disclosure.

A previous systematic review on factors associated with self-disclosure in individuals with mental health problems found that stigmatisation and anticipated negative responses were the most mentioned reasons for concealment (Grice et al., 2017). Similar findings were described by Brohan et al. (2012) who explored self-disclosure of mental health problems in the workplace. However, employees also described positive experience such as support. Unlike individuals with an obvious and noticeable stigmatised attribute, individuals with a concealable stigmatised identity must face self-disclosure decisions almost every day (Chaudoir & Fisher, 2010; Pachankis, 2007). A range of studies have explored self-disclosure in different health conditions such as HIV (Petrak et al., 2001), cancer (Henderson et al., 2002) or epilepsy (Pembroke et al., 2017).

Social media can provide a valuable tool to communicate about one's stigmatised identity in order to share experiences and seek support (Coulson, 2005; Naslund et al., 2016). Research also suggests that individuals with concealable stigmatised identities use social media to disclose their identity and share personal illness experiences. For example, in a study by Sannon et al. (2019), semi-structured interviews were conducted with 19 people with invisible chronic health conditions such as fibromyalgia to explore their use of social media platforms for self-disclosure. The authors found that participants sought and gained informational and emotional support on various platforms (e.g., Facebook, Reddit), becoming more comfortable disclosing with time as they became more experienced with their conditions.

In the dementia field, research has extensively looked at the process and impact of health professionals disclosing a diagnosis of dementia to individuals and the impact of this on individuals. Several literature reviews have been conducted, exploring: the process of diagnostic disclosure *to* patients and family members (Bamford et al., 2004; Werner et al., 2013); ethical and practical issues around health professionals disclosing the diagnosis to patients (Carpenter & Dave, 2004); people with dementia's personal preferences regarding receiving the diagnosis (van den Dungen et al., 2014); the impact of receiving the diagnosis on individuals (Mitchell et al., 2013; Robinson et al., 2011); and common practices in disclosing a diagnosis from the perspectives of people with dementia, family carers, and healthcare professionals (Yates et al., 2021). However, no literature review has specifically explored disclosure *by* people with dementia to others, a topic that is of crucial importance as talking about one's diagnosis is a prerequisite to remaining socially active and experiencing optimal social health. Moreover, gaining a more comprehensive understanding of self-disclosure as it is described by people with dementia themselves will aid the development of the digital 'Who to tell, how and when' intervention, ensuring it adequately addresses their needs. Therefore, this systematic review aimed to explore the factors involved in people with dementia's decision to disclose their diagnosis to other people, both online and offline, through identifying and synthesising relevant studies.

2.3 Methods

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 guidelines (Page et al., 2021). A protocol for a wider review regarding self-disclosure and neurological disorders, including dementia, was registered in advance with the PROSPERO systematic review protocol registry (https://www.crd.york.ac.uk/prospero/; protocol number CRD42020192495). This chapter will only focus on dementia.

2.3.1 Search strategy

A comprehensive search strategy was developed in collaboration with a medical and psychology subject librarian at University College London. The search strategy was piloted and revised accordingly. As mentioned above, the initial search was part of a wider appraisal of the literature to explore the concept of ‘self-disclosure’ in chronic neurological conditions including dementia, epilepsy, multiple sclerosis, Parkinson’s disease, amyotrophic lateral sclerosis, Huntington’s disease, and migraine. I conducted a systematic search of the MEDLINE, PsycINFO, Embase, CINAHL, Emcare, and Scopus databases on 23rd June 2020. The search terms were combined using the Boolean operators ‘AND’ and ‘OR’, with wildcards and truncation where applicable, and adapted for each database. The full search strategy can be found in Appendix A. No language or date restrictions were applied to capture all available literature. Forward and backward searches were conducted of the included articles, with the latest forward search conducted on 10th of November 2023.

2.3.2 Eligibility criteria

The SPIDER strategy (Sample, Phenomenon of Interest, Design, Evaluation, Research type) was used as a tool to shape the eligibility criteria. SPIDER is based on the PICO strategy (Population, Intervention, Comparison, Outcome) and has been developed to be more suitable for qualitative and mixed-methods studies (Cooke et al., 2012). The SPIDER strategy for this review was as follows:

- **S**ample: people with dementia
- **P**henomenon of **I**nterest: self-disclosure of a diagnosis of dementia to other people
- **D**esign: any type of original research study
- **E**valuation: insight into views, experiences, attitudes, perceptions, beliefs, or feelings regarding self-disclosure
- **R**esearch type: peer-reviewed articles presenting qualitative, quantitative, or mixed-methods studies

Articles were included if (1) the study included participants with an existing diagnosis of dementia; (2) the study described how participants disclosed or concealed their diagnosis in a social context outside of the workplace; and (3) the study described primary research results obtained using a qualitative, quantitative, or mixed methods approach. Articles were excluded if (1) participants were under 18 years of age; (2) participants were health professionals disclosing or concealing a diagnosis of dementia to or from a patient; and (3) they were non-empirical or non-peer-reviewed papers.

2.3.3 Study selection and data extraction

Records retrieved from the electronic database searches were exported to EndNote X9, where duplicates were removed. I then screened the titles of retrieved articles.

Abstracts were screened if articles could not be excluded based on their title. Full-text articles were then reviewed independently by me and a second reviewer (MMU). Titles, abstracts, or full-text articles in languages other than English, German, or Dutch were translated using the artificial intelligence applications Deepl (https://www.deepl.com/translator) and ChatGPT (https://chat.openai.com/, as suggested by Chen (2023). We resolved any conflicts through discussion or consultation with my primary supervisor (GC). A standardised spreadsheet was created for this review in Microsoft Word in which MMU and I independently extracted the following information from included studies: author(s), publication year, country, study aim, study design and methodology including outcome measures, if applicable, characteristics of participants, and key findings. After data were extracted, MMU and I met again to discuss any potential queries.

2.3.4 Quality appraisal

The methodological quality of articles included in this review was assessed using the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018), which includes two screening questions and five additional questions pertaining to quantitative, qualitative, and mixed-methods studies. The MMAT's versatility for different study methodologies made it a suitable choice for the diverse range of studies expected in this review. I conducted the appraisal together with a fourth reviewer (JB). Both of us conducted the appraisal independently in Excel, with disagreements resolved by discussion. No overall scoring was applied, and studies were not excluded based on the quality appraisal.

2.3.5 Data synthesis

Extracted data were tabulated. Study and participant characteristics were synthesized narratively. Included studies were uploaded to NVivo 12 to facilitate data synthesis. A thematic synthesis for the included studies was then conducted following the three stages outlined by Thomas and Harden (2008). In step 1, text in the results section of each article relevant to the study aims was coded line-by-line. This included both first- (e.g., participants' quotes) and second-order (e.g., descriptions and interpretations by the authors) constructs (Toye et al., 2014). First-order constructs included quotes from people with dementia. In studies where dyads had been interviewed, quotes from family carers were also eligible as these often built on what the person with dementia had said. In step 2, descriptive themes were developed by looking for differences and similarities of codes and grouping them together. In the final step, overarching analytical themes were generated, which remained close to the constructs described in the included studies. MMU and I carried out steps 1 and 2 independently for all studies, with step 3 carried out by me. Interpretation of the data and identification of themes was discussed with my primary supervisor (GC).

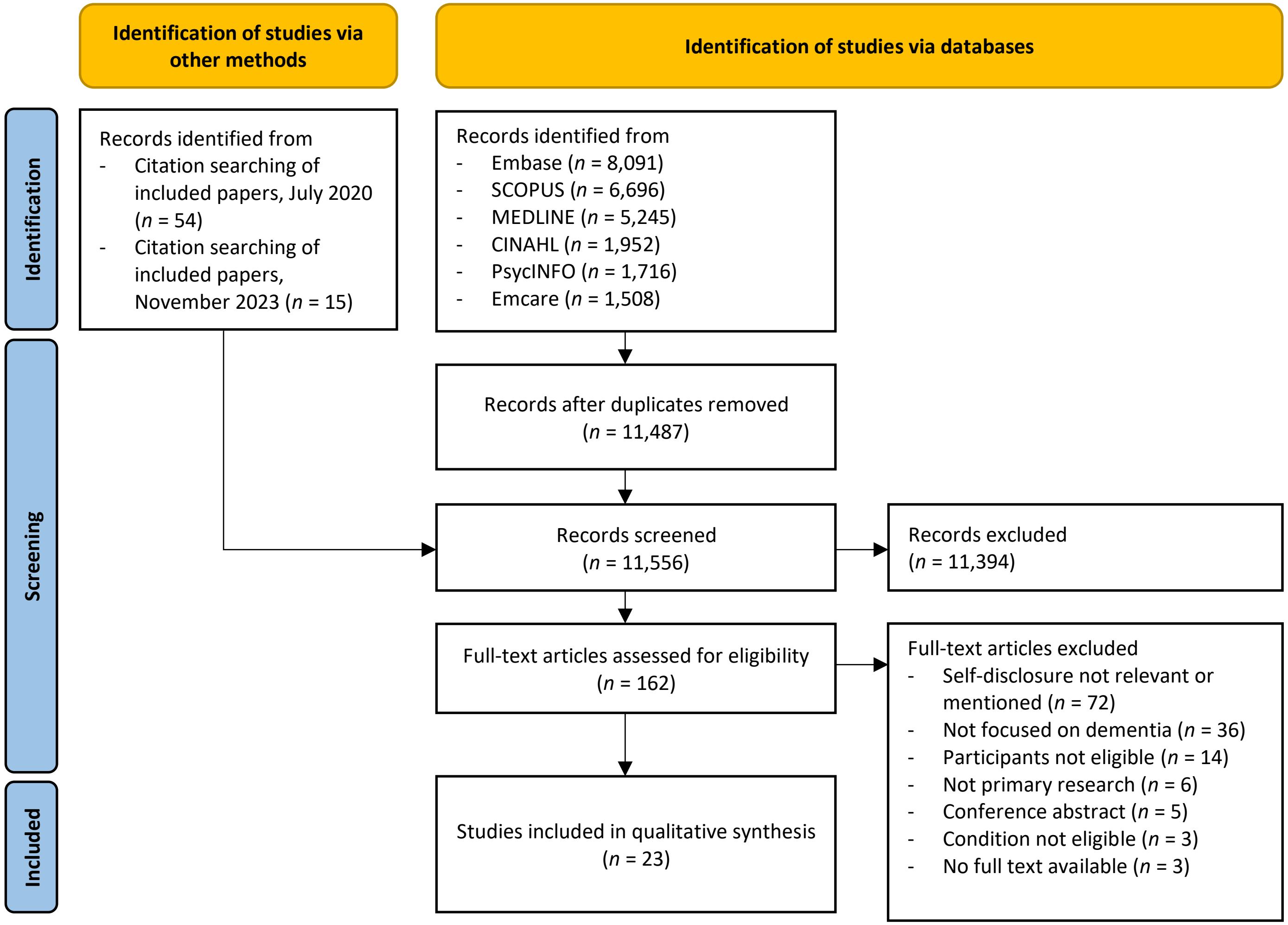
2.3.6 Patient and public involvement

To establish whether quotes from participants of included studies reflected the personal experiences of people with dementia, I held two separate discussions with two PPI groups. Access to these groups was facilitated by the Centre for Research in Public Health and Community Care (CRIPACC) at the University of Hertfordshire, where I conducted my first DISTINCT secondment. One week before the discussions, the group members, hereafter referred to as PPI contributors, were sent an information sheet with an overview of the purpose of the meeting, the main discussion points, and example quotes from participants of included studies (see Appendix B). The discussions were conducted online using Zoom due to the COVID-19 pandemic. I facilitated the groups with another researcher from CRIPACC, with a third researcher taking notes. The meeting with the first group, the Stevenage Dementia Involvement Group, consisted of a discussion on the topic of 'receiving and sharing a dementia diagnosis' (a report of this meeting can be found here: https://arc-eoe.nihr.ac.uk/stevenage-dementia-involvement-group). This group consists of people with dementia and family carers. The second meeting was conducted with the Public Involvement Research group at the University of Hertfordshire, which consists of experienced PPI contributors including people affected by dementia. During the meetings, it was ensured that all PPI contributors had time to express their ideas and opinions and that there was enough time to answer questions (Brooks et al., 2017). Involving PPI contributors in a systematic review is useful when assessing the relevance, applicability, and validity of findings that may come from a range of sources with people with lived experience and does not require ethical approval (Bunn et al., 2015; NIHR, 2021). No personal or demographic information was collected from the contributors.

2.4 Results

A total of 25,208 unique titles/abstracts were identified across the six databases. After de-duplication, the titles and abstracts of 11,556 articles were screened and then 162 were retrieved for full-text screening. Two forward and backward searches were conducted, one in July 2020 and the second one in November 2023. The first and second search led to the screening of an additional 54 and 15 articles, respectively. In total, 23 articles were included in this review. A PRISMA flowchart of the screening and selection process for these articles is presented in Figure 2.1.

Figure 2.1. PRISMA flow chart



2.4.1 Study characteristics

The characteristics of included studies, including their aims, methodology, and findings, are presented in Table 2.1. Studies were published between 2000 and 2023. Only three studies specifically aimed to explore people with dementia's experience or preferences around disclosing their diagnosis to others (Hellström & Torres, 2013; O'Connor et al., 2018; Weaks et al., 2015). One included study discussed findings related to online disclosure of a diagnosis (Castaño, 2020).

2.4.1.1 Study origins

The studies were conducted in a range of predominantly high-income countries. Six studies were conducted in the UK (Husband, 2000; Langdon et al., 2007; Pipon-Young et al., 2012; Weaks et al., 2015; Windle et al., 2023; Xanthopoulou & McCabe, 2019), three each in Canada (MacRae, 2008; O'Connor et al., 2018; Werezak & Stewart, 2009) and Sweden (Bielsten et al., 2018; Hedman et al., 2013; Hellström & Torres, 2013), and two were conducted in Norway (Johannessen et al., 2018; Telenius et al., 2020). One study each was conducted in Australia (Stockwell-Smith et al., 2019), Brazil (Oliveira et al., 2023), Chile (Gajardo et al., 2021), Denmark (Thoft & Ward, 2022), Finland (Pesonen et al., 2013), the Netherlands (Vernooij-Dassen et al., 2006), and the United States (Harris, 2012). One study, exploring online blogs, did not specify where the writers originated from (Castaño, 2020). The original language of the article by Gajardo et al. (2021) was Spanish, which was translated as outlined in section 2.2.3. All other articles were in English.

Table 2.1. Characteristics of studies included in review

Study and location	Research aims	Sample	Methodology	Key findings relating to self-disclosure of diagnosis
1. Bielsten et al. (2018), Sweden	To identify content for a self-management guide, using outcomes of previous research and data from dyadic interviews	Five married dyads Two female and three male PWD, aged 71-77 All diagnosed with AD	In-person semi-structured interviews and written comments from participants Thematic analysis, combining inductive and deductive processes	Reasons for disclosure included fighting stigma and reducing stress of 'holding it in' Disclosure facilitated stress reduction and increased levels of support and understanding
2. Castaño (2020), online	To explore how metaphors shape the lived experiences of people with YOD	Internet blogs by ten PWD (five female, five male)	Primary content analysis of 622 blog posts publicly accessible on the internet Metaphor identification procedure and discourse analysis	Reason for disclosure included challenging stereotypes Having an invisible illness facilitated concealment Individuals were concerned about potential negative reactions
3. Gajardo et al. (2021), Chile	To describe the experiences of living with dementia following diagnosis	Eleven PWD (five female, six male), aged 64-82 All diagnosed with AD	In-person interviews Content analysis using open coding	Reason for concealment included a lack of understanding in others Disclosure facilitated stress reduction and support Participants carefully chose who to disclose to, based on a level of trust
4. Harris (2012), USA	To explore if remaining friendships have a meaningful impact on the experience of early-stage dementia	Eight PWD (all female), aged 59-85 87% AD, 13% other All identified as White	In-person in-depth interviews Grounded theory	Reasons for disclosure included explaining symptoms Not disclosing the diagnosis to friends meant friendships were more difficult to maintain

Study and location	Research aims	Sample	Methodology	Key findings relating to self-disclosure of diagnosis
5. Hedman et al. (2013), Sweden	To describe how people with mild and moderate AD express their sense of self	Twelve PWD (five female, seven male), aged 60-80 All diagnosed with AD	In-person semi-structured interviews Content analysis using Harré's social-constructionist theory of selfhood	Reasons for disclosure included wanting to be oneself and to explain symptoms
6. Hellström & Torres (2013), Sweden	To explore what couples living with dementia want to know and disclose about the diagnosis	Twenty married dyads Ten female and ten male PWD, aged 61-80 AD was the most common diagnosis	In-person semi-structured interviews Qualitative analysis identifying themes	Findings presented as themes Five disclosure patterns: 1) want to know and tell (no reservations about it); 2) want to know and tell (some reservations about it); 3) want to know but do not want to tell; 4) want to know but cannot decide if we want to tell; and 5) cannot agree on neither knowing nor telling Majority of dyads disclosed diagnosis freely Reasons for concealment included uncertainty how to disclose, past negative reactions and treatment, and wishes to not be treated differently Invisible symptoms made disclosure more difficult Disclosure was found to be helpful to avoid others guessing

Study and location	Research aims	Sample	Methodology	Key findings relating to self-disclosure of diagnosis
7. Husband (2000), UK	To explore the proportion of PWD capable of engaging in discussion about their diagnosis, worries and effects of these worries	Ten PWD (seven female, three male), aged 61-72	In-person structured interview Content analysis and frequency counts	Reasons for concealment included being ashamed and fear of negative treatment, including being called incompetent and not being listened to All participants were worried others would find out about the diagnosis
8. Johannessen et al. (2018), Norway	To explore the existential experiences and coping mechanisms of people with YOD	Ten people with YOD (seven female, three male), aged 49-67	Longitudinal exploratory descriptive study with a duration of two years In-person semi-structured interviews Modified grounded theory	Reasons for concealment included wishes for normalcy, and diminish impact of the condition on oneself Participants controlled outer image by concealing Being younger and healthy looking made concealment easier
9. Langdon et al. (2007), UK	To explore how PWD's perception of their condition and their understanding of others' reactions to them had changed	Twelve PWD (six female, six male) aged 66-87 50% VAD, 33.3% AD, 8.3% FTD, 8.3% LBD Nine identified as White and three as Black Caribbean	In-person semi-structured interviews Interpretative phenomenological analysis	Reasons for disclosure included advocacy and educating others Reasons for concealment included fear of misconceptions, stigma, and being talked about
10. MacRae (2008), Canada	To examine the meaning of AD to people with early-stage AD	Eight PWD (two female, six male), aged 60-85 All diagnosed with AD	In-person semi-structured interviews Themes established through inductive and deductive data analysis	Reasons for disclosure included explaining symptoms and educating people about misconceptions Reasons for concealment included perceived negative assumptions

Study and location	Research aims	Sample	Methodology	Key findings relating to self-disclosure of diagnosis
11. O'Connor et al. (2018), Canada	To explore the diagnostic disclosure process for PWD in relation to stigma, discrimination, and social citizenship	Eight PWD (two female, six male), aged 57-82	In-person group discussions with monthly meetings over sixteen months Deductive approach with social citizenship in mind and discourse analysis strategies	Findings presented descriptively Reasons for disclosure included fighting stigma and educating others, empowering oneself and others, explaining symptoms, and gaining social support Reasons for concealment included fear that relationships would change, fear of discrimination, and fear of being treated differently Disclosure could lead to loss of 1) growth opportunities, 2) active participation, and 3) meaningful activities
12. Oliveira et al. (2023), Brazil	To explore experiences of self-stigma in PWD living in Brazil	Six PWD (five female, one male), aged 73-87 All identified as White	In-person semi-structured interviews Critical Narrative Inquiry Inductive and deductive analysis, informed by existing stigma theory	Reasons for concealment included fear of judgment and anticipated negative reactions
13. Pesonen et al. (2013), Finland	To explore shared experiences of receiving a diagnosis of dementia for PWD and family members, and to understand how they manage their lives after diagnosis	Eight dyads Five female and three male PWD, aged 51-74 75% AD, 25% LBD	In-person low-structured, in-depth interviews Constant comparative analysis using grounded theory	Reasons for concealment included sparing close relatives from grief PWD wanted to remain in control over who would be told about the diagnosis

Study and location	Research aims	Sample	Methodology	Key findings relating to self-disclosure of diagnosis
14. Pipon-Young et al. (2012), UK	To explore the broader experiences of people with YOD, including beneficial support as well as areas in need of change	Eight people with YOD (seven female, one male), aged 60-67 87.5% AD, 12.5% mixed dementia Six identified as White British, and one each as White/Asian and Black	In-person semi-structured interviews Thematic analysis	Reasons for disclosure included explaining symptoms Reasons for concealment included uncertainty about possible reactions and perceptions of participants
15. Stockwell-Smith et al. (2019), Australia	To explore the impact of early-stage dementia on dyads' confidence in their capacity to manage dementia-related changes, and to access appropriate support	Thirteen dyads Five female and eight male PWD, aged 66-87	In-person semi-structured interviews Thematic analysis	Reasons for concealment included fear of stigma and difficulties accepting the diagnosis
16. Telenius et al. (2020), Norway	To explore the perceived needs of people with dementia	35 PWD (19 female, 16 men), aged 59-92	In-person semi-structured interviews Qualitative content analysis	Reasons for concealment included a perceived lack of understanding Concealment led to social withdrawal and a decrease in meaningful activities
17. Thoft & Ward (2022), Denmark	To explore the lifeworld perspective of PWD experiencing and managing everyday life	Twelve PWD (three female, nine male), aged 65-82 50% AD, 33.3% unknown, 16.7% VD	In-person semi-structured interviews Analysis with existing hermeneutic phenomenology in mind	Disclosure helped to alleviate the stress of trying to hide dementia, facilitated support, and help to raise awareness All participants had disclosed their diagnosis

Study and location	Research aims	Sample	Methodology	Key findings relating to self-disclosure of diagnosis
18. Vernooij-Dassen et al. (2006), The Netherlands	To describe and understand the impact of receiving a diagnosis for PWD and family carers over time	Eighteen dyads Four female, fourteen male PWD, with a mean age of 71	In-person semi-structured interviews two and twelve weeks after receiving a diagnosis Grounded theory	Disclosure explained symptoms Family and friends often responded positively to disclosure
19. Weaks et al. (2015), UK	To explore the experiences of PWD and family members regarding sharing the diagnosis with others	Five PWD and one family member Three female, two male PWD, aged 68-79 All diagnosed with AD	In-person interviews and participant observation over a six-month period Grounded theory	Findings presented descriptively, covering a range of topics related to disclosure, including attitudes of change regarding disclosure over the research period Reasons for disclosure included explaining symptoms, worries that AD is hereditary, stress of not telling, unburdening carers, feeling that society is more understanding, and to make needs known Reasons for concealment included privacy, wishes for normalcy, protecting others, embarrassment, fear of stigma, worries of straining the relationship, worries of negative reactions, and others potentially putting information forward Concealment was associated with social isolation, difficulty accessing appropriate support, and stress

Study and location	Research aims	Sample	Methodology	Key findings relating to self-disclosure of diagnosis
20. Werezak & Stewart (2009), Canada	To explore the process of learning to live with early-stage dementia	Six PWD, aged 61-79 83.3% AD, 16.7% VAD	In-person semi-structured interviews Grounded theory	Reasons for concealment included uncertainty about potential reactions
21. Williamson & Paslawski (2016), Canada	To explore the concept of resilience and factors associated with it among people with dementia and their care partners	Five family carers Seven PWD (four female, three male), aged 65-82	In-person semi-structured interviews Thematic analysis	Reasons for disclosure included decreasing embarrassment, educating people, explaining symptoms, and facilitating support Disclosure contributed to increased wellbeing
22. Windle et al. (2023), UK	To develop a conceptual model of resilience in PWD to inform service development and health and care practices	Ten family carers Eight PWD (four female, four male), aged 51-81 37.5% AD, 25% PCA, 25% mixed, 12.5% PSP	In-person stakeholder engagement meetings, and online semi-structured interviews Thematic analysis	Disclosure led to less personal embarrassment and more public awareness and understanding Openness about diagnosis acted as resilience reserve
23. Xanthopoulou & McCabe (2019), UK	To explore people's experiences of cognitive decline and receiving a diagnosis of dementia	Sixty-one PWD (34 female, 27 male), aged 65-91 60% AD, 20% VAD, 21.2% mixed dementia/other	In-person semi-structured interviews Thematic analysis	Reasons for concealment included worry of being called incompetent, stigma, and worry of being treated differently Participants put increasing effort into hiding symptoms

Note. AD = Alzheimer's disease; FD = Frontotemporal dementia; LBD = Lewy Body dementia; PCA = Posterior cortical atrophy; PSP = Progressive supranuclear palsy; PWD = People with dementia; VAD = Vascular dementia; YOD = Young-onset dementia

2.4.1.2 Study participants

The number of participants was generally small, with sample sizes ranging between five and 61. In total, the studies represented 299 people with dementia and 79 family carers. A total of seven studies included dyads consisting of a person with dementia and a carer as study participants (Bielsten et al., 2018; Hellström & Torres, 2013; Pesonen et al., 2013; Stockwell-Smith et al., 2019; Vernooij-Dassen et al., 2006; Williamson & Paslawski, 2016; Windle et al., 2023). Four studies focused on individuals in the early stages of their diagnosis (Harris, 2012; Pesonen et al., 2013; Stockwell-Smith et al., 2019; Werezak & Stewart, 2009), while three studies specifically focused on the experiences of people with young-onset dementia (Castaño, 2020; Johannessen et al., 2018; Pipon-Young et al., 2012). Full demographic characteristics of people with dementia were not provided by all studies. Of those that did, participants' age ranged between 49 and 92, representing the experiences of 149 female and 143 male people with dementia. Fourteen studies specified the type of dementia participants had been diagnosed with (Bielsten et al., 2020; Gajardo et al., 2021; Harris, 2012; Hedman et al., 2013; Hellström & Torres, 2013; Langdon et al., 2007; MacRae, 2008; Pesonen et al., 2013; Pipon-Young et al., 2012; Thoft & Ward, 2022; Weaks et al., 2015; Werezak & Stewart, 2009; Windle et al., 2023; Xanthopoulou & McCabe, 2019). Alzheimer's disease was present in all of them, while participants in nine studies also had other forms of dementia (Harris, 2012; Hellström & Torres, 2013; Langdon et al., 2007; Pesonen et al., 2013; Pipon-Young et al., 2012; Thoft & Ward, 2022; Werezak & Stewart, 2009; Windle et al., 2023; Xanthopoulou & McCabe, 2019). Four studies reported the ethnic backgrounds of participants (Harris, 2012; Langdon et al., 2007;

Oliveira et al., 2023; Pipon-Young et al., 2012). Among them, 29 identified as White, three as Black Caribbean, one as White/Asian, and one as Black.

2.4.1.3 Study design and methods

Studies applied mainly a cross-sectional study design. One study used a longitudinal design (Johannessen et al., 2018). All 23 studies employed a qualitative methodology. Twenty-one studies conducted in-depth or semi-structured interviews, with one study additionally incorporating observation methods (Weaks et al., 2015). One study collected data from an advisory group that was set up as part of a larger research project utilising participatory action research (O'Connor et al., 2018), and another study conducted a primary analysis of internet blogs (Castaño, 2020). The study by Windle et al. (2023) collected data through stakeholder engagement meetings as well as semi-structured interviews. One study conducted parts of its data collection online (Windle et al., 2023). The remaining studies collected their data in person.

The studies utilised a range of different approaches to data analysis. Six studies each used thematic analysis (Bielsten et al., 2018; Hellström & Torres, 2013; Pipon-Young et al., 2012; Stockwell-Smith et al., 2019; Williamson & Paslawski, 2016; Windle et al., 2023; Xanthopoulou & McCabe, 2019) or a grounded theory approach (Harris, 2012; Johannessen et al., 2018; Pesonen et al., 2013; Vernooij-Dassen et al., 2006; Weaks et al., 2015; Werezak & Stewart, 2009). Four studies used content analysis (Gajardo et al., 2021; Hedman et al., 2013; Husband, 2000; Telenius et al., 2020). One study each used interpretative phenomenological analysis (Langdon et al., 2007), a hermeneutic phenomenology approach (Thoft &

Ward, 2022) or qualitative analysis not further specified (Hellström & Torres, 2013). Oliveria et al. (2023) used inductive and deductive analysis, while MacRae (2008) applied an inductive approach only. The study by Castaño (2020) employed discourse analysis to analyse individuals' blog entries. A deductive approach in combination with elements of discourse analysis was applied by O'Connor et al. (2018).

2.4.2 Quality appraisal

The results of the quality appraisal can be found in Table 2.2. The studies were mainly well-reported. Two studies (Harris, 2012; Husband, 2000) did not specify the data analysis process and the steps taken during analysis. Hedman et al. (2013) and Husband (2000) did not provide adequate information on the data collection methods used. In addition, the latter study did not provide quotes from participants to support developed themes. Missing or inadequate information resulted in incoherence between data sources, collection, analysis, and interpretation in all three studies (Harris, 2012; Hedman et al., 2013; Husband, 2000).

2.4.3 Thematic synthesis

Studies described a range of factors contributing to an individual's decision to disclose their diagnosis. These were grouped into three themes and five subthemes. Details of studies supporting each theme and subtheme can be found in Table 2.3. In the description of the themes and subthemes, quotes by participants are accompanied by their gender and age, if this information was available.

Table 2.2. Quality appraisal of included studies using the MMAT

	Methodological quality criteria of qualitative studies				
Study	Is approach appropriate to answer study's research question?	Are data collection methods adequate?	Are findings adequately derived from data?	Is interpretation substantiated by data?	Is there coherence between data sources, collection, analysis, and interpretation?
Bielsten et al. (2018)	Y	Y	Y	Y	Y
Castaño (2020)	Y	Y	Y	Y	Y
Gajardo et al. (2021)	Y	Y	Y	Y	Y
Harris (2012)	Y	Y	N	Y	N
Hedman et al. (2013)	Y	?	Y	Y	?
Hellström & Torres (2013)	Y	Y	Y	Y	Y
Husband (2000)	Y	?	N	N	N
Johannessen et al. (2018)	Y	Y	Y	Y	Y
Langdon et al. (2007)	Y	Y	Y	Y	Y
MacRae (2008)	Y	Y	Y	Y	Y
O'Connor et al. (2018)	Y	Y	Y	Y	Y
Oliveira et al. (2023)	Y	Y	Y	Y	Y
Pesonen et al. (2013)	Y	Y	Y	Y	Y
Pipon-Young et al. (2012)	Y	Y	Y	Y	Y

Stockwell-Smith et al. (2019)	Y	Y	Y	Y	Y
Telenius et al. (2020)	Y	Y	Y	Y	Y
Thoft & Ward (2022)	Y	Y	Y	Y	Y
Vernooij-Dassen et al. (2006)	Y	Y	Y	Y	Y
Weaks et al. (2015)	Y	Y	Y	Y	Y
Werezak & Stewart (2009)	Y	Y	Y	Y	Y
Williamson & Paslawski (2016)	Y	Y	Y	Y	Y
Windle et al. (2023)	Y	Y	Y	Y	Y
Xanthopoulou & McCabe (2019)	Y	Y	Y	Y	Y

Note. Y = Yes; N = No; ? = Can’t tell

Table 2.3. Articles contributing to generated themes and subthemes

Themes	Concealment	Stigma and fear		Taking control		
Study		Fear of stigma	Negative reactions and losses	Explaining	Awareness and advocacy	Reduction of stress and burden
Bielsten et al. (2018)					X	X
Castaño (2020)	X	X			X	
Gajardo et al. (2021)			X			
Harris (2012)				X		
Hedman et al. (2013)				X		
Hellström & Torres (2013)	X	X	X	X		
Husband (2000)		X				
Johannessen et al. (2018)	X	X				
Langdon et al. (2007)		X			X	
MacRae (2008)		X		X	X	
O’Connor et al. (2018)		X	X	X	X	X
Oliveira et al. (2023)		X				
Pesonen et al. (2013)	X					
Pipon-Young et al. (2012)	X	X		X		
Stockwell-Smith et al. (2019)	X	X		X		
Telenius et al. (2020)		X				
Thoft & Ward (2022)					X	X
Vernooij-Dassen et al. (2006)				X		
Weaks et al. (2015)	X	X		X	X	X
Werezak & Stewart (2009)		X	X			
Williamson & Paslawski (2016)				X	X	X
Windle et al. (2023)					X	X
Xanthopoulou & McCabe (2019)		X				

2.4.3.1 Theme 1: Concealment

In seven studies, participants were described as actively concealing their diagnosis to feel ‘normal’ and like their old selves as well as to be seen as such (Castaño, 2020; Hellström & Torres, 2013; Johannessen et al., 2018; Pesonen et al., 2013; Pipon-Young et al., 2012; Stockwell-Smith et al., 2019; Weaks et al., 2015). Individuals wanted to diminish the effect of the diagnosis on themselves and “not enlarge it by talking about it” (Johannessen et al., 2018, p. 5). One 64-year-old women in the study by Pipon-Young et al. (2012) stated, “I just want to be normal, until it’s obvious that I’m not” (p. 606). Another female participant, aged 62, said, “I haven’t said anything to anybody … I wouldn’t because they see me as I was before” (p. 606). Weaks et al. (2015) described one female participant, aged 77, who was hesitant to disclose her diagnosis as she felt it would lead to a loss of control as it would inhibit her ability to present an intact or normal self. Difficulties accepting the diagnosis were discussed as hindering disclosure in one study (Stockwell-Smith et al., 2019).

Another reason for actively concealing one’s diagnosis was the wish to shield family and significant others from potential grief, which was described in two studies (Pesonen et al., 2013; Weaks et al., 2015). Participants anticipated that relatives would struggle to adjust to the diagnosis as a result of being confronted with the potential losses associated with dementia, spending “many sleepless nights crying” (Pesonen et al., 2013, p. 493). One 74-year-old women interviewed by Weaks et al. (2015) talked about her decision to withhold the diagnosis from other people, stating, “there is no point in worrying them all starting now you know” (p. 772).

In three studies, it was suggested that participants used the invisible nature of their condition to hide their diagnosis from others due to a concern how others might respond (Castaño, 2020; Hellström & Torres, 2013; Johannessen et al., 2018). Some who considered disclosing found it difficult as others “did not quite grasp that something was wrong” (Hellström & Torres, 2013, p. 161). Being “healthy outside and ill inside” (p. 5), one participant with young-onset dementia in the study by Johannessen et al. (2018) utilised the invisible nature of their condition to make others believe they were well and to avoid talking about their diagnosis, because “they are all concerned that I should pull myself together, and that is impossible” (p. 5).

2.4.3.2 Theme 2: Stigma and fear

The theme ‘stigma and fear’ emerged as an important one from 14 studies, including the three studies that focused exclusively on self-disclosure in people with dementia (Hellström & Torres, 2013; O’Connor et al., 2018; Weaks et al., 2015). Two subthemes were identified summarising how stigma and fear influenced disclosure. The first subtheme, ‘fear of stigma’, describes a concern that disclosure might facilitate negative reactions or treatment. The second subtheme, ‘negative reactions and disclosure-related losses’, describes actual experiences of negative reactions.

Subtheme 1: Fear of stigma

In 14 studies, the authors and participants described concerns that disclosing the dementia diagnosis would lead to stereotyping, prejudice or discrimination

(Castaño, 2020; Hellström & Torres, 2013; Husband, 2000; Johannessen et al., 2018; Langdon et al., 2007; MacRae, 2008; O'Connor et al., 2018; Oliveira et al., 2023; Pipon-Young et al., 2012; Stockwell-Smith et al., 2019; Telenius et al., 2020; Weaks et al., 2015; Werezak & Stewart, 2009; Xanthopoulou & McCabe, 2019). Participants described worrying that others might be judgemental or think less of them. For example, one 68-year-old male participant noted: "I wouldn't want people to think I was doolally ... I think that could be disastrous," (Weaks et al., 2015, p. 772). There was a concern about "how their relationship will change" (p. 47), as described by one man in the study by O'Connor et al (2018). A 59-year-old male participant interviewed by Hellström and Torres (2013) said that he was concerned about the label associated with dementia. In two studies that outlined fear of stigma in more detail, the authors described that "stigma was positioned in relation to perceptions of mental illness" (O'Connor et al., 2018, p. 47) and that participants "strongly associated dementia with mental illness" (Stockwell-Smith et al., 2019, p. 634)

There was a concern that disclosing the diagnosis might have negative consequences or result in negative treatment. An 84-year-old female participant said: "I was very worried about it, but I didn't tell anybody. I felt they might have taken me away" (Stockwell-Smith et al., 2019, p. 632). Similarly, Husband (2000) described that the majority of participants felt ashamed of their diagnosis and would fear being called incompetent or being laughed about, while Castaño (2020) concluded that blog entries revealed a worry that other people's attitudes towards the bloggers would change. Telenius et al. (2020) described that one female participant, in her late 70s, who was not open about her diagnosis, had chosen to leave a gaming group due to criticism from other players. Fear of judgment had led her to withdraw from an activity she enjoyed. Blog entries analysed by Castaño (2020) suggested individuals aimed to avoid negative interactions:

> *When you say the word dementia, people shrink back in horror and then they deny the possibility*. (p. 124)

Remarks made by some participants suggested that they themselves held negative beliefs about the condition. This was described in three studies (Johannessen et al., 2018; Langdon et al., 2007; Xanthopoulou & McCabe, 2019). According to one female participant, a diagnosis of Alzheimer’s disease meant “you are ready for a nursing home” (Johannessen et al., 2018, p. 5). Langdon et al. (2007) describe another female participant, aged 75, explaining that saying one has dementia “can make you sound as if you’re very gnarled” (p. 10).

Subtheme 2: Negative reactions and losses

In four studies, participants described actual negative reactions upon disclosing their diagnosis, which had led to a reluctance to disclose subsequently (Gajardo et al., 2021; Hellström & Torres, 2013; O’Connor et al., 2018; Werezak & Stewart, 2009). Participants in two studies explained that friends had started to pay close attention to them or would talk about them behind their back (Hellström & Torres, 2013; Werezak & Stewart, 2009). One 64-year-old woman interviewed by Gajardo et al. (2021) described the opposite, saying that people had started to ignore her once they knew about the diagnosis. Similar experiences were discussed by O’Connor et al. (2018), with participants noting a loss of opportunities and activities due to disclosure. As a result, some had become more selective in who they would share their diagnosis with. One male participant reflected on an interview for a volunteering position:

> *I was following the practice to always tell people I had Alzheimer's. Well the last couple of times, as soon as the Alzheimer's word came out, the interview cooled. I didn't get a phone call back so sometimes now I don't tell people.* (O'Connor et al., 2018, p. 48)

The authors note, however, that several participants who described instances of negative treatment had difficulty naming these experiences as discrimination. O'Connor et al. suggest that they "were denied the experience of feeling justifiably angry. Instead, [there was a] tendency to discount or brush off one's feelings …" (p. 50).

2.4.3.3 Theme 3: Taking control

Participants actively disclosed their condition to others, taking control over perceptions associated with their diagnosis. Participants illustrated that being open about their diagnosis increased feelings of empowerment and control. For example, one male participant in the study by O'Connor et al (2018) explained that it was important through disclosure "to be able to empower yourself to take charge of the situation" (p. 49). Similarly, one female participant explained "you take control … in freely talking about it" (p. 49). In their group discussions, the participants also noted that one had to be open about the diagnosis in order to manage it "in the best way possible for your own wellbeing” (p. 49) or to access support. Within this main theme, three subthemes emerged from the data synthesis: ‘explaining’, ‘awareness and advocacy’, and ‘reduction of stress and burden’.

Subtheme 1: Explaining

The subtheme ‘explaining’ emerged from ten studies; it describes how several participants took control by disclosing their diagnosis to explain symptoms or behaviour. Participants wished to explain that behaviours perceived by others as odd or questionable was related to their dementia, to avoid others guessing. In the study by Harris (2012), one female participant explained that she had disclosed her condition to friends because “they will wonder how come you don’t remember this? And how come you are reacting this way” (p. 311). Participants described sharing their diagnosis with others to make them understand that dementia-related behaviours they may show, or experience, were out of their control (Hedman et al., 2013; Hellström & Torres, 2013; O’Connor et al., 2018; Pipon-Young et al., 2012; Stockwell-Smith et al., 2019; Vernooij-Dassen et al., 2006; Weaks et al., 2015). A 70-year-old male participant explained that he disclosed so others “could understand. Because I know that it goes a bit wobbly” (Hedman et al., 2013, p. 726). Related to a perception that others might think negatively about the person with dementia, one carer interviewed as part of the dyadic study by Stockwell-Smith et al. (2019) noted: “…we tell most people, because she's not just funny in the head, sort of thing. It's a medical condition…” (p. 632).

Additionally, some participants noted that they disclosed their condition pre-emptively, even before they had shown any noticeable behaviour (MacRae, 2008; Williamson & Paslawski, 2016). For example, one female participant in the study conducted by Williamson and Paslawski (2016) stated that she would "tell people ahead of time so if I make a mistake, I don't feel silly" (p. 8).

Subtheme 2: Awareness and advocacy

Nine studies described how people with dementia actively disclosed their diagnosis to raise awareness and understanding about the condition among family, friends, and the general public (Bielsten et al., 2018; Castaño, 2020; Langdon et al., 2007; MacRae, 2008; O'Connor et al., 2018; Thoft & Ward, 2022; Weaks et al., 2015; Williamson & Paslawski, 2016; Windle et al., 2023). Participants wanted to bring "dementia out of the cupboard" (Castaño, 2020, p. 124) and normalise it as condition that is common "like a broken arm or broken leg" (MacRae, 2008, p. 404).

It was described that participants actively disclosed to educate other people about the condition. One male participant interviewed by MacRae (2008) said he told "everybody every chance" (p. 400) he got so others would understand what dementia is. O'Connor et al. (2018) noted that most of their participants described stigma as a "pervasive problem that needed to be named and addressed" (p. 47). For example, one male participant believed that "the word has to get out there that this is one of the important things, stigma …" (p. 47). Through self-disclosure, participants would also raise awareness about the stigma of dementia. Similarly, Castaño (2020) concluded that some of the bloggers "agreed on the fact that being open about it has benefits to them and their families and that open awareness was necessary to change social perceptions of dementia" (p. 124). For example, the author cited one male participant who had written that dementia should be brought “out of the cupboard” (p. 124) and that he told people openly “to challenge the stereotype” (p. 124). In another study, one female participant, aged 76, hoped that disclosing her condition would strengthen existing relationships by raising awareness about her dementia (Thoft & Ward, 2022).

In two studies, participants described sharing their diagnosis because they felt that society had already become more understanding towards people with dementia (Bielsten et al., 2018; Weaks et al., 2015). One 79-year-old man interviewed by Weaks et al. (2015) explained that “today’s society was much more open and accepting with no need to hide away such a diagnosis” (p. 772). Similarly, one participant in the study by Bielsten et al. (2018) noted that “it has become much more accepted” (p. 1725).

Subtheme 3: Reduction of stress and burden

In six studies, self-disclosure was perceived as beneficial because it alleviated stress and burden some participants experienced from initially not speaking about their diagnosis (Bielsten et al., 2018; O’Connor et al., 2018; Thoft & Ward, 2022; Weaks et al., 2015; Williamson & Paslawski, 2016; Windle et al., 2023). Bielsten et al. (2018) described participants feeling relieved once they had disclosed their diagnosis as it “reduced stress due to not having to cover up symptoms” (p. 1725). This was echoed by Weaks et al. (2015). For example, one male participant, aged 68, explained that not disclosing increased the stress of ‘holding the diagnosis in’ due to “trying to keep everything on the surface going while things are just not really quite the same” (p. 773). Thoft and Ward (2022) described similar observations. Though most participants interviewed by Gajardo et al. (2021) said that they concealed their diagnosis, one 82-year-old man explained that informing his family had been helpful as it reduced tensions and problems that he encountered with them. Self-disclosure also led to a reduction of feelings of embarrassment, described by Windle et al. (2023).

Thoft and Ward (2022) described that disclosure enabled access to support for participants. Access to support was also echoed by Weaks et al. (2015) and Williamson and Paslawski (2016) who described that several participants found that self-disclosure resulted in additional support should they need it. The authors also mentioned that self-disclosure enabled family carers to advocate for additional support.

2.4.4 PPI contributions

Two rounds of discussions with two PPI groups consisting of people with dementia and family carers living in England were held over Zoom in February and March 2021. Five PPI contributors attended the first meeting and seven the second one. In both rounds of discussions, I presented quotes from participants of the included studies, asked whether these matched the contributors' experiences, and invited comments on the quotes as well as on their own experiences. contributors agreed with findings from the literature, emphasising the individual and sometimes complex nature of disclosure. All had direct experience with disclosing a dementia diagnosis, while some stated they disclosed selectively. Those who talked openly with all stated that their primary reason was to explain behaviour that others might perceive as peculiar, odd, or even unsettling. If behaviour seemed out of place, being able to attribute it to dementia was considered valuable and helpful, as it helped others comprehend what was going on. Some contributors shared that though they had disclosed the diagnosis openly, their social network had become smaller because of friends turning away. Such remarks highlighted the difficulties associated with the stigma of dementia. It was noted, however, that these reactions had not influenced subsequent self-disclosure. The contributors also brought new insights to the findings. It was suggested that the person with dementia's age might influence their disclosure decision-making, with older individuals being potentially less likely to disclose as dementia might be one of many illnesses and therefore not noteworthy, potentially highlighting the comfortable stance the contributor had. It was stressed that cultural differences, including upbringing, as well as an individual's ethnic background could influence their decision to disclose. In addition, contributors noted that research could benefit from exploring reactions from others towards the disclosure, as individuals unaffected by dementia might not always know how to respond. Insights into this area could potentially support people with dementia in feeling more comfortable sharing their diagnosis.

2.5 Discussion

This systematic review is the first to examine and synthesise evidence related to factors associated with people with dementia disclosing their diagnosis to their social networks. The review highlights that disclosing a diagnosis of dementia to social networks is best understood as a multifaceted process that can affect the social health of individuals in various ways. Factors associated with disclosure were often connected and rarely existed in isolation. Though the number of reviews exploring self-disclosure in concealable stigmatised health conditions in adults are limited, the ones that have been conducted seem to echo this complexity (Brohan et al., 2012; Evangeli & Wroe, 2017; Gray et al., 2000; Grice et al., 2017; Guo et al., 2020).

2.5.1 Principal findings

Only three of the 23 studies identified had self-disclosure of a dementia diagnosis as the primary focus (Hellström & Torres, 2013; O'Connor et al., 2018; Weaks et al., 2015). This suggests that self-disclosure has largely been neglected in dementia research. It can be assumed, however, that this topic is of importance for people with dementia, as it was discussed in the 20 studies that did not focus on self-disclosure. Additionally, only one study described aspects of self-disclosure in an online context (Castaño, 2020). Seeing that this population engages with ICT, including social media (e.g., Talbot & Coulson, 2023), and individuals are known to utilise social media platforms to disclose or share sensitive information (e.g., Andalibi, 2017), including sensitive health information (Sannon et al., 2019), this highlights an important point that requires consideration in future research.

The stigma of dementia was found to be one of the main factors associated with self-disclosure. This underlines the well-reported stigma of dementia (e.g., Alzheimer's Disease International, 2019; Herrmann et al., 2018). Concerns of people with dementia regarding stigma became particularly evident as the majority of studies within the 'stigma and fear' theme described anticipated stigma, that is, thinking that disclosure will provoke a negative reaction from others (Quinn & Chaudoir, 2009). This concern among people with a concealable stigmatised identity has also been discussed in other systematic reviews (Benson et al., 2015; Howells et al., 2021). In addition, findings from this review imply that some people with dementia themselves hold negatives attitudes regarding their diagnosis. For example, participants used derogatory language comparing having a dementia diagnosis with being “doolally” (Weaks et al., 2015, p. 772). This internalisation of negative attitudes and stereotypes, also called self-stigma (Corrigan & Watson, 2002), has previously been described in people with dementia (Bhatt et al., 2023; Burgener, Buckwalter, Perkhounkova, Liu, et al., 2015). This review highlights the pervasive nature of the social experience of a dementia diagnosis, resulting in experiences of stigma, which can lead to a loss of social and meaningful opportunities for people with dementia (Biggs et al., 2019). While stigma can impede all domains of the social health framework, it is especially relevant for the third domain ‘the ability to actively participate in social activities’, as stigma and concealment can negatively affect a person’s sense of social belonging and engagement in meaningful social interactions (Newheiser & Barreto, 2014).

The findings revealed that disclosing the diagnosis offered individuals with a feeling of taking control of it, including its meaning. Similar to a qualitative study on self-disclosure in people with brain injury, this review found that self-disclosure was used as a way of explaining the cause of behavioural changes to avoid others guessing about the nature of one’s difficulties (Riley & Hagger, 2015). Self-disclosure also offered a reduction of stress related to having to present oneself in social settings in ways that do not feel authentic, adding to the discussions regarding the self and agency in dementia considering its progressive nature (Caddell & Clare, 2010; van der Byl Williams & Zeilig, 2023). Overall, these findings indicate that individuals are enabled to preserve their autonomy, aligning with the second domain of the social health framework ‘the ability to manage life despite the disease’. Findings also highlight the use of self-disclosure to raise awareness. This is closely related to the concept of advocacy or self-advocacy described in the dementia literature, that is, people with dementia and family carers publicly making their voices heard to raise awareness and fight stigma, which has been found to play a role in both face-to-face (Hillman et al., 2018; Seetharaman & Chaudhury, 2020) and online settings (Anderson et al., 2017; Talbot et al., 2021). Awareness raising and advocacy also plays a role in shaping social health. By engaging in these efforts, individuals are able to actively shape their social environment and engage socially.

2.5.2 Strengths and limitations

Given that the majority of papers have been published in the last decade, this review provides a timely and valuable insight into this important area of research. A strength of this review is its systematic and comprehensive search of articles without language or date restrictions. Inclusion and exclusion criteria were specified using an established search tool and with support from a subject librarian. The quality appraisal and thematic synthesis followed established methodology (Hong et al., 2018; Thomas & Harden, 2008). Multiple reviewers were used for data screening/extraction and quality appraisal. In addition, this review benefitted from involving people affected by dementia as PPI contributors to validate its findings and shed light on areas for future research (Pollock et al., 2017).

This review identified only three studies that focused their study aims on exploring self-disclosure in people with dementia. This indicates both a research gap as well as a potential bias in the synthesis, which could have led to a skewed representation of factors associated with self-disclosure in people with dementia. To ensure the quality of included studies, only peer-reviewed articles were eligible for inclusion. It is possible that relevant information from other sources was therefore missed. However, as this is the first review to collate and synthesise this important area of research, the study provides an important step for future exploration.

A further possible limitation is the decision to appraise the quality of included articles using a tool developed for mixed-methods research (Hong et al., 2018). As this study was part of a larger review focusing on different neurological disorders, it was anticipated that studies would have adopted a range of different methodologies. While established using rigorous testing and revisions (Hong et al., 2019), the criteria of the MMAT are more general than those of appraisal tools specifically developed for qualitative studies. However, as studies were not excluded based on the appraisal, the influence of using this tool on the data synthesis should be minimal.

Another limitation is that almost all studies were conducted in Western high-income countries. Therefore, not all dimensions of the topic may have been covered by the included studies. Meetings with the PPI contributors also highlighted the need to explore factors related to an individual’s cultural and ethnic background to understand self-disclosure among people with dementia.

Finally, it is important to note that data collected for the studies reflect a particular subset of people with dementia. Firstly, the studies likely did not include participants in the moderate to severe stages of their condition, as dementia is less concealable during these stages, and participants would have likely been less able to make decisions and take actions regarding disclosure. Secondly, participants needed to be open to sharing their views and experiences in settings that required personal contact with one or more researchers. Data collected through more anonymous methods, especially considering the stigma of dementia, might have yielded different findings and, as a result, could have affected the synthesis of this review.

2.5.3 Implications

The findings from this systematic review have several implications. For the digital adaptation of ‘Who to tell, how and when’, quotes taken from included studies could be useful to be added to the adaptation as they provide valuable information on self-disclosure. There are also implications for future research. Firstly, this review focused on self-disclosure in people with dementia in a social context *outside* of the workplace. Reasons for not including workplace settings were twofold. Firstly, no prior review could be identified which explored factors related to self-disclosure in people with dementia in any context. Secondly, disclosing a health condition in the workplace often involves a distinct set of dynamics and considerations (Butler & Modaff, 2016), and people with dementia can face particular challenges in the workplace (Ritchie et al., 2015). However, considering these challenges and the likelihood that more individuals of working age will receive a diagnosis of dementia, it is recommended that future reviews also focus on work-related disclosure in people with dementia.

Only three of the 23 included studies focused on self-disclosure in dementia; in the remaining ones, self-disclosure emerged as an incidental finding. This suggests that self-disclosure has not received much attention in the dementia field. As concealing or disclosing a concealable stigmatised identity can have many implications (Chaudoir & Fisher, 2010), including loss of opportunities that were also identified in this review, it is recommended to explore experiences with self-disclosure in people with dementia further. This may include disclosure recipients' reactions, as suggested by the PPI contributors, or exploring factors related to self-disclosure further through a social health lens to elucidate how stigma, social support, or individual resilience intersect with social health outcomes related to disclosure.

Furthermore, the existing literature notably lacks longitudinal studies and comprehensive explorations of changes over time in relation to self-disclosure among individuals with dementia, with only one longitudinal study identified (Johannessen et al., 2018). Although changes over time were briefly mentioned in one of the studies (Weaks et al., 2015), they were not sufficiently explored. Given this gap, and because self-disclosure is flexible and dynamic (Chaudoir & Fisher, 2010), conducting research that delves into the dynamic nature of self-disclosure over time is recommended. This type of research can also support the development of targeted interventions as they can be tailored to an individuals' disclosure levels.

Finally, while a number of factors were identified in the studies that may account for some of the variance in people with dementia disclosing their diagnosis to other people, existing research does not provide a framework or model aiming to explain differences in people with dementia who disclose versus those who do not.

It is therefore recommended that future studies quantitatively examine factors involved in the decision to disclose a diagnosis of dementia to social networks. One relevant factor could be stigma resistance, which has been found to be an important aspect in people with mental health problems regarding self-disclosure (Firmin et al., 2017). Identifying variables like stigma resistance could prove insightful to support people with dementia in navigating the post-diagnostic disclosure process while maintaining social health.

2.6 Chapter summary and conclusion

The decision of people with dementia to disclose their diagnosis to social networks is complex and multifaceted, with multiple factors at play. While stigma can hinder or constrain self-disclosure, it also presents opportunities for empowerment and social health. This review brings together the existing literature on self-disclosure by people with dementia thus providing a rich repository of quotes which can be used in the further development of the 'Who to Tell How and When' intervention. Also highlighted in this review are gaps in the literature, particularly the limited attention given to self-disclosure in online spaces by people with dementia, and longitudinal or narrative approaches to understanding the way in which a person with dementia may adjust their approach to self-disclosure of their diagnosis over time. As a step towards addressing the knowledge gaps identified in this chapter, subsequent studies in this thesis explore self-disclosure over time and self-disclosure online. More particularly, Chapter 3 delves deeper into the complexities of self-disclosure using a narrative approach to capture online disclosure and changes in self-disclosure over time whilst Chapter 4 explores self-disclosure by people with dementia on social media.

Chapter 3: “It's just getting the word out there”: A narrative analysis exploring people with young-onset dementia disclosing their diagnosis to others

3.1 Chapter overview

The systematic review in Chapter 2 highlights the ‘snap-shot’ nature of prior research into self-disclosure of a diagnosis by people with dementia. By using predominantly thematic analyses, grounded theory approaches, or content analyses of cross-sectional data, prior studies showed that while self-disclosure is often associated with feelings of stigma, it can enable individuals to take control of their diagnosis and support their social health. Yet, there remains a gap in understanding how approaches to disclosure evolve over time, given that individuals are faced with disclosure decisions on an ongoing basis, as well as how individuals disclose online. Utilising a narrative approach, the present chapter builds on these gaps by providing a comprehensive exploration of the dynamics of self-disclosure on a personal and interpersonal level, including changes over time and disclosure on social media.

3.2 Introduction

The systematic review in Chapter 2 highlighted the complexity of self-disclosing a dementia diagnosis and its relationship with social health. However, despite the insights provided, it is notable that only three qualitative studies, focusing on self-disclosure in offline contexts, were identified at the time of writing this thesis.

These studies employed diverse methodologies, utilising interviews (Hellström & Torres, 2013), interviews with observations (Weaks et al., 2015), and group discussions (O'Connor et al., 2018), each with distinct approaches to analysis such as grounded theory (Weaks et al., 2015), deductive analysis with elements of discourse analysis (O'Connor et al., 2018), and qualitative analysis (Hellström & Torres, 2013). Two of these studies included both a person with dementia and a family member or spouse (Hellström & Torres, 2013; Weaks et al., 2015). Additionally, all but one study applied a cross-sectional study design. While this offers an important 'in-the-moment' look at self-disclosure, longitudinal data as well as explorations of the dynamics of self-disclosure over time are required to get a more comprehensive understanding of self-disclosure, as disclosure-related support might be required at various stages of the diagnosis.

Given the central role of self-disclosure in social interactions, understanding its dynamics is crucial for supporting social health in people with dementia. Adding to the methodologies of studies included in Chapter 2 and recognising the need for a more comprehensive exploration of self-disclosure in dementia, this study adopts a narrative approach to delve deeper into the personal stories of people with dementia. By allowing participants to share their stories in their own words, the narrative approach offers a unique depth of insight into the personal experiences of self-disclosure and evolvement over time. A narrative approach also offers the opportunity to explore how self-disclosure evolves with time (Sparkes, 2005), which was previously touched upon by Weaks et al. (2015).

3.2.1 A narrative approach to dementia

Engaging in storytelling and creating personal narratives enables individuals to construct and communicate their experiences, identities, and meaning of the world (Moen, 2006; Riessman, 2008). Narratives also offer insights into individuals' life trajectories over time as they represent more than just a mere 'snapshot' of someone's life at a set point in time (Carless & Douglas, 2017). These perspectives are integral to 'narrative psychology', which is interested in how people organise their experiences and make connections between them, particularly in understanding the experience of living with illness. Interest in the role of narratives as an approach to understanding illness has grown since the 1980s (e.g., Bury, 1982; Kleinman, 1988). For example, it has been suggested that chronic illness represents a 'biographical disruption' to a person's life, altering one's sense of self, identity, and relationships (Bury, 1982).

In recent years, the application of narrative approaches has extended its focus to exploring the unique challenges posed by chronic illness (e.g., Brown & Addington-Hall, 2008; McMahon et al., 2012). In dementia research, the majority of existing narrative inquiries seem to have focussed on the experiences of family carers or couples living with dementia (e.g., Brooks et al., 2014; Davies, 2011; Tretteteig et al., 2017). A few studies have also explored the experiences of people with dementia through their personal narratives (Buggins et al., 2021; Lea & Synnes, 2021), with Buggins et al. (2021) describing participants' narratives as "vivid and multi-faceted" (p. 1244). Supporting people with dementia to share their personal stories offers a valuable opportunity for researchers to understand their lived experiences and contribute to a deeper understanding of the dementia journey.

3.2.3 Study aims

In light of the restricted qualitative methodologies utilised by the studies included in Chapter 2, this study aimed to better understand experiences of disclosing a diagnosis of dementia through a narrative inquiry. Specifically, it focused on the following questions:

1. How do people with dementia experience diagnosis disclosure on a personal and interpersonal level, both offline and online?
2. How does disclosure change over time for people with dementia?

3.3 Methods

3.3.1 Study design

This qualitative exploratory study adopted a narrative approach to explore people with dementia's experience with disclosing or concealing their diagnosis to and from other people. I conducted semi-structured interviews with participants between February and June 2022.

3.3.2 Participants and recruitment

Inclusion criteria were having a diagnosis of dementia, being over the age of 18, being fluent in English, and having capacity to provide informed consent. Participants were recruited through Join Dementia Research (JDR; https://www.joindementiaresearch.nihr.ac.uk/), a UK-based platform that connects people affected by dementia with research studies, UK-based dementia charities and organisations (e.g., Young Dementia Network, DEEP), and social media. Study advertisements were placed on websites, newsletters, and social media. I emailed individuals who had taken part in another study forming part of this PhD and had consented to be contacted to gauge their interest in participating.

3.3.3 Procedure

Individuals interested in participating received the Participant Information Sheet (see appendix C) via email. Those who wished to take part were then contacted by me via phone or email to discuss the following: (1) the consent procedure (i.e., signing an online or hardcopy consent form; see Appendix D), (2) receiving the study incentive (i.e., email or post), and (3) interview details (i.e., date and time; online or over the phone due to the COVID-19 pandemic). They were informed that the interview would last up to one hour. They were also given the option of receiving the interview questions in advance of the interview. Participants received a reminder via email one day before their scheduled interview. After the interview was completed, I asked participants to provide their demographic information (age, ethnic group, gender, living situation, type of dementia, and time since diagnosis; see Appendix F). All interviews were audio-recorded. Participants received a debrief email containing information about dementia-related organisations and charities should they wish to seek further support (see Appendix E). Every participant received a high-street voucher worth £12 in appreciation of their time and effort.

3.3.4 Development of topic guide

The semi-structured interviews were informed by a topic guide. The first draft of the topic guide was derived from a set of questions used in a previous project carried out by clinical psychology trainee DH on disclosure of the dementia diagnosis to social networks by family carers of the person with dementia (link to DH's thesis: https://discovery.ucl.ac.uk/id/eprint/10134601/). I adapted DH's topic guide after consultations with my supervisors GC and KS to make it suitable for use with people with dementia and made slight adjustments to include disclosure on social media. The final topic guide (see Appendix G) consisted of open-ended questions related to individuals' experience disclosing their diagnosis (e.g., 'Since you were told you had dementia, what kinds of conversations do you and people who are close to you, for example, your partner/spouse or friends, have about the diagnosis, between yourselves?'). I also asked participants if and in what ways they used social media to disclose their diagnosis (e.g., 'Have you mentioned your diagnosis on social media? If yes, what information do you share?'). Throughout the interviews, I encouraged participants to expand on their answers using prompts (e.g., 'Can you tell be more about …') to gain a greater understanding of the topics discussed.

3.3.5 Epistemological approach

As narrative research is concerned with how individuals construct their experiences into stories, including individuals' interpretation, meaning-making, and some of the psychological and social consequences of them, I took the position that there is no knowable, objective reality or truth that can be 'uncovered'. Instead, I adopted a social constructionist approach for this study, assuming that individuals' realities are shaped not by direct influence from social and material structures, but rather by their interpretations of these structures (Silver, 2013). Rooted in psychology and sociology, social constructionism, as described by Burr (2015), views people's knowledge and understanding of the world as deeply influences by their history and culture. Adopting this approach, I aimed to explore and understand how people with dementia have constructed their reality by examining their use of language and narratives to describe their experiences with diagnosis disclosure (Willig, 2019).

3.3.6 Data analysis

All interviews were transcribed verbatim with the help of the automatic transcription platform Scrintal. While checking the transcripts for correctness, I applied a denaturalised transcription process in which I omitted distracting filler words such as ‘um’ or repeated words if they distracted from the content or meaning of what was said (Oliver et al., 2005). All participants were given a pseudonym and information making them potentially identifiable such as locations were removed (Saunders et al., 2015).

I then conducted a narrative analysis. There is no definitive way to conduct a narrative analysis and many approaches exist (Riessman, 2008). In this study, I based the analysis on Crossley’s (2007) approach to narrative analysis, as it was specifically developed to analyse narratives related to illness. The analysis was carried out by me and a second researcher (WQK) in Microsoft Word. First, we both repeatedly read the interview transcripts in order to become familiar with each narrative. We then separately identified the narrative tone, imagery, and themes based on McAdams (1993) for each transcript. Narrative tone resembles the content of the story as well as how it was told by the person. Imagery refers to the characteristic set of images that personal narratives express, for example, through the use of metaphors. Themes resemble the dominant themes or patterns in a personal narrative. After this, we met up with GC to discuss our interpretation of these concepts. The third step consisted of combining the concepts into one coherent story for each participant. For this step, I wrote a short summary of each narrative, drawing on the descriptive phase of Murray's (2015) approach. In doing so, each narrative was 'restoried', so that the summaries were placed in chronological order (Cresswell, 2007). Lastly, I conducted a cross-case analysis to establish similarities and differences between the narratives.

3.3.7 Ethics

Ethical approval was granted by the UCL Ethics Committee (ethics ID number: 1696/001; see Appendix H). The initial approval was based on DH's approval submission for his earlier study with family carers of people with dementia. To include people with dementia as participants, an ethical amendment was submitted and approved (see Appendix I). All participants received written study information prior to taking part. In accordance with the Mental Capacity Act 2005 (Ministry of Justice, 2005), participants were assumed to have capacity unless demonstrated otherwise, for example, during the set-up phase when potential participants who had expressed interest were contacted to discuss the study details and determine their ability to understand and retain this information. Everyone provided written informed consent. I checked consent again at the start of each interview.

3.4 Findings

A total of ten participants consented to take part in the study. Although it had not been the intention, all but one participant had young-onset dementia. As misconceptions around dementia and age featured strongly in participants' accounts, and to avoid too much heterogeneity, a decision was reached to only include the nine transcripts pertaining to people with young-onset dementia in the analysis. The demographic details of these participants can be found in Table 3.1. The mean age was 63.7 years (*SD* = 3.93). Three participants were male, and the majority (*n* = 7) had been living with dementia for more than three years (range: 1-10 years). Everyone identified as White British, and all but one lived with their spouse, while Rachel lived alone. Six of the participants had disclosed their diagnosis on social media. In the interview with Arthur, his wife clarified points if he struggled to find the right words.

Table 3.1. Characteristics of participants

Pseudonym	Age	Gender	Type of dementia	Time since diagnosis	Disclosed on social media
Brian	60-64	Male	PCA	5-7 years	Yes
Amy	60-64	Female	FTD	>7 years	No
Rachel	65-69	Female	AD	1-3 years	No
Heather	55-59	Female	AD	1-3 years	Yes
Ruth	65-69	Female	AD & VD	5-7 years	Yes
Jane	60-64	Female	AD	5-7 years	Yes
Arthur	65-69	Male	FTD	3-5 years	No
Eileen	65-69	Female	VD	>7 years	Yes
Charles	55-59	Male	AD	3-5 years	Yes

Note. AD = Alzheimer's disease; FTD = Frontotemporal dementia; PCA = Posterior cortical atrophy; VD = Vascular dementia

3.4.1 Narrative summaries

Interview duration ranged from 25 to 62 minutes, with a mean of 42 minutes. Each participant presented a unique narrative, with variations in narrative speed and flow. Table 2 provides an overview of the analyses of core narrative, themes, tone, and imagery for each participant. Subsequently, a summary of each narrative is given which includes a description of these concepts and participant quotes. Words added or revised for context or to ensure anonymity are enclosed in [], whilst an ellipsis (…) indicates omitted text.

Table 3.2. Findings from analysis of core narrative, themes, tone, and imagery

Pseudonym	Core narrative	Themes	Tone	Imagery
Brian	Routinising disclosure	- Mitigating potential misunderstandings - Activism and the notion of equality - Responding to challenging situations	Proud Certain Comfortable	“I see two moons”
Amy	“Caring is sharing”	- Finding a new purpose	Optimistic Hopeful Strong minded	Carer
Rachel	“It’s part of me, it’s not all of me”	- Disclosure initiates support - Being more than dementia	Strong Defiant Disappointed	“Mummy as usual”
Heather	“You mention that word dementia, and it just changes everything”	- Balancing role loss and keeping a sense of self - Differential attitudes and stigmatisation - Navigating life with dementia	Disheartened Uncertain Hopeful	“Swept under the carpet”
Ruth	“I recognise its limitations, but I dismiss it. It’s not part of me”	- Acceptance leads to openness - Positive responses facilitate disclosure - Re-evaluating disclosure	Strong Defiant Capable	“It’s just another ailment”
Jane	“If somebody needs to know, I tell them”	- Supporting myself and others - Natural expansion of disclosure	Calm Independent Strong Encouraging	“Another weight lifted off”
Arthur	“I don’t hide my disability”	- Navigating openness and potentially hurtful reactions - Social withdrawal to maintain dignity - Invisible illness	Disappointed Determined Thoughtful	Sunflower lanyard
Eileen	“I’m pretty much out and proud”	- Keeping silent: Initial shame and embarrassment - Cyclical process of positive reinforcement - Raising awareness through advocacy and charity work	Passionate Assured Defiant	Loud and proud
Charles	“I could sit and talk all day about it”	- New network and purpose - Disclosure for oneself and others - Getting the word out there	Cheerful Optimistic Satisfied	“Straight from the horse’s mouth”

Brian is in his early sixties and has a diagnosis of posterior cortical atrophy. He lives with his spouse. The core narrative identified in Brian’s story is ‘routinising disclosure', illustrating the openness and routine he developed regarding disclosure. His type of dementia is rare, and symptoms may be unfamiliar to people, which meant he often had to explain himself to others to avoid misunderstandings. For example, outsiders would assume he was drunk due to his movement difficulties. Over the years, he became a vocal activist and is proud to share his experiences with others: "There's a saying up here …, [states phrase], meaning we all come from the same place… no one is better than anyone else, so I'm not frightened talking to a [Member of Parliament] or anyone". He is not ashamed of his diagnosis and finds it merely a "different way of retirement", expressing comfort and positivity sharing his diagnosis with others. Positive reactions from others, such as an interest to learn more about his condition, and empathy have been an encouragement for Brian to disclose. However, he also experienced negative reactions, for example, people not believing him and friends turning away. Though he has no problems sharing his diagnosis, he is more inclined to tell those people he sees regularly: "The postman knows because we see him every day. But not the Amazon driver".

Amy is in her mid-sixties and received her diagnosis of frontotemporal dementia more than seven years ago. At the time, she was working in the healthcare sector, but was made redundant after receiving her diagnosis. She found this change difficult. The core narrative identified in Amy's story is "caring is sharing". She identifies herself as a carer and is very open about her diagnosis to support other people with dementia. Through supporting others, she has been able to carry on the caring function she fulfilled when working: "I tell people because I can't change the diagnosis. And if you see someone with a problem, I want to help".

Since dementia is not a visible condition, disclosing the diagnosis helped her to explain difficulties and have others make allowances for her.

Rachel is in her mid-sixties and has a diagnosis of Alzheimer’s disease. She described her journey to getting the diagnosis as difficult. Living alone, her cousin was with her when she received the diagnosis; she then told her sons and close friends. She lives in a village where the “jungle drums” gradually spread the word for her. Rachel has been supported by a health professional who advised her “to be like you are in life anyway, very open”, so “people are more aware” and can make allowances for her. She shares her diagnosis openly and quickly in settings where she may need support, for example, in the local shops. She would sometimes show a card that says that she has young-onset dementia. Sharing her diagnosis with people in her wider social circle has been more “difficult” at times. Some people would react dismissively and “say things that are not appropriate or not kind”, while there have also been situations where someone laughed about her behind her back. Though Rachel’s family has generally been supportive, one of her sons has had a difficult time adjusting to the diagnosis. In his company, Rachel would try to act like “mummy as usual”, resulting in her feeling “exhausted” at the end of the day. The core narrative identified in Rachel’s story is “It’s part of me, it’s not all of me”. Rachel used these words to describe that she “absolutely” does not want to be defined by the diagnosis. She explained she worried about disclosing her diagnosis in the beginning because of that, saying “once I said it, there would be no coming back from it”. However, realising that she wanted to “explain [her] actions” and that she would gradually need more support, especially since she lived alone, has led her to share her diagnosis with others.

Heather is in her late fifties and has Alzheimer's disease. Her core narrative revolves around her mostly negative experiences sharing her diagnosis and preserving her sense of self. After "feeling very empty, feeling very depressed" following her diagnosis, she, together with her husband, made the decision to share her diagnosis with others. She told her immediate family first, describing their disbelief. Heather then told her friends, mostly over the phone, and people in her wider social circle, saying that most of them stopped speaking to her. At appointments, doctors would only speak to her husband even when she was in the same room. Overall, Heather experienced a lot of stigmatising attitudes, with people assuming she lacked capacity or was too young to have dementia, as well as a lack of empathy: "Not one person really has asked me how I was feeling … I don't' think I even got a hug … you can see the shock and horror in people's faces when you tell them". To fight the negative attitudes and stigma and to support other people with dementia, she became active on social media, started blogging, and has been uploading hobby videos online. Sharing her diagnosis helped her to accept it: "It's out in the open and so I can get on and live my life, and I don't have to hide from anybody. I could just be me".

Ruth is in her late sixties and has mixed dementia. She lives with her husband and has a close relationship with her family and friends. Her core narrative consists of a strong belief that she is more than her diagnosis. She felt shocked when she received the diagnosis, but quickly discussed it with her family and a close friend to move forward and live in the present, and to implement support strategies. Initially hesitant to disclose it more widely, she quickly decided to "not let it beat [her]", that "it's just an illness like any other illness", and that she was still the same person, which helped her be open about her diagnosis. She disclosed her diagnosis to everyone she felt was “relevant”, including friends, people in her church, and local shops. Friends have been showing a lot of empathy, which enabled Ruth to also share difficult days with them and be met with understanding. However, people in her church have been dismissive and she is not able to contribute like she used to: “I feel quite excluded … It really disappoints me a lot”. She has since become more selective about whom she shares her diagnosis with to avoid having it “affect other people’s opinion of [her] before they get to know [her]”. She is also reluctant to disclose her diagnosis when it is not apparent, sharing the strong sentiment that she does not want to be defined by dementia. Ruth has become a strong dementia advocate, sharing her story in formal and non-formal contexts to show others that people with dementia can live well.

Jane is in her early sixties and lives with her spouse. Her core narrative reflects her openness about her Alzheimer’s diagnosis that she has been demonstrating from the beginning. Her children were initially worried the condition was hereditary, and she and her family expected the late stage of dementia to come “really, really quickly”. Her main reasons for sharing her diagnosis were to explain her symptoms and to receive support when needed, which would “[give] them permission to help [her] and … [make] it easier for them to … offer that help”. Her disclosure has “naturally expanded”, though she said: “I don't go out shouting it, … ‘Oh, I've got dementia.’ But if somebody needs to know, I tell them”. She also does not mind if people share her diagnosis with others. Jane disclosed her diagnosis to the local shops, which have been supporting her and have since undergone training to become more dementia friendly. She also carries a card in her phone case to make herself known as someone living with dementia, if needed. Despite her wishes for support, it was important to her that other people did not make decisions for her if she was able to do it herself. Reactions from others have been positive, but she was clear she did not want sympathy, because “that’s not why [she’s] telling them”. She has been sharing her life with dementia on social media to raise awareness and to support others, saying, “You hope by putting on something that has happened to you, that you help somebody else … So, you get tips about how to cope with things or problems that will sort of arise”.

Arthur is in his late sixties and has a diagnosis of frontotemporal dementia. Receiving the diagnosis came as a relief to him and his wife as he was repeatedly misdiagnosed as having mental health difficulties. The core narrative identified in his story is “I don’t hide my disability”. In the beginning, he shared his diagnosis with his sons and stepdaughters. While his stepdaughters were understanding and supportive, he said his sons “are in denial” because he can “walk and talk”. After telling his immediate family, he disclosed his condition to people in his wider social circle and village. His experience sharing the diagnosis has mostly been a positive one, though some had difficulties believing him because the condition is not readily visible. Arthur has stopped seeing people who are not understanding: “I want to be somewhere where I can do the things that I like to do in a safe environment with people that know of my condition, are empathic towards it, but not mollycoddling me”. However, consequently, he has become more socially isolated. His reasons for sharing his condition were to raise awareness, especially since his dementia is considered a rare one, and to stay true to himself as “it’s not fair to myself or to my wife to deny the fact that I have this condition”. He can be selective about whom he discloses his exact diagnosis to, with empathy being a quality he looks for in order to decide whether to disclose his condition or not.

Eileen is in her mid-sixties and has vascular dementia. She lives with her partner. Her core narrative revolves around being “out and proud” with her life with dementia. When she first learned about her diagnosis, she felt “gobsmacked” and embarrassed and had a difficult time adjusting to it, partly because she thought that dementia was for “old people”. In the beginning, she only discussed the diagnosis with her partner and immediate family, being highly selective about whom she would disclose to and choosing only people whom she felt she could trust and “wouldn’t go away and start gossiping about it”. After a social care professional advised her to get in touch with a dementia organisation, she trained as a dementia friend and started sharing her story. Gradually, Eileen disclosed her diagnosis to her neighbours and then to people outside of her social circle. Receiving positive reactions from others acted as a positive reinforcer. However, she also experienced dismissive reactions: “[They] would say, ‘Oh, but you’re fine … You don’t look like you’ve got dementia’. And now I find these things quite irritating because what does someone with dementia look like?”. Disclosing her diagnosis has led to people acknowledging her needs and inquiring how she is feeling, which she appreciates. Over the years, she has become an active and vocal supporter of the dementia community, taking part in national fundraising and outreach activities, stating, “My life is really good … I have a real sense of purpose”.

Charles, who lives with his spouse and children, is in his late fifties and has Alzheimer’s disease. The core narrative of his story is “I could sit and talk all day about it”. This narrative was frequently present in Charles’s story as he explained his willingness to share his diagnosis openly with anyone. When he was diagnosed, he felt shocked and depressed, having had to give up his job and driver's licence. His family was very supportive but friends "were a different kettle of fish". People he had known for decades turned away from him due to the "stigma that surrounds dementia". His attitude to his diagnosis changed when he struck up a friendship with a dementia outreach worker who asked him if he wanted to be involved in awareness raising activities, which he has been doing "ever since". Since then, he has been very open about the diagnosis, wearing a lanyard to identify himself as having dementia. He finds disclosing his diagnosis "very therapeutic" and hopes that his openness can "make things better for [other] people living with dementia". Charles has become a vocal dementia activist and advocate, setting up a local support group for people with young-onset dementia after finding that most groups in the area were set up for older people. His experience with disclosing his diagnosis has been "a mixed bag of fish". While many people were accepting, some, including medical professionals, did not believe that dementia can occur at a younger age.

3.4.2 Cross-case analysis

While every participant's narrative was unique, there appeared to be some similarities between them, for example, in terms of their experiences with other people's reactions towards them. An exploration of these through a cross-case analysis generated three cross-case 'themes': 1) "It's just an illness like any other", 2) changes over time, and 3) interpersonal relationships and support.

3.4.2.1 “It's just an illness like any other”

The theme “It's just an illness like any other” represents both the acceptance demonstrated in all participants’ narratives and their strong stance against stigma associated with dementia. This was also evident in the strong and defiant tone of several of the narratives. While all participants acknowledged the dementia-related impairments, Brian, Jane, Charles, Amy, Heather, and Ruth emphasised that they felt that the condition had not altered their personalities and identities. This perspective motivated their decision to openly share their diagnosis, with several drawing comparisons between dementia and other medical conditions, as illustrated by the following quotes:

> *I'm not embarrassed, it's just me, just a fact of life.* (Brian)
>
> *In my opinion, if they had a problem with that or they couldn't deal with it, that was their problem. That wasn't mine.* (Jane)
>
> *I like to go out and about. I like to do things. Just because one day I'm diagnosed with dementia, I shouldn't be allowed not to do those things anymore. I should still be allowed to do those things.* (Charles)
>
> *… I realised that there was no reason for me to keep quiet about it, it's just an illness like any other illness, nothing to be ashamed of or anything like that, and I just was quite open about it, the way you would be open about anything else.* (Ruth)

Rachel, though accepting of her diagnosis, seemed to feel more strongly than the other participants that she did not want her diagnosis to dominate conversations, saying, “I'd rather not be defined by it and I'm very worried about letting myself down as well”. This perspective may have been influenced by the fact that she lived by herself.

All participants extensively discussed the stigma attached to dementia and highlighted that the act of sharing their diagnosis served as a means to raise awareness about the condition and actively confront stigma. Rachel, Heather, Jane, and Eileen drew comparisons between the stigma historically associated with cancer and the current dementia stigma. Jane noted, “If somebody had a cancer diagnosis, they wouldn't actually say the word. And dementia can be a bit like that where I don't think it should be”. Given that all participants had been diagnosed with young-onset dementia, Brian, Rachel, Heather, and Eileen employed the act of sharing their diagnosis to fulfil a dual role concerning the stigma associated with dementia: not only to combat it but also to increase awareness and challenge the misconception that dementia exclusively affects older individuals:

> *I want people to understand that anyone ... Yeah, I think of any age, but certainly people in their fifties and sixties can get dementia. I want people to know that.* (Brian)
>
> *… the big, big, big problem is that people think dementia is for old people. And it is for old people and I know that … But there are many people still trying to, like me, sort of get on with things in life and be part of life and people don't understand really what dementia is … But if you don't tell*

> *people about dementia on a wider platform and about young dementia, then you can't expect people to know because they just think it's like 'they forgot their keys' or 'it's quite funny'.* (Rachel)

> *And there's lots of people that are under the age of 60 that have dementia, under the age of 50 and 40. And so for me, I wanted to bring more awareness that just because I've got dementia doesn't mean to say I have to sit in a chair. We can still live …* (Heather)

Brian and Arthur encountered unique experiences of stigma associated with their rare forms of dementia. This included instances where family members, friends, and sometimes professionals did not believe their diagnosis. Brian, for instance, recounted the following situation:

> *… We asked for a care package so the care manager came out and she didn't believe it … she just said you didn't need any help so there's nothing I can do for you, because I was talking and everything else.* (Brian)

To raise awareness and combat stigma, Brian, Charles, Heather, Ruth, Eileen, and Jane had taken on active roles as dementia activists and advocates, sharing their personal experiences on TV and participating in dementia outreach and education activities. All of them also shared their diagnosis on social media to raise awareness and educate people. For example, Jane explained wanting to combat the negative assumptions she felt many people without dementia had about the condition: "It's just to raise awareness and to break down the stigma that's attached to having a dementia diagnosis (…) that it’s okay to talk about it.” Similarly, Heather emphasised the importance of “getting the word out there” and “[trying] and make it a more positive experience rather than a negative one” as a reason for actively disclosing her dementia identity on social media.

Rachel and Eileen discussed their approaches of addressing derogatory comments about dementia or those affected by it, with Eileen saying, “I do tell people who I don't think will understand, because I think they need to learn a bit more about it … now I would step in and say, "Hang on a minute, that's not appropriate".

Brian, Rachel, Jane, Arthur, and Charles had adopted readily visible strategies in their daily lives to make themselves known as individuals living with a disability. These strategies included the use of a white cane for Brian, dementia identification cards carried by Jane and Rachel, and the display of hidden disability sunflower lanyards by Arthur and Charles. As Charles explained, the lanyard “tells everybody I live with dementia ... I'm quite happy with that”. Most of them disclosed their diagnosis in person. Jane and Eileen explained that they had told some family members or friends who lived further away over the phone, with Eileen additionally having told some people via email. However, Eileen had noticed that people found it difficult sometime to hear it over the phone “because it is quite a big thing to tell people”.

3.4.2.2 Changes over time

A second cross-case theme was *changes over time* regarding disclosure. These changes ranged from being more secretive in the beginning to becoming very open, to self-disclosing widely at first but becoming more selective over time. While gradually coming to terms with their diagnosis, Heather, Eileen, and Ruth described becoming more open and confident with time:

> *When I was first diagnosed, I only told my maybe closest friend and my husband and my son who is older … I didn't really want to talk about it. And then, as I became used to the idea and 'so I am not going to let this illness beat me', I was quite open about it.* (Ruth)
>
> *… We walked out of the clinic feeling very empty, feeling very depressed … I just went home in a sort of a daze really. So, I couldn't face telling anybody on that day until I sort of got things worked out in my head … So, it took me a while to sort of pick myself up and think 'right', the only way forward now is positive because I don't want to just sit there and do nothing, because I'll just deteriorate quicker.* (Heather)
>
> *It's changed since I first got the diagnosis, because initially I was very embarrassed and almost ashamed. And so, I only spoke with my close partner and also my family, but I didn't tell anybody else. I also didn't believe them. I couldn't believe that I had dementia. But almost 10 years on now, I'm very happy to talk about it.* (Eileen)
>
> *I mean, I didn't come home from the diagnosis and go straight out telling people. I didn't tell people for a long time, but I didn't exactly feel ashamed. I just felt that once I said it, there would be no coming back from it.* (Rachel)

While Ruth was initially reluctant to disclose her diagnosis and gradually changed her perspectives on her own, Heather had support from her husband in making the decision to be open about her diagnosis. Charles, Eileen, and Rachel discussed how they received support from professionals, which helped them shift their mindsets and become more comfortable with and open about their diagnosis:

> *When I was first diagnosed, I thought it was the end of the world ... It was for the fact that there was a lady called [name of woman] who is from the [name of region] Dementia-Friendly Initiative Programme, and I thought I want to let my kids find out a bit more about dementia, about Alzheimer's, and [name of woman] was doing a dementia presentation ... And then from there [name of woman] and I struck a kind of friendship, and ever since we go out and about doing dementia awareness presentations.* (Charles)
>
> *When I was first diagnosed, I probably spent about 18 months being really depressed about it and not telling anybody, because I was ashamed and embarrassed. And then a local young-onset worker came … to talk to me about how I was coping … I said to her, 'Oh, what's the point? I'm really fed up. What is my purpose now?' And she advised that I did some training with the Alzheimer's Society to be a dementia friend. So, I started to do some dementia friends sessions locally, and I realised that actually, my story was different."* (Eileen)
>
> *I've had marvellous support from someone called [name of occupational therapist] … He comes to see me and has done since [my] diagnosis … And*

> *we talk about me as a person and my past life and how I am. So, he's led me to pathways that help me to be able to share that I have dementia."* (Rachel)

For Brian, Jane, Eileen, Charles, and Arthur the diagnosis came a as a relief, as it provided long-awaited answers for the symptoms they were experiencing. Receiving the diagnosis meant they could explain to others what was going on as Jane explained, "… to let people know why I was acting the way I was acting, so they were aware". This felt especially helpful for Brian and Arthur whose dementia symptoms were distinct from the more prevalent symptoms of Alzheimer's disease. For example, Brian's dementia includes visual impairments, which led him to adopt a humorous self-disclosure approach to evoke other people's interest: "… I usually start off by saying, 'Oh, I see two moons,' and that gets them going".

Over time, Ruth and Arthur had become more selective about whom they would disclose to. Both had experienced a lack of understanding from people in the past, which seemed to have played a role in their decisions, as Ruth explained:

> *I don't want it to colour their opinion of me anymore, because it is a stigma attached to dementia and I found that through the church members, not my close friends, but leaders, church members. And I don't want to affect other people's opinion of me before they get to know me. Yeah, get to know me, see what I'm really like and then I might tell them.* (Ruth)

3.4.2.3 Interpersonal relationships and support

All participants spoke about the effect that sharing their diagnosis had on both existing and newly-formed relationships and the support they received from others. The first people that the participants shared their diagnosis with were family members and close friends. While the majority experienced positive reactions, Brian, Rachel, Arthur, and Heather spoke about how (some of) their children and, in Heather's situation, her parents, responded with disbelief and shock to the diagnosis. For example, Brian recounted how his children "didn't believe it" because "I don't show signs of memory loss or confusion". Heather's narrative was defined by her profound disappointment after having been repeatedly met with negative reactions and that "not one person was positive". Recounting her parents' reaction to her diagnosis, she said:

> *They're both in their eighties, so they took it pretty badly. And this is where the stigma again comes in with dementia … Well, the question was, "How long have you got to live?" ... how do you answer that question? Because I don't know. And I just looked at my mom and I said, "How long have you got to live?" [light laughter], and sort of threw the question back, because nobody knows how long they've got to live.* (Heather)

Similarly, Rachel, Ruth, Eileen, Heather, and Brian experienced dismissive reactions from others when they shared their diagnosis. For example, Eileen described hearing remarks from neighbours such as "you don't look like you've got dementia", which she found "quite irritating". Rachel had developed a somewhat defiant demeanour at times. For example, she recalled an instance where acquaintances she met on the street started laughing about her memory problems, which prompted Rachel to fire back at them with a feisty remark.

Charles, Arthur, Heather, and Brian also reflected on reactions of individuals who had been close to them prior to the diagnosis but had, as Charles put it, “just stopped coming around”. In contrast to the other participants, the four of them experienced the loss of some or all of their friends after they had shared their diagnosis. For example, Brian made the decision to resign from a club, because its members were dismissive and lacked understanding. As a result, he said, “I have withdrawned [sic] myself and in some respects have become more isolated”. Charles speculated that “the whole diagnosis process just scared them off once I was diagnosed with the dementia”. Ruth, who had disclosed her diagnosis to her church pastor, said that she did not get asked to actively participate in church activities anymore. Consequently, she said “I feel quite excluded and as by association, my husband feels the same”. She also stated that she regretted having disclosed her diagnosis at church. Despite these challenges, their narratives were optimistic and confident, as Brian remarked, “it’s their problem not mine”.

In their narratives, Brian, Amy, Charles, Jane, Heather, Arthur, and Ruth highlighted the importance of peer support groups they engaged with. These groups not only offered valuable support but also provided a platform for forging new connections with like-minded people. Brian captured this feeling of close-knit support, saying, “We all understand each other and protect each other”. Charles had even started his own peer support group. Furthermore, Brian, Heather, Ruth, Charles and Amy cited wanting to support other people with dementia as a motivating factor for sharing the diagnosis. For example, Amy emphasised the importance of helping others who are newly diagnosed, stating, “If you meet somebody who's newly diagnosed with it, or something like it, then you're helping them to learn to live with it”. For Heather, Brian, Ruth, Jane, and Charles, peer support was also enabled through the use of social media. For example, Jane described using social media to share her personal story and to support others who were coping with dementia-related struggles: “You hope by putting on something that has happened to you, that you help somebody else …”, while Brian had relied on social media to stay in touch with other people with dementia during the COVID-19 pandemic. Heather had started posting her crafts projects on social media, which enabled contact with other people with dementia.

Rachel, Ruth, and Jane shared that disclosing within their social networks facilitated opportunities for others to offer support and make allowances for them. Jane underscored this by saying, “… if you don't tell people you're not giving them permission to help … then they don't know is it okay to ask [Jane] if she's okay”. However, she further stressed her preference for consent-based support, explaining, “… the thing I've always, always told people is ‘Don't presume you know what I need, ask me’”. Rachel and Jane also talked about disclosing their diagnosis to staff working in their local shops or on public transport if they needed additional support, with Rachel noting, “… they're always extremely helpful and kind”.

Among all participants, only Rachel recalled having actively concealed her diagnosis. She shared that she had developed a close friendship with someone and believed it had the potential to evolve into a romantic relationship but decided to not pursue it any further once she was diagnosed “because that wouldn’t be fair to somebody you were in a relationship with”. In addition, Rachel, Heather, and Brian discussed instances in which they made conscious efforts to conceal their symptoms when in the presence of others, particularly family members. However, all of them stated that these efforts would leave them feeling tired:

> *… my parents are still alive, and I think it's so difficult for them. So, I try to be as normal as I possibly can so that they don't see any changes, whether they do or not I don't know. But I always come away from a visit feeling exhausted because I've had to try so hard to be the old [Heather] instead of the new [Heather].* (Heather)
>
> *I can see with [son 1], he gets quite distressed so I find I feel exhausted when I come away from there because I try so, so hard not to do something silly or let the side down … You sort of play acting in a way. Covering it, which of course compounds the problem, because then they think you're fine. You become your own victim of your own successful acting skills.* (Rachel)
>
> *… when I'm with other people, I will use all my energy to keep going, not to hide it but just so that I'm part of a group and take part.* (Brian)

Interviews were conducted with ten people with dementia, with a mean age of 65.3 years (see Table 4.4). Most of the participants were female (*n* = 7), had Alzheimer’s disease (*n* = 5), were living with their spouse (*n* = 9), and had been diagnosed more than five years ago (*n* = 6).

3.5 Discussion

In this study, I aimed to explore people with dementia's experiences of disclosing their dementia diagnosis through a narrative approach, including how their openness changes over time and disclosure on social media. This allowed participants to present their individual stories while also enabling comparison of their experiences. Of the nine internet-using participants (i.e., all communication prior to participating took place over email), six had disclosed their dementia diagnosis on social media. The cross-case analysis of the nine narratives revealed similarities and differences in the narratives regarding experiencing dementia as "an illness like any other", the effect of time on changes in disclosure, and the interplay between disclosure and interpersonal relationships. In the following discussion, I highlight important insights.

3.5.1 Principal findings

Contrary to a previous qualitative study (Hellström & Torres, 2013), all participants in this study had disclosed their diagnosis. The findings reveal that participants experienced disclosure as a personal and multifaceted journey. In their narratives, they highlighted the ability and importance of preserving their identity, which included disclosing their diagnosis, while acknowledging the challenges posed by dementia. While there has been an ongoing debate regarding how much the self persists in people with dementia (Caddell & Clare, 2010), participants in this study showed a strong determination in staying true to themselves. Similar to findings from an ethnographic study by Birt et al. (2023), the participants demonstrated acceptance of their diagnosis by considering dementia as just one part of their lives rather than the dominant one. With time, acceptance of the diagnosis allowed several participants to share their diagnosis more widely within their social networks and beyond. Diagnosis acceptance has also been suggested to play a pivotal role in people with dementia preserving their identities (Birt et al., 2017). As such, accepting one's diagnosis, and disclosing it as a consequence, aligns closely with the second domain of the social health framework, 'the ability to manage life with some degree of independence', as it enables individuals to cope with the difficulties associated with dementia, among other things. While another interview study conducted with nine people with young-onset dementia proposed that participants experienced a consistent loss of the self (Busted et al., 2020), participants in this study felt confident in themselves even if they had to adjust to the changes caused by their dementia. This emphasises the importance of recognising individuals' identities beyond their condition or diagnosis.

Most of the participants shared their views on the stigma associated with dementia, with several actively confronting it both in-person as well as on social media. Their shared narratives illustrated a strong commitment to raising awareness about the condition and challenging popular misconceptions, which was also found to be an important factor for self-disclosure in Chapter 2. Similar to a qualitative study conducted with participants with neurological impairments, including young-onset dementia (Hutchinson et al., 2018), the participants in this study talked about the misconceptions that dementia is 'an invisible illness' and related to 'old age'. To confront this stigma, most participants would also disclose their diagnosis to people they had only just met or did not have a personal relationship with. Some also utilised strategies such as wearing a visible disability lanyard to support their openness. Strategies like these have been described by communication researchers exploring how individuals disclose secrets, though an existing level of trust has generally been described as a prerequisite to self-disclosure (Afifi & Steuber, 2009).

Another approach for participants to combat stigma included taking on roles as activists. Active advocacy aligns with the broader discourse on the role of people with dementia as agents of change in shaping public perceptions, policies, and interventions (Hagan & Campbell, 2021). Additionally, the participants in this study seemed to have 'blossomed' in their new roles as dementia advocates. Chapter 2 also highlighted advocacy as an important factor for self-disclosure. Findings from this chapter suggest that advocacy can offer opportunities for empowerment (van Corven et al., 2021), thus enabling them to use their competencies and talents. This aligns with the first domain of the social health framework (i.e., 'the capacity to fulfil one's potential and obligations'). This aspect was further emphasised by a recent systematic review appraising the literature on the involvement of people with dementia in advocacy, which found that advocacy can provide people with dementia with a strong sense of purpose by enabling them to make contributions that extend beyond themselves (Weetch et al., 2021). This seems particularly relevant for people with young-onset dementia who are often confronted with additional aspects of loss such as loss of employment (Greenwood & Smith, 2016).

The participants' narratives also revealed complex dynamics within interpersonal relationships following diagnosis disclosure. While many received understanding and support from family and friends, others encountered disbelief and shock, echoing findings from previous qualitative research on the varied reactions of social networks to a dementia diagnosis (Pipon-Young et al., 2012). Moreover, the loss of social connections and lack of empathy following disclosure was an experience for some participants in this study. These findings highlight the importance of the third domain of the social health framework, which emphasizes the ability to actively participate in social activities. Research on disclosure of a concealable stigmatised identity suggests that the reaction of the disclosure recipient is an important factor that can predict the positive consequences of disclosure (e.g., social support). This aspect, also a part of the Disclosure Process Model by Chaudoir and Fisher (2010), suggests that the recipient's reaction can influence future self-disclosure. Indeed, some participants in this study had become more selective in their disclosure due to negative reactions from others, while others had become more open.

Several participants found understanding and support by joining peer support groups, either in person or online, an aspect that can enrich the post-diagnostic experiences of people with young-onset dementia (Gerritzen et al., 2023). These groups provided valuable support and facilitated new connections, a beneficial feature that has been described as a sense of 'collective strength' in a previous qualitative interview study (Clare et al., 2008). As a result, participants who were initially very open about their diagnosis but encountered strained reactions from their social networks found a supportive community in these groups. These findings underscore the need for enhanced societal understanding and the potential strain that stigma and fear can place on existing relationships (Rewerska-Juśko & Rejdak, 2020), while also highlighting the positive impact of peer support networks in fostering a sense of belonging among people with dementia. This suggests that peer support can positively influence the third domain of the social health framework.

3.5.2 Strengths and limitations

This is the first study to explore self-disclosure in people with dementia employing a narrative approach. A strength of this approach is the rich and unique insight that could be gathered, providing a detailed image of participants' experiences with disclosure. Although not set up this way, this study is unique in its exploration of self-disclosure among people with young-onset dementia. While this study adds to the body of dementia research that includes the voices of people with dementia, it has certain limitations. Firstly, all participants came from a similar socio-economic background, and primarily a White ethnic background. The aim of narrative research is not to produce generalisable findings since each narrative is unique. However, future narrative research would benefit from a more diverse sample encompassing various backgrounds and cultures, particularly given that individuals from different ethnic backgrounds may experience dementia-related stigma differently (Herrmann et al., 2018). Secondly, all participants in this study were living with young-onset dementia, representing a small but important minority within the wider population of people with dementia. Their disclosure experiences may therefore differ from the experiences of people with late-onset dementia. One explanation may be the requirement of remote data collection due to COVID-19 regulations at the time, as age seems to play a role in the acceptance of ICTs that were used in this study (Lythreatis et al., 2022). However, it may also suggest that younger people with dementia may encounter unique challenges related to diagnosis disclosure. This is particularly pertinent as the majority of participants in this study referred to the stigma associated with being younger than people may expect. Thirdly, despite my aims to recruit a diverse sample representing various levels of openness, all participants in this study were comfortable disclosing their diagnosis as needed. The experiences of people with dementia who do not feel comfortable sharing their diagnosis may therefore differ. This potential bias, whereby studies on diagnosis disclosure tend to attract participants who are more comfortable sharing their condition, has been previously reported (Bhatt et al., 2023; Pembroke et al., 2017). Thus, future research could consider purposive sampling to include people with dementia who are hesitant to disclose their condition, enabling a more comprehensive exploration of narratives related to concealing one's diagnosis.

3.5.3 Implications

The findings from this study provide implications for the further development of the 'Who to Tell, How and When' intervention, healthcare professionals and wider society. As revealed in the narratives, disclosure was not always a straightforward process. Negative reactions such as disbelief from family, friends, and the wider community are common and can, in some cases, contribute to social isolation, thus limiting social health. Furthermore, it is important to recognise that adjusting to the diagnosis can be a staged process that may be filled with many emotions (Robinson et al., 2011). Health professionals should be aware of this and provide individuals and their families with appropriate post-diagnostic resources and services to help them navigate disclosure and their own dementia journey, such as 'Who to tell, how and when', aimed at empowering people with dementia in their disclosure process (Bhatt et al., 2020). When designing services for individuals who are adjusting to a new diagnosis and considering how to share it with their social networks, it is not only important to acknowledge the expertise of people with dementia, but also to actively incorporate it. Conducting research *with* instead of *about* people with dementia aligns with an approach that is respectful of their continuing citizenship (Birt et al., 2017).

Additionally, the narratives highlighted misconceptions about dementia in general and young-onset dementia in particular that individuals are faced with. The experiences of participants who actively engaged in advocacy and awareness-raising work also emphasise the importance of reducing the prevalent stigma and empower people with dementia (Alzheimer's Disease International, 2019). This underscores the ongoing need for initiatives that aim to establish dementia-friendly communities and support individuals' social health. Research into the effectiveness of these interventions and programmes is also warranted to gather evidence-based insights into how to best foster awareness and promote acceptance of dementia within society.

3.6 Chapter summary and conclusion

This chapter takes a narrative approach to offer unique insights into the disclosure process from the perspective of people with dementia, including its relationship with social health. The findings reveal that individuals undergo a personal and evolving journey in managing self-disclosure, influenced by stigma and other people's reactions, with implications for the further development of the 'Who to

Tell, How and When' intervention. Moreover, the chapter highlights the potential of social media for advocacy purposes and support networks. Building on the factors identified in Chapter 2, this chapter underscores the importance of online and offline peer support and the use of visible strategies in disclosure decisions, which are both relevant for the adaptation of 'Who to tell, how and when'. Chapter 4 focuses in more depth on the role of social media in facilitating or supporting the disclosure process.

Chapter 4: Self-disclosure and social media use among younger and older people with dementia: An internet-mediated mixed-methods study

This chapter is a version of a peer-reviewed published paper, Kohl et al., (2023). The full citation for this paper is:

Kohl, G., Koh, W.Q., Scior, K., & Charlesworth, G. (2023). Self-Disclosure and Social Media Use Among Younger and Older People with Dementia: An Internet-Mediated Mixed-Methods Study. *International Journal of Human-Computer Interaction,* 1-11. *https://doi.org/10.1080/10447318.2023.2265728*

4.1 Chapter overview

As described in previous chapters, one way of disclosing one's stigmatised identity is by posting or sharing information on social media. Chapter 3 highlighted its relevance for people with dementia, with online self-disclosure enabling opportunities for social health. However, there remains a gap in the current literature on the use of social media for self-disclosure, as identified in Chapter 2. While Chapter 3 provided insights into online self-disclosure, further research with a larger sample is warranted. Consequently, the current chapter describes a mixed-methods study that explores how people with dementia use social media and how they communicate their diagnosis or other dementia-related information on their social media accounts.

4.2 Introduction

Many mainstream and everyday ICTs hold considerable potential to support social health in people with dementia. For example, they can facilitate greater independence by assisting individuals in managing various aspects of daily life (Meiland et al., 2017), aligning with domain two of the social health framework (i.e., ‘the ability to manage life with some independence’). They can also facilitate social engagement and participation (Heins et al., 2021), contributing to domain three of the framework (i.e., ‘the ability to actively participate in social activities’). One such ICT is ‘social media’ defined as “a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allows the creation and exchange of User Generated Content” (Kaplan & Haenlein, 2010, p. 61). Social media have become a means of interpersonal communication allowing people to share their thoughts, emotions, and experiences.

Although social media use has increased by around 40% across all age groups since 2015, an age gradient remains. Whereas 92-99% of internet-using individuals aged 16-54 used social media in 2022, equivalent figures for the 55-64 and 65+ age brackets are 86% and 70%, respectively (Ofcom, 2023). A motivating factor for social media use by adults over the age of 65 is to stay connected with family and friends (Newman et al., 2021). In light of the COVID-19 pandemic and government restrictions, these online spaces have become more important for people over the age of 65 (Haase et al., 2021) and for people with dementia (Talbot & Briggs, 2022) to stay socially connected, thereby supporting their social health, in addition to having widened people’s use of ICT-based communication (M. H. Nguyen et al., 2020). In recent years, interest has grown in the use of social media to disseminate general dementia-related information (e.g., Robillard et al., 2013; Shu & Woo, 2021), mainly considering the use of social media by family caregivers of people with dementia (e.g., Anderson et al., 2017; Bachmann, 2020). A limited, but growing, number of studies have also explored the use of social media by people with dementia themselves such as online discussion forums (Johnson et al., 2020; Mehta et al., 2020; Rodriquez, 2013; Talbot & Coulson, 2023), blogs (Kannaley et al., 2019), Facebook (D. Craig & Strivens, 2016), Twitter (Mehta et al., 2020; Talbot et al., 2020a, 2020b, 2021; B. Thomas, 2017), as well as a variety of different platforms (Johnson et al., 2022; see Table A1 in Appendix J for an overview). The majority of studies on social media and people with dementia focused on younger people with dementia (D. Craig & Strivens, 2016; Talbot et al., 2020b, 2021; Thomas, 2017) or did not specify the age of their samples, probably because they had collected and analysed secondary data (Johnson et al., 2020; Kannaley et al., 2019; Mehta et al., 2020; Rodriquez, 2013; Talbot & Coulson, 2023). Studies that reported reasons for the use of social media platforms found that individuals used them for social support and community building (D. Craig & Strivens, 2016; Johnson et al., 2020, 2022; Kannaley et al., 2019; Mehta et al., 2020; Rodriquez, 2013; Talbot & Coulson, 2023; Thomas, 2017), sharing or discussing everyday life and experiences (Kannaley et al., 2019; Mehta et al., 2020; Talbot et al., 2020b; Talbot & Coulson, 2023), awareness raising (D. Craig & Strivens, 2016; Kannaley et al., 2019; Talbot et al., 2020b), and (re)shaping one’s identity post-diagnosis (D. Craig & Strivens, 2016; Talbot & Coulson, 2023; Thomas, 2017). Whilst these studies have provided evidence that people with dementia use social media, few studies have included or explicitly focused on older people with dementia and most research has been informed by publicly available social media content as opposed to data collected directly from individuals. In addition, their sample sizes are either relatively small or not reported.

The use of social media has the advantage of facilitating and enhancing connections with others, but also the potential disadvantage of attracting negative reactions, or even personal attack (Naslund et al., 2020). People with dementia can face prejudice and experience discrimination in their everyday lives as a manifestation of the stigma of dementia (Herrmann et al., 2018), which may result in their choice to hide their diagnosis from others (O'Connor et al., 2018). Whilst the concealment or disclosure of one's illness status on social media has been explored among individuals with other chronic health conditions (Kaushansky et al., 2017; Sannon et al., 2019), less is known about how people with dementia use social media platforms to acknowledge their dementia diagnosis or share dementia-related information, with only one study identified in Chapter 2 (Castaño, 2020). Chapter 3 added additional insights, but the sample was small with only six participants disclosing their diagnosis online, all of whom were people with young-onset dementia. We currently do not know if there are differences between people with young-onset dementia and people with dementia aged 65 and older who use social media. Therefore, in this exploratory research, I aimed to explore (1) how people with dementia use social media, (2) how social media use differs between people with young-onset dementia and older people with dementia, and (3) how people with dementia disclose their diagnosis or share dementia-related information on their social media accounts.

4.3 Methods

4.3.1 Study design

I applied a convergent mixed-methods study design, combining quantitative and qualitative methods, to answer the research questions (Creswell & Plano Clark, 2018). I set up a cross-sectional online survey comprising closed-ended and open-ended questions on the Qualtrics platform (https://www.qualtrics.com) to collect quantitative and qualitative data. Data collection took place between February and June 2022.

4.3.2 Recruitment

I applied a convenience sampling strategy. Recruitment took place through the JDR platform and UK-based dementia organisations (e.g., DEEP Network, Young Dementia Network). Study details for the survey were advertised on websites, in newsletters, and on Facebook and Twitter (see Appendix K). To increase diversity of the survey sample in terms of ethnicity, I approached individuals registered on JDR who identified as being from an ethnic background other than White via email to gauge their interest in taking part in the survey (see Appendix L for the email template). Eligibility criteria included having a form of dementia, ability to read and understand English, ability to provide informed consent, and having access to an internet-enabled device.

Sample size for the survey was determined through power analysis using G*Power (version 3.1.9.7; Faul et al., 2007) for multiple linear regression, based on independent variables that were collected but fall outside of the scope of this study.

With power set to 80%, a medium effect size ($f^2 = 0.15$), and a significance level of 0.05, it was calculated that a sample of 116 would be required.

4.3.3 Data collection

Socio-demographic information collected included age, gender, ethnicity, living situation, education level, employment status, marital status, country of residence, type of dementia diagnosis, and time since diagnosis. Survey respondents' use of social media and whether they used social media to share dementia-related information was explored using open-ended and closed-ended questions created for this study. If respondents answered 'yes' to the question if they used social media, they were asked about their frequency of use, which platforms they used, if they shared dementia-related content on them, and if so, the kinds of dementia-related content they published on them. The survey was piloted with colleagues from DISTINCT and adjusted according to their feedback.

4.3.4 Patient and public involvement

In the course of the study development, I consulted members of EWGPWD about the research topic and accessibility of the online survey. The EWGPWD was established by Alzheimer Europe and its partner associations and consists of people with dementia who are active advisers on international research projects (Alzheimer Europe, 2022). During the meeting, the group highlighted the importance of the study topic, describing some of their personal experiences of disclosing their diagnosis. They advised me to shorten the Participant Information Sheet and Informed Consent form, to increase the font size of all text, and to add more space between items to increase readability. They also suggested recruiting survey respondents based outside of the UK as the EWGPWD members, who are all based in different European countries, felt this topic was relevant for people with dementia across various countries. Based on their suggestions and recommendations, I revised the survey and submitted an ethics amendment to the UCL Ethics Committee; all amendments were approved and incorporated into the study. Appendix M contains information on the ethical approval for this study.

4.3.5 Ethical approval

The Research Ethics Committee at University College London approved the study [ethics ID: 19537/001]. Participation was voluntary, and all survey respondents provided online informed consent in Qualtrics prior to taking part. They had the option of resuming the survey within seven days once paused.

4.3.6 Data analysis

I analysed quantitative data in IBM SPSS Statistics version 25. Demographic data were summarized using descriptive statistics. Social media users and non-users were compared based on their age using the independent sample *t*-test or Chi-squared test. Results were considered significant at $p < .05$. Qualitative data were analysed using qualitative content analysis, a systematic method that enables researchers to broadly describe and quantify phenomena for the purposes of building a conceptual map or categories (Elo & Kyngäs, 2008). I entered responses to the open-ended questions of the survey into NVivo 12 and analysed them inductively (Elo & Kyngäs, 2008), following the four-step qualitative content analysis approach described by Erlingsson and Brysiewicz (2017). I conducted the analysis together with a DISTINCT colleague (WQK). We both conducted the first three steps of the analysis independently, while the fourth step was conducted by me, with the final set of categories discussed with WQK and my primary supervisor (GC). First, we familiarized ourselves with the data by reading the survey responses several times. Second, we considered descriptions of social media use and the types of dementia information posted or shared on social media were meaning units. If the same type of information shared was described multiple times, these descriptions were conjoined into a single meaning unit. Third, we independently condensed the meaning units, labelled each with a code, and met up to review and refine the codes. Finally, I grouped the codes into categories on the basis of similarities and discussed the final set of categories with WQK and my primary supervisor (GC). Frequencies were counted for codes and categories related to types of dementia-related information posted or shared on social media (Hsieh & Shannon, 2005).

4.4 Results

4.4.1 Characteristics of survey sample

Among the 165 internet-using individuals who consented to take part in the survey, 143 successfully completed it, and 27 of these respondents were under the age of 65. The total sample consisted of 88 males, 54 females, and one person who did not disclose their gender. Respondents' age ranged from 44 to 95, with a mean age of 71 years (*M* = 71.81, *SD* = 9.48). Alzheimer's disease was the most common form of dementia (*n* = 69). Of the 28 respondents who had been diagnosed with other forms of dementia, most (*n* = 13) had mixed dementia followed by posterior cortical atrophy (*n* = 5). Sixty respondents had been living with the condition for more than three years (42%). Eighty-six respondents had continued their education after secondary or high school. Other types of education included specific qualifications (*n* = 3), certificates (*n* = 2) or college (*n* = 2). The majority were retired (*n* = 119) or unable to work (*n* = 12), and two respondents stated they worked full time as dementia advocates. Most respondents lived with their partner (*n* = 109). Other living situations included living with a partner and children (*n* = 2), assisted living or care (*n* = 2), and living in close proximity to family (*n* = 1).

4.4.2 Characteristics of social media users

Out of the whole sample, 77 respondents identified as social media users and 66 as non-users. The demographic characteristics of the social media users and non-users are detailed in Table 4.1. Of these respondents, 22 were younger than 65 years, which is 81.5% of all younger respondents, and 55 were 65 years and older, which is 47.4% of all older respondents. A comparison of users and non-users revealed a significant difference for age, $t(141) = 5.047$, $p < .001$, with users being younger ($M = 68.4$, $SD = 9.5$) than non-users ($M = 75.8$, $SD = 7.7$).

Table 4.1. Characteristics of social media users and non-users

Characteristics	Users (*n* = 77)	Non-users (*n* = 66)
Gender, *n* (%)		
Male	49 (63.6)	39 (59.1)
Female	28 (36.4)	26 (39.4)
Not specified	0	1 (1.5)
Age in years, *M* (SD), min-max	68.39 (9.5), 44-88	75.80 (7.84), 58-95
Ethnicity, *n* (%)		
White	74 (96.1)	66 (100)
Black	1 (1.3)	0
Mixed	1 (1.3)	0
Jewish	1 (1.3)	0
Type of dementia, *n* (%)		
Alzheimer's disease	33 (42.9)	36 (54.6)
Vascular dementia	11 (14.3)	8 (12.1)
Lewy Body dementia	9 (11.7)	3 (4.6)
Frontotemporal dementia	11 (14.3)	4 (6.1)
Other	13 (16.9)	15 (22.7)
Time since diagnosis, *n* (%)		
0-12 months	14 (18.1)	17 (25.8)
1-3 years	27 (35.1)	25 (37.9)
3-5 years	20 (26.0)	13 (19.7)
>5 years	16 (20.8)	11 (16.7)
Country of residence, *n* (%)		
UK	71 (92.2)	65 (98.5)
Ireland	0	1 (1.5)
Canada	3 (3.9)	0
USA	2 (2.6)	0
Netherlands	1 (1.3)	0
Level of education, *n* (%)		
University	34 (43.6)	27 (40.9)
Technical/trade school or apprenticeship	14 (17.9)	11 (16.7)
Secondary/high school	24 (31.2)	22 (33.3)
Primary/elementary school	0	3 (4.6)
No schooling	1 (1.3)	0
Other	4 (5.2)	3 (4.6)
Employment status, *n* (%)		
Employed[a]	9 (11.7)	1 (1.5)
Unable to work	10 (13.0)	2 (3.0)
Retired	56 (72.7)	63 (95.5)
Other	2 (2.6)	0
Marital status, *n* (%)		
Married/in a relationship	62 (80.5)	49 (74.2)

Divorced	5 (6.5)	7 (10.6)
Widowed	6 (7.8)	10 (15.2)
Single/never married	4 (5.2)	0
Living situation, *n* (%)		
With partner	60 (77.9)	49 (74.2)
With family member	4 (5.2)	3 (4.6)
Alone	9 (11.7)	13 (19.7)
Other	4 (5.2)	1 (1.5)

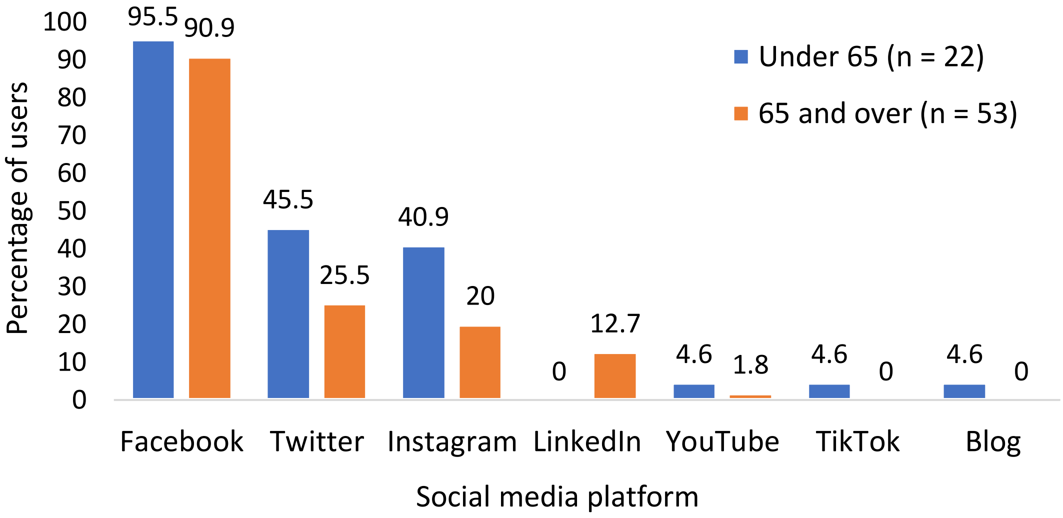
M = Mean; *SD* = Standard deviation

[a] = Includes full-/part-time work and self-employment

4.4.3 Social media platforms and frequency of use

Of the 77 social media users, two older respondents did not report which social media platforms they used. Figure 4.1 provides an overview of the platforms that 75 respondents reported using. Facebook was the most commonly used social media platform for both younger and older respondents (*n* = 71), followed by Twitter (*n* = 24), Instagram (*n* = 10), and LinkedIn (*n* = 7). Most respondents (*n* = 43) reported using only one platform. Two platforms were used by 18 respondents, three platforms by 10 respondents, and four platforms by three respondents, with one respondent using five platforms. A higher proportion of younger people than older people posted on all forms of social media with the exception of LinkedIn, which was only used by older respondents.

Figure 4.1. Percentage of social media platforms used by age



When asked about their frequency of use, a large proportion (51/77) indicated that they used social media frequently (several times per week or more; see Table 4.2). Younger respondents used social media more frequently than older respondents, $\chi^2(1, N = 77) = 5.58, p = .031$.

Table 4.2. Frequency of social media use by age

Response	Under 65 (*n* = 22)	65+ (*n* = 55)
	n (%)	*n* (%)
Once every few months or less	1 (4.5)	5 (9.1)
About once a month	2 (9.1)	5 (9.1)
Several times per month	0	6 (10.9)
About once per week	0	7 (12.7)
Several times per week	5 (22.7)	5 (9.1)
Daily	14 (63.6)	27 (49.1)

4.4.4 Disclosure of dementia-related information on social media

Half of the respondents (*n* = 39) reported that they disclosed their diagnosis and/or shared dementia-related information on their accounts; seven individuals did not respond to this question. Thirty-eight respondents commented on the kinds of information they posted or shared on their accounts; however, one response was deemed ineligible because the respondent did not clearly clarify what type of information they posted or shared. This resulted in the analysis of 37 responses, of which 14 had been provided by respondents under the age of 65. Twenty codes were derived from respondents' descriptions of their social media posts. These codes were further clustered into three categories: 1) advocacy and awareness, 2) the dementia journey, and 3) peer support. An overview of the categories and codes, along with their descriptions and the frequencies of comments for each category and code, are provided in Table 4.3. Examples of respondents' quotes for each code can be found in Table A2 in Appendix N. The majority of respondents (26/37, 70.3%) posted or shared information that falls into just one of the three categories identified. Ten respondents (one younger and nine older respondents) posted or shared content relevant to two categories, and one younger respondent posted or shared content relevant to all three categories. Of those who had a prevailing purpose for posting (i.e., activities fall within a single category), a higher proportion of younger respondents focused on advocacy and awareness (5/12, 41.7%) or peer support (2/12, 16.7%) compared to older respondents (advocacy and awareness: 4/14, 28.6%; peer support: 1/14, 7.1%). Older respondents (9/14, 64.3%) were proportionately more likely to focus on sharing the dementia journey compared to their younger counterparts (5/12, 41.7%).

Table 4.3. Frequencies of comments by category and code for dementia-related information posted and shared on social media by younger (*n* = 14) and older people with dementia (*n* = 23)

Categories and codes	Description	Frequency of comments, *n* (%)	
		Under 65	65+
Advocacy and awareness, total		*n* = 17	*n* = 17
Dementia in general	General information and facts about dementia	2 (11.8)	5 (29.4)
Personal advocacy work	Own work as a dementia advocate or activist	2 (11.8)	5 (29.4)
Fundraising	Own and other people's fundraising campaigns	4 (23.5)	0 (0)
Dementia events	Information about events related to dementia	2 (11.8)	2 (11.8)
Awareness campaigns	Sharing awareness campaigns or videos made to raise awareness about dementia	2 (11.8)	1 (5.8)
Research findings	Results of studies on dementia	0 (0)	2 (11.8)
Research opportunities	Studies currently recruiting participants	1 (5.8)	1 (5.8)
Answering questions	Answering questions about dementia	1 (5.8)	0 (0)
News	News items about dementia	1 (5.8)	0 (0)
Thoughts on stigma	Sharing personal thoughts on dementia stigma	2 (11.8)	1 (5.8)
The dementia journey, total		*n* = 7	*n* = 20
Living with dementia	Personal experiences of having dementia	4 (57.1)	9 (45.0)
Own diagnosis	Informing others of one's dementia diagnosis	1 (14.3)	4 (20.0)
Explaining symptoms	Own symptoms to explain behaviour and make others understand	0 (0)	2 (10.0)
Mental state	Current feelings and wellbeing	0 (0)	2 (10.0)
Living well with dementia	Positives about having dementia	1 (14.3%)	1 (5.0)
Poetry	Poems about dementia and living with it	0 (0)	2 (10.0)
Crafts	Posts about crafts made by the participant	1 (14.3)	0 (0)
Peer support, total		*n* = 4	*n* = 5
Support group information	Sharing details about support group meetings	2 (50.0)	2 (40.0)

For others affected by dementia	Supporting other people with dementia or caregivers	2 (50.0)	1 (20.0)
For oneself	Receiving support from other people with and without dementia	0 (0)	2 (40.0)

In summary, in this study I aimed to compare the social media use in people with dementia above and below the age of 65. I found that over half of the survey respondents used social media, with younger people with dementia being more likely to be active social media users than older people with dementia. Facebook was the most popular platform for both age groups, but younger users used a more diverse range of platforms than older users. Around 50% of respondents disclosed their diagnosis or shared other dementia-related information on their accounts.

4.5 Discussion

4.5.1 Principal findings

In this convergent mixed-methods research, insights were gained into the use of social media by people with dementia and how they acknowledge their diagnosis or share other dementia-related information on their accounts. The proportion of social media users in the sample was comparable with proportions observed in the general population for those aged 55-64 (86% vs. 81.5%), but much lower for those over the age of 65 (70% vs. 47.4%; Ofcom, 2023). The sample was relatively small and more people with dementia aged 65 and above took part in this internet-mediated research. However, it may be that younger people with dementia are more likely to have adopted social media prior to the dementia onset, whereas older people with dementia might have actively or passively avoided adopting new technology. Also, similarly-aged counterparts might have continued to learn new technologies, with research suggesting that trainings can be useful to improve digital literacy in older people (Bevilacqua et al., 2021).

Social media were perceived as valuable spaces for people with dementia to advocate for themselves and other people affected by the condition, raise awareness, and fight negative stereotypes associated with dementia. Additionally, users could share aspects of their daily lives and current state of mind, fostering reciprocal peer support on their social media accounts. These findings align with those from Chapter 3, which also highlighted the role of social media in facilitating peer support in people with dementia. As previously noted, peer support is an important aspect of the third domain of the social health framework (i.e., ability to participate in social activities).

Most of the existing research studies which explored the use of social media by people with dementia have primarily harvested social media data (e.g., D. Craig & Strivens, 2016; Kannaley et al., 2019) or had relatively small sample sizes (D. Craig & Strivens, 2016; Kannaley et al., 2019; Talbot et al., 2020b). The current study addresses these limitations by collecting primary data directly from people with dementia and having a larger sample size. To my knowledge, this study made use of the largest sample of younger and older people with dementia so far that contributed to this kind of research. Globally, there is a higher percentage of women than men with dementia (Beam et al., 2018). However, like previous social media research among people with dementia (Talbot et al., 2020a), this sample consisted of more men than women. The high proportion of men in the sample could suggest that internet-mediated dementia research amplifies the male voice.

The findings suggest that people with dementia, particularly those with young-onset dementia, use social media platforms to make their voices heard, advocate for change, and reshape the perception of living with dementia into a positive narrative. This aligns with prior research examining the use of Twitter by people with dementia (Talbot et al., 2020b, 2021), which demonstrated how individuals used their accounts to challenge stereotypes and raise awareness about dementia within society. In addition, findings from Chapter 3 underscored that people with dementia disclose their diagnosis online for the aim of advancing activism efforts. Activism and advocacy in people with dementia have previously been linked to the formation of a “collective illness identity” (Hillman et al., 2018). This suggests that sharing a space, including online spaces, with other people with dementia who share the goal of fighting dementia stigma, can contribute to forming an identity post diagnosis. In addition, social media might give people with dementia the opportunity of supporting their personhood as they are in control of the content created on social media (Astell, 2006; Hennelly & O’Shea, 2022). Similar to Chapter 3, these findings relate back to the first and third domain of the social health framework.

The social media platforms were used by both younger and older people with dementia as an avenue to share their experiences of living with dementia as well as for peer support, mirroring previous research (Talbot et al., 2020b; Johnson et al., 2022), Since appropriate in-person dementia support services are often lacking or are difficult to access (Giebel et al., 2021), the findings indicate that social media is a promising virtual medium of support for people with dementia. This may especially be the case for people with rare forms of dementia such as Lewy body dementia (Killen et al., 2016) or young-onset dementia (Stamou et al., 2021), or those who live in rural areas (Arsenault-Lapierre et al., 2023).

4.5.2 Limitations

While this research has promising findings, it is subject to some limitations. Firstly, participants in this study were convenience samples, with the majority of survey respondents being male and well-educated, and almost all were from a White ethnic background. It is likely that people with dementia from a minority ethnic or cultural background, whose experience of living with dementia or the stigma associated with it may differ (Berwald et al., 2016; Giebel et al., 2015), will use social media differently, including their decision to disclose their condition or share other dementia-related information on their social media accounts. Secondly, I used a cut-off of 65 years to differentiate between younger and older people with dementia. However, a portion of older individuals may have been diagnosed before reaching the age of 65, potentially impacting the categorisation of participants in these age groups. Thirdly, the survey did not inquire whether social media users shared or posted dementia-related information publicly or privately, limiting the ability to differentiate between both behaviours. This differentiation may be important for individuals who are concerned about their privacy, particularly considering the dementia stigma. Finally, participants who took part in the survey were given the opportunity to take part in a semi-structured interview. It is, therefore, possible that some individuals took part in the survey as well as in an interview, and that their experiences align. Due to the anonymity of the survey, it is not possible to establish which individuals took part in both studies. As such, the codes established for the qualitative strand (i.e., dementia-related information posted or shared on social media) may have been duplicated for participants who took part in both studies. Nevertheless, since the purpose of the qualitative strand was to gain a deeper understanding of how participants disclose their diagnosis and share or post dementia-related information on social media, the codes or their frequency are not critical to the understanding of this phenomenon.

4.5.3 Implications

Corroborating recent research on social media use (e.g., Talbot et al., 2020a) and people with dementia adopting and adapting everyday technologies (Gibson et al., 2019), and contrary to the stereotype that older people lack technological ability (Mariano et al., 2022), a large proportion of people with dementia seem to be active on social media. Subsequent generations will have more experience using technology and, therefore, be more technologically savvy. As such, social media may become increasingly important for this population. This may be particularly relevant for clinicians, dementia organisations, and policymakers who could signpost people with dementia to social media as one useful medium for (peer) support. Implications for the ‘Who to Tell, How and When’ intervention are that people with dementia may be able to derive the peer support element of the intervention through use of social media platforms. For future research, I recommend exploring the proportion of posts created on each platform to gain a deeper understanding of which platforms are especially important to people with dementia. It is also recommended to explore why internet-using people with dementia are not active on social media, and why those who do have one or more social media accounts decide not to disclose their dementia identity on them. This may be useful to increase the accessibility of social media as a tool for support for people with dementia.

The majority of survey respondents and interviewees for this study were recruited through social media, an avenue that has previously been proposed as useful in dementia research (Bartlett et al., 2019). This study highlights the potential of this recruitment strategy, which could be relevant for other researchers wishing to explore the personal experiences of people with dementia.

4.6 Chapter summary and conclusion

People with dementia adopt and adapt everyday technologies for their own purposes, including the use of technology-mediated social networking. Findings from Chapter 2 revealed that little is known about people with dementia sharing their diagnosis on social media, or that research on social media use by people with dementia has been limited by small sample sizes and homogenous social media platforms. To fill these gaps, the current chapter explores how people with dementia use social media and disclose their diagnosis on them. The findings show that social media are used by both younger and older people with dementia. Aligning with findings from Chapter 3, this chapter found that social media provides individuals with a platform to make their voices heard and raise awareness and share their personal experiences of living with the condition. It enables individuals to engage in reciprocal peer support, which is of relevance to the peer support element of the ‘Who to tell, how and when’ intervention, the digital adaptation which is the focus of Chapter 5. Overall, social media can be a valuable tool for self-disclosure, as well as a potentially important support for enhancing or maintaining social health.

Chapter 5: Digital adaption of the ‘Who to tell, how and when’ intervention

5.1 Chapter overview

The previous chapters explored both offline and online self-disclosure in people with dementia. The findings revealed that self-disclosure is multifaceted. While challenges exist, there are also benefits to disclosure such access to support, suggesting that self-disclosure can have positive implications for social health. As outlined in Chapter 1, limited support for self-disclosure prompted the development of ‘Who to tell, how and when’. Recognising the growing importance of digital technologies before, during, and after COVID-19, and the value of them for people with dementia as highlighted in Chapters 3 and 4, this chapter will focus on adapting ‘Who to tell, how and when’ for digital delivery using an iterative, user-centred design approach.

5.2 Introduction

As highlighted in Chapter 1 to 4, people with dementia engage with everyday digital technologies, and a variety of internet-based health interventions for social health exist to support individuals (A. R. Lee et al., 2021; Pinto-Bruno et al., 2017). It is important to design these technologies according to the needs and preferences of people with dementia to ensure its usability and a positive user experience. This can address barriers mentioned in Chapter 1, such as a lack of interest and inappropriate design (Czaja et al., 2006). User-centred design can be a helpful approach to address these barriers.

5.2.1 User-centred design

User-centred design, a human-computer interaction approach, prioritises end users' wishes, needs, and preferences in the development of digital technologies and internet-based interventions (Lyon & Koerner, 2016). It involves understanding the context in which users will interact with a product and actively involve them in the design, development, and evaluation phases. The goal of user-centred design is to create tools that are intuitive, accessible, and enjoyable for end users, resulting in a positive user experience (Hartson & Pyla, 2019). In the case of dementia, researchers and developers can create interventions utilising digital technologies that align with individuals' specific capabilities. This is especially important considering the progressive nature of dementia. For example, instructions on how to use a specific device or tool can be adapted based on the stage of dementia, with more complex instructions being used for people in the early stages of the condition (Bird & Lim, 2022).

Different internet-based interventions for people with dementia have been developed using user-centred design. For example, Fox et al. (2022) developed an app to assess changes in cognitive function using an iterative process with continued input from people with dementia across several development cycles. The authors concluded that actively involving people with dementia in the development helped identify and address usability issues early and sped up the development process. Rai, Schneider et al. (2020) developed an app based on Cognitive

Stimulation Therapy by identifying users' preferences, gathering feedback on prototypes, and pilot testing. Neal et al. (2023), whose project was also part of DISTINCT, developed and evaluated an app aimed at people with dementia's social health by enhancing their social participation and self-management skills. However, it is still not common to apply a user-centred design in all phases from development through pilot testing of digital technologies for people with dementia. For instance, a recent narrative synthesis review of the development, feasibility, and pilot testing of technology-based interventions for people with dementia found that of 21 studies only three included people with dementia themselves (Rai, Barroso, et al., 2020).

5.2.2 Implementation and technology acceptance

Despite the availability of numerous interventions utilising digital technologies for dementia care, very few are implemented or embedded into practice (Christie et al., 2018). Ensuring the sustainability of these interventions during their development is therefore important to ensure that individuals will have access to effective interventions. In addition, the use of a theoretical framework in the development of these interventions is recommended to enhance their efficacy (Van Gemert-Pijnen et al., 2011; Webb et al., 2010).

An important aspect of developing, or adapting, sustainable interventions using digital technologies is ensuring that the intervention will be accepted by the population it is aimed at. Different models have been used to evaluate technological interventions during their development, one of which is the Technology Acceptance Model (TAM). The TAM is a relatively simple model that proposes that users come to accept and use a technology based on its perceived usefulness (i.e., how useful the technology will be to achieve a desired goal) and perceived ease of use (i.e., how effortless it will be to use the technology; Davis, 1989). In addition, the concept of credibility is considered an important aspect that enhances the persuasiveness of digital health interventions, thereby increasing users' adherence to and acceptance of it (Riegel et al., 2020; Van Bruinessen et al., 2014). The TAM has been applied in the development of internet-based health interventions (Heinsch et al., 2021), including in the development and evaluation of technologies for people with dementia (Cruz et al., 2020; Mishra et al., 2023).

5.2.3 Study aims

The studies described in Chapters 2 to 4 explored both offline and online self-disclosure, providing valuable insights for the digital adaptation of the existing 'Who to tell, how and when' intervention. Therefore, in this chapter, I use a user-centred design approach to adapt the manualised 'Who to tell, how and when' intervention for digital delivery, responding to the increasing use of digital technologies among individuals, including those with dementia. Adapting the intervention has two important potential benefits. Firstly, a digital adaptation could enhance the intervention's accessibility for individuals who may feel uncomfortable taking part in group interventions or prefer to remain anonymous. This seems especially relevant considering the stigma of dementia outlined in Chapter 1, which was found to be a factor associated with self-disclosure in Chapters 2 and 3. Secondly, it would provide individuals who live rurally or are unable to travel the opportunity to take part in the intervention from the comfort of their own homes. The relevance of digital delivery has been underscored by the COVID-19 pandemic, which coincided with the majority of this PhD research. The pandemic has heightened the need for community-based interventions to be delivered remotely and digitally (Golinelli et al., 2020). Consequently, this chapter responds to a demand for innovative, digitally accessible interventions that can support people with dementia amidst changing circumstances and increased digital technology use.

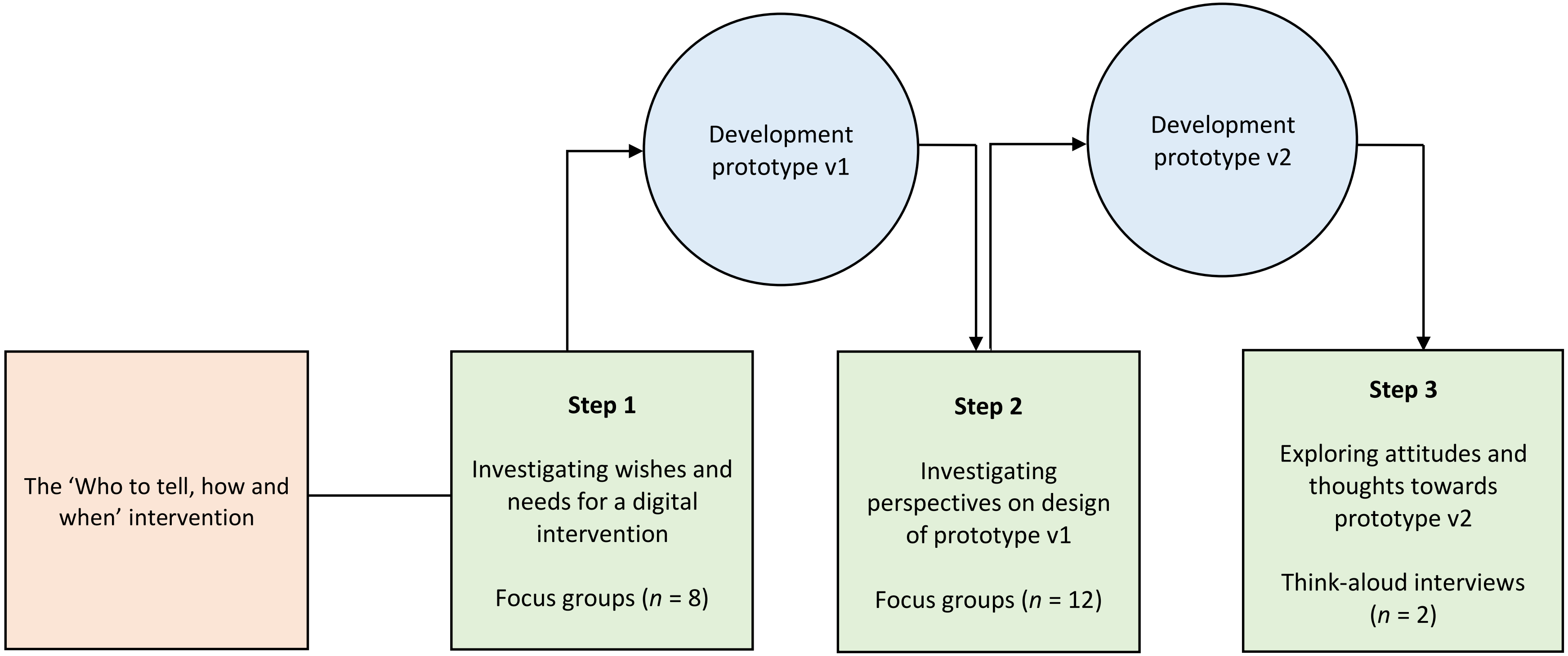
5.3 Methods

5.3.1 Study overview

The adaptation of ‘Who to tell, how and when’ comprised three steps and included two rounds of focus groups and one round of think-aloud interviews with people with dementia and family carers. The data collection formed part of a research study and was not conducted as part of PPI.

Figure 5.1 provides an overview of the steps taken in this study. In step 1, I conducted focus groups to explore participants’ preferences regarding mode of delivery, digital peer support, and thoughts on ways to ensure the intervention’s credibility. I finished this step with developing a low-fidelity prototype called prototype version 1 (v1) based on data collected from participants in the focus groups. In step 2, I conducted a second round of focus groups, presenting participants with mock-ups of prototype v1 to receive feedback on the design and ‘look and feel’ of it. In step 3, I adapted prototype v1 into prototype version 2 (v2) based on data collected in step 2 and conducted think-aloud interviews to gather feedback on it. In this chapter, the methods and results of the study are presented separately for each step to provide a clear overview of the iterative process. They are subsequently compiled and elaborated on in the discussion. Data collection for all three steps and prototype development took place between July and September 2022.

Figure 5.1. Three steps of moving 'Who to tell, how and when' online



5.3.2 Approach to adaptation

A user-centred design was applied to adapt the existing paper-based ‘Who to tell, how and when’ intervention for digital delivery. This approach was chosen to ensure that the intervention is tailored to the needs and wishes of people with dementia and involves active engagement with users throughout the design and development of a product or system (Årsand & Demiris, 2008). Ultimately, a user-centred approach supports the development of an intervention that is relevant, usable, easily accessible, and positively affects the overall user experience (Harte et al., 2017). With these objectives in mind, I adhered to existing recommendations on developing dementia-friendly web-based content during the adaptation. These included creating a product that is easy to navigate and has a well-structured layout, using contrasting colours, a simple structure of the text, and clear and dementia-friendly language (Schnelli et al., 2021; Williams, 2017). Additionally, I used findings from Chapters 2 to 4 to inform the adapted intervention whenever feasible.

5.3.3 Participants and recruitment

Participants were eligible to take part in this study if they had been diagnosed with dementia or were a current or former family carer of someone with dementia. People with dementia had to be able to provide written informed consent. All participants had to be over the age of 18, have sufficient English skills to manage the tasks involved, and have access to an internet-enabled device. A convenience sample of people with dementia and family carers was recruited through the Research Network of the UK-based Alzheimer’s Society. This network consists of people with dementia and current and former carers who are interested in contributing their personal experiences of dementia to a wide range of research-related topics (Alzheimer's Society, 2021). Facilitators of the Research Network shared the study details with the network's members via email. I also presented them at one of the network's online meetings. Members interested in participating could email me upon which they were sent the Participant Information Sheet (see appendix O).

The steps undertaken in this study were completed with participants from a pool of seventeen members of the Research Network, five of whom were people with dementia. Table 5.2 provides an overview of the demographic characteristics of the participants. Most participants were male (*n* = 8) and from a White ethnic background (*n* = 16). Alzheimer's disease was the most common form of dementia (*n* = 10) for both people with dementia and carers. Carers were adult offspring (*n* = 6), spouses (*n* = 5) or another family member (*n* = 1) of a person with dementia. The majority of individuals they supported were male (*n* = 7), and all were from a White ethnic background.

Table 5.2. Demographic characteristics of participants

Characteristics	People with dementia (*n* = 5)	Family carers (*n* = 12)
Gender, *n*		
Male	4	4
Female	1	8
Age in years, *M* (*SD*), min-max	69 (11.62), 49-76	64.33 (12.38), 40-85
Ethnicity, *n*		
White	5	11
Asian	0	1
Type of dementia, *n*		
Alzheimer's disease	3	7
Vascular dementia	1	4
Mixed dementia	1	1
Time since diagnosis[a], *n*		
1-2 years	1	0
2-5 years	2	4
More than 5 years	2	8
Living situation[b], *n*		
With spouse or partner	4	-
Assisted living	1	-

Note. [a] = seven carers identified as former carers, hence 'time since diagnosis' is generally high for this group; [b] = item was only presented to people with dementia

5.3.4 Ethical approval

Ethical approval was obtained from the University College London Research Ethics Committee (ethics ID: 19537/002; see appendix P). All participants received oral and written information prior to their decision to participate. Informed consent was obtained from all participants, either in writing or online using the platform Qualtrics (https://www.qualtrics.com). As participants were active members of the Research Network who had contacted me themselves to participate, it was assumed that everyone had capacity to provide consent. I also checked capacity via email when discussing the study details. At the start of each focus group or interview, I repeated the main points of the consent form (e.g., participation is voluntary; see appendix Q) and re-checked consent.

5.4 Step 1: Establishing preferences, and development of prototype v1

The first step consisted of focus groups with people affected by dementia to establish preferences and wishes regarding the digital adaptation and develop prototype v1.

5.4.1 Methods for step 1

5.4.1.1 Procedure

One week before the scheduled focus groups, I emailed participants a document with information on the aim of the ‘Who to tell, how and when’ intervention, its development, and the content of the intervention sessions (see appendix R). Due to the COVID-19 pandemic, the focus groups were conducted using Zoom. I sent all participants a reminder via email two days before the meeting. The groups were led by me. During the discussions, I was supported by a UCL Master’s student (SC) and DISTINCT colleague (PH) who took notes. After the discussions, I sent participants a debrief email with contact details for dementia organisations (see appendix S) and a £15 retail voucher redeemable online and in shops across the UK.

5.4.1.2 Data collection

A semi-structured topic guide was developed based on the concepts perceived usefulness, perceived ease of use, and credibility (see appendix T). Questions in the topic guide related to participants' preferences for the intervention platform (e.g., website or app), potential barriers to using the platform, peer support elements (e.g., implementing an online forum), and the influence of well-established organisations in guiding participants to the intervention.

Focus groups were chosen for this study as they are frequently used in research on the development and evaluation of technological products and offer the benefit of identifying a range of opinions in a relatively short timeframe (Adams & Cox, 2016). I followed guidelines on conducting focus groups with individuals with cognitive impairments, such as creating accessible PDF documents that I sent everyone one week prior to the meeting (Jones et al., 2021). Each focus group lasted one hour.

5.4.1.3 Data analysis

The discussions were audio-recorded and transcribed verbatim, following a denaturalised transcription process (Oliver et al., 2005). Participants received a pseudonym. Data analysis was conducted using NVivo 12, employing qualitative content analysis. Qualitative content analysis was chosen because it offers a systematic approach to describing phenomena and allows for the transformation of textual data into a structured and concise summary of key findings and facts (Elo & Kyngäs, 2008; Erlingsson & Brysiewicz, 2017). This method was deemed appropriate for the study as it was used to focus on describing and categorising participants' preferences. The analysis followed the approach outlined by Erlingsson and Brysiewicz (2017) and centred on identifying manifest (i.e., literal meaning of words) meanings in the data using an inductive and deductive approach (Elo &

Kyngäs, 2008). The analysis was jointly conducted by SC and myself, except where otherwise indicated, and we consulted with my primary supervisor (GC). To familiarise ourselves with the data, we thoroughly read and re-read the transcripts. We considered data related to the preferences of the first prototype as 'meaning units', coding each unit independently. We analysed data deductively using the two elements of the TAM and the concept 'credibility', and inductively to explore perspectives that had not yet been considered. Subsequently, SC and I met to discuss our individual analysis, after which we met with GC to discuss our thoughts. Thereafter, I independently collated codes into categories (i.e., group of codes sharing context, capturing participants' preferences regarding the intervention) and themes (i.e., expressing underlying meaning found in two or more categories). Finally, I conducted a final discussion with GC and SC before finalising the themes.

5.4.2 Results from step 1

Three focus groups were conducted with eight participants in total, three of whom were people with dementia. Three themes were generated: 1) variety and options, 2) accessibility, and 3) trustworthiness. These themes align with 'perceived usefulness', 'perceived ease of use', and 'credibility', respectively. Quotes are followed by the participant's ID, with PWD being used for 'person with dementia' and FC for 'family carer', and their age. Words added or revised for context or to ensure anonymity are enclosed in [], whilst an ellipsis (…) indicates omitted text.

5.4.2.1 Theme 1: Variety and options

To explore which digital platform participants would like to use the adaptation on, participants were asked about their opinions on different platforms and ways to deliver the intervention content and peer support elements relevant to the face-to-face intervention. When discussing the platform of the intervention, for example, an app or a website, participants showed a preference for website content based on their assumption of potential time commitment to the intervention:

> *If I download an app, it’s gotta [sic] be one I’m gonna [sic] use all the time and yours, I’m only going to use it once. The website, I’m probably going to visit a couple of times to get information. But I'm not going to be on it daily, so it's got to be a website.* (PWD3, 72)

One participant said that it would be useful to access the adapted intervention for access outside of typical working hours, especially for individuals who develop dementia at working age or family members who may still be working: “I think a bit of awareness that there’s lots of people in the early onset space and catering for that … and being aware that not just them, but their families might be working. That would be useful too” (FC2, 40). It was also suggested to offer the digital intervention content in different ways, if possible, such as offering a downloadable workbook.

Several participants expressed interest in an interactive intervention that would be engaging and fun to use. This could be incorporated in the digital intervention content such as the exercises. For example, one participant said the following:

> *It would be almost a cartoon type thing, a light-hearted look … imagine a mannequin walking across the screen saying, 'Okay, you've got this diagnosis. What do we do next? Who do we tell next' and then jumping through different pages … leaping through to different areas using multimedia to its fullest extent.* (PWD3, 72)

Additionally, participants discussed their opinions on peer support elements of the digital 'Who to tell, how and when' intervention through which participants could interact with each other. One participant felt that linking to a discussion forum like 'Talking Point', which is run by the Alzheimer's Society, would be valuable: "… when mum was first diagnosed, I found them [forums] really useful for the odd questions I had about how things were going for her" (FC3, 54). However, one participant with dementia noted that an online discussion forum may trigger despair and pessimism due to some of the negative content of the posts. Zoom was considered a useful platform for peer support as this would be more interactive than simply reading the digital content: "I think a lot of people have got very used to online environments now … I think [it] would make the delivery more productive than somebody just sitting and reading through a presentation" (FC3, 54). However, others were less positive about Zoom due to not being able to remain anonymous: "If they don't want to talk about Alzheimer's, they certainly ain't gonna [sic] come to a [Zoom] group like that" (PWD2, 72). In response to whether anonymity was important in online peer support meetings, it was suggested to use a fictitious name or having one’s camera off, but that anonymity should be a choice and not a requirement.

5.4.2.2 Theme 2: Accessibility

As highlighted in the previous section, participants discussed the option of including Zoom for peer support in the digital adaptation. They felt that this software was generally easy to use and just required “a click of a button” (FC3, 54). Some carers expressed difficulties with the control functions in Zoom such muting oneself. None of the people with dementia mentioned having had problems with accessing meetings on Zoom, suggesting that in this study people with dementia may have been more used to online meetings than the carers.

One participant suggested having a facilitator present during the online peer support meetings to help with potential troubleshooting or to teach them beforehand how to use the platform: “I’ve got people in my Zoom group who didn’t dream they could use it and now having talked through how to do it a couple of times, they can do it” (PWD2, 70).

When asked about potentially having to access the intervention with an email address and a password, many participants responded negatively, saying that this would make accessing the intervention for people with cognitive impairments difficult: “You’re putting a barrier in the way. I wouldn’t do it” (FC2, 40). In order to make the digital intervention accessible for a large number of people, participants discussed the option of downloading a workbook from the intervention platform. While several were in favour of having this option, some participants disliked this suggestion due to individuals potentially having difficulties downloading documents online. One participant said her mother would find it difficult due to her indifference toward all kinds of technology: “She really doesn't engage digitally at all nowadays … so to try and get her to engage [with a PDF download] that was on a screen, I think she would find it quite foreign” (FC3, 54). Another participant said that although they used touchscreen technology, downloading a document was not easy and a hardcopy version was therefore preferred: “[I] was tech-savvy, but I have difficulty with downloading documents. I prefer to get things through the post in hard copy … and I'm not the one with Alzheimer's, so, my wife certainly wouldn't be able to do it” (FC5, 63).

5.4.2.3 Theme 3: Trustworthiness

This theme encompasses participants’ opinions on the credibility of the intervention when it is being created with or recommended by dementia organisations. Some participants mentioned that the first place they went to for support was the Alzheimer’s Society, with one participant noting that this organisation and people working for it could be useful in recommending the intervention to people affected by dementia: “You can’t do what you're trying to do without somebody pointing us people to you. And as I said, this Alzheimer's support lady just would phone me … she's the right person to tell me” (FC4, 73). One participant felt that, overall, having dementia charities or memory services recommend an online intervention would ensure a range of individuals can access it, thereby increasing its credibility. When discussing whether an online ‘Who to tell, How and When’ intervention would be more trustworthy if it was created with the help of an organisation like the NHS or UCL, several participants agreed, pointing to the organisations' positive reputations.

5.4.2.4 Summary of findings from step 1

The aim of step 1 was to establish the needs and wishes of people with dementia and carers in accessing the digital 'Who to tell, how and when' intervention. This included potential platforms, ways to enhance its accessibility, and transferring the face-to-face peer support element of the intervention to a digital setting. Based on the focus groups, I established that I needed to consider several points for the development of the first prototype. Participants preferred the intervention being self-guided and hosted on a website. The self-guided design was motivated by participants' expressed preference for accessing the intervention outside of typical working hours. To ensure ease of use, no log-in feature should be required on the website. Considering the importance of providing varied access options, the inclusion of a downloadable printable manual on the website would be valuable. To bolster the intervention's credibility, information on the intervention developers should be provided. Similar to findings from Chapter 3 and 4, participant highlighted the value of peer support, and a digital peer support option would be useful for the intervention, for example, an online discussion forum or group Zoom calls.

5.4.2.5 Development of prototype v1

To create the first prototype, I used the cloud-based platform Wix (https://www.wix.com) as it is known for its user-friendly interface, offering both free and paid plans that allow for customisable website development without the need for commissioning a software company. For this study, the free version of Wix sufficed as I aimed to develop a low-fidelity prototype. A low-fidelity prototype is a modelled prototype with limited technical functionality, which was deemed adequate for this study to obtain initial feedback from participants and to adjust and improve the prototype easily (McElroy, 2016). In further

I added the content from the manualised 'Who to tell, how and when' intervention to the website. This included session descriptions, participant quotes, and session exercises (Bhatt et al., 2020). To ensure that the information was easily comprehensible without the presence of a facilitator, I added supplementary text to the session descriptions and some exercises. I enriched the website's engagement factor, as suggested by focus group participants in step 1, by including photographs from a freely available age-positive image library (https://ageingbetter.resourcespace.com/pages/home.php).

Based on the points taken from the first step, I decided to create a website for the digital adaptation, without a log-in feature. I also decided to include the option of downloading the manual from the website. However, as the aim of the second step was to gather feedback on the design of the adaptation, and since I would not have been able to work through the entire website in the focus group sessions, I decided not to develop the download function in the first low-fidelity prototype. The same was the case for the peer support option. To enhance the intervention's credibility, I included a 'meet the team' page, with photos of the researchers involved in the project, as well as background information on the development of the intervention. Logos of UCL and the Alzheimer's Society were also added to the homepage for credibility purposes.

I developed the website using a light design with white, grey, yellow, and black colouring. The decision for a light design was based on data collected in Chapter 3 and 4, describing participants wishes to highlight ‘living well with dementia’, which I felt could be conveyed with a light colour design.

When individuals access the website, they reach the homepage of the intervention (see Figure 5.2). This page contains a brief introduction to the intervention. The top menu leads individuals to the other pages of the website. There are two ‘get started’ buttons displayed: one as part of the top menu and one on the bottom of the homepages.

Figure 5.2. Homepage of prototype v1

The 'Who to tell, how and when' programme

How to talk about the dementia diagnosis?

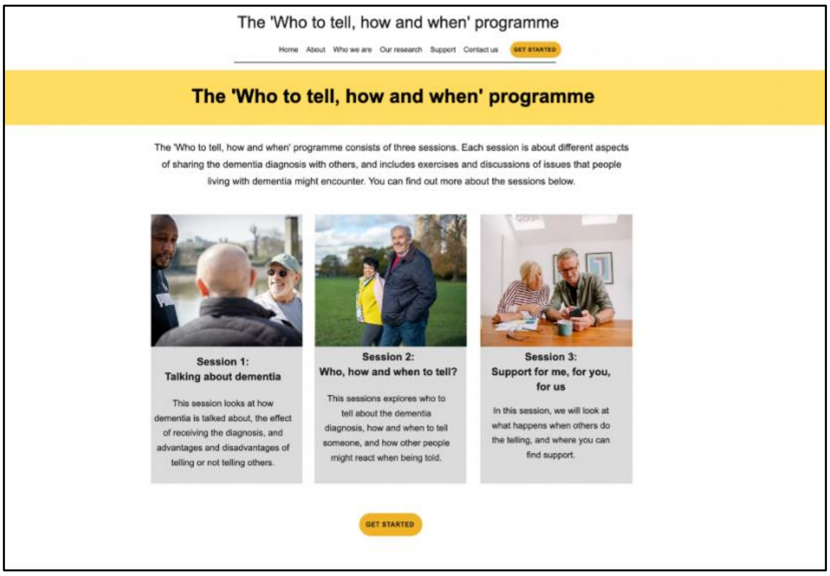
The 'Who to tell, how and when' programme is a tool for people living with dementia and those supporting and/or caring for them who are worried about or feel uncomfortable sharing the diagnosis with other people.

In three sessions, you will loot at who you might want to tell about the dementia diagnosis, how you could do that and when. We want to help you feel comfortable with the decision you make, whether you decide to tell or not.

Developed at University College London in collaboration with the Alzheimer's Society UK

By clicking on the ‘get started’ button at the top or bottom of the homepage, individuals are led to the start page of the intervention (see Figure 5.3). There is a brief overview of what each of the three sessions entails, which are accompanied by photographs taken from the age-friendly library.

Figure 5.3. Start page of ‘Who to tell, how and when’ as used in prototype v1



The 'Who to tell, how and when' programme

The 'Who to tell, how and when' programme

The 'Who to tell, how and when' programme consists of three sessions. Each session is about different aspects of sharing the dementia diagnosis with others, and includes exercises and discussions of issues that people living with dementia might encounter. You can find out more about the sessions below.

Session 1:
Talking about dementia

This session looks at how dementia is talked about, the effect of receiving the diagnosis, and advantages and disadvantages of telling or not telling others.

Session 2:
Who, how and when to tell?

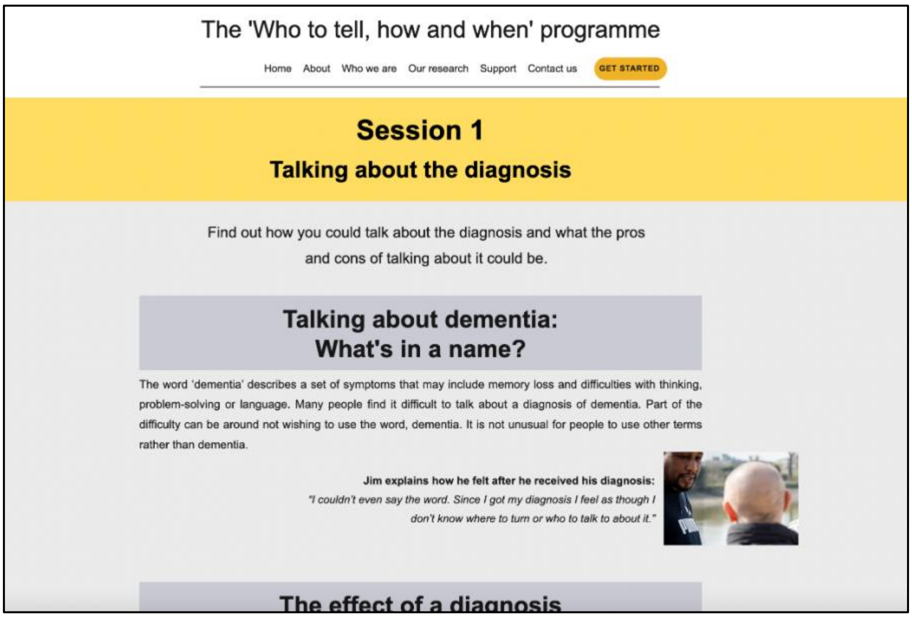
This sessions explores who to tell about the dementia diagnosis, how and when to tell someone, and how other people might react when being told.

Session 3:
Support for me, for you, for us

In this session, we will look at what happens when others do the telling, and where you can find support.

Another ‘get started’ button at the bottom directs individuals to the first session called ‘Talking about the diagnosis’ (see Figure 5.4). The text on this page as well as the quote have been taken from the manual and supplemented with a photograph taken from the image library.

Figure 5.4. First page of session 1 used in prototype v1



The 'Who to tell, how and when' programme

Session 1
Talking about the diagnosis

Find out how you could talk about the diagnosis and what the pros and cons of talking about it could be.

Talking about dementia:
What's in a name?

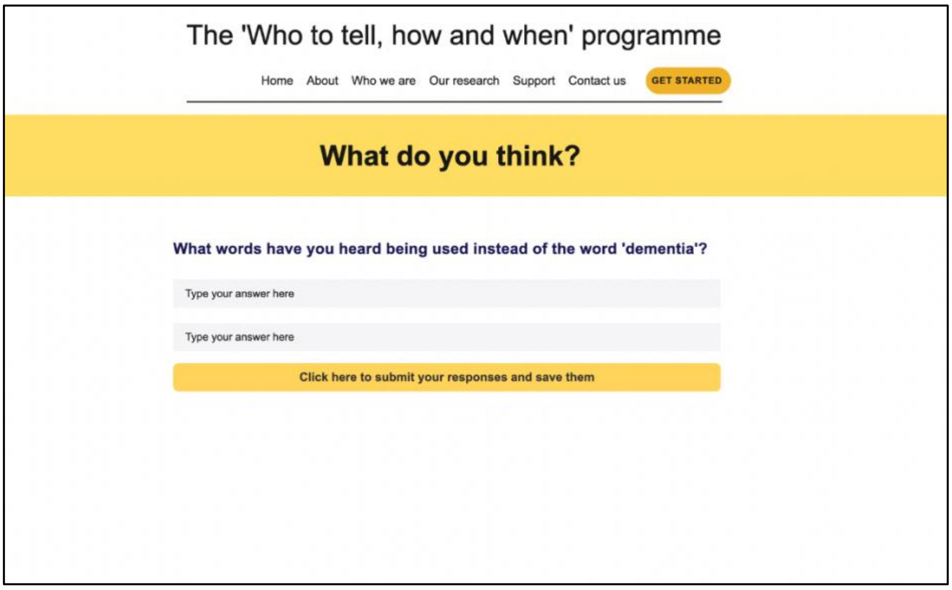
The word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. Many people find it difficult to talk about a diagnosis of dementia. Part of the difficulty can be around not wishing to use the word, dementia. It is not unusual for people to use other terms rather than dementia.

Jim explains how he felt after he received his diagnosis:
“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.”

The effect of a diagnosis

By scrolling down this page, individuals are presented with a ‘next’ button (not visible in figures shown here), which directs them to the first exercise of session 1 (see Figure 5.5). This exercise, taken from the manual, asks individuals to think about alternative words they have heard being used instead of the word dementia. The form is fillable, and individuals are asked to submit their responses by clicking on the button below the form.

Figure 5.5. Session 1, exercise 1 used in prototype v1



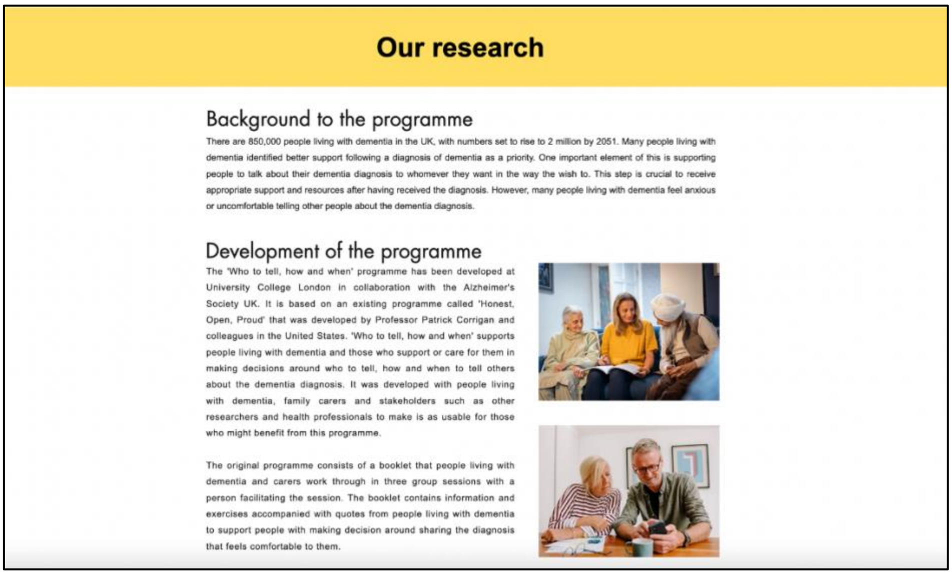
The 'Who to tell, how and when' programme

What do you think?

What words have you heard being used instead of the word 'dementia'?

Another page on the website provides information on the intervention development (Figure 5.6), which can be accessed through the top main menu.

Figure 5.6. Information on intervention development used in prototype v1



Our research

Background to the programme

There are 850,000 people living with dementia in the UK, with numbers set to rise to 2 million by 2051. Many people living with dementia identified better support following a diagnosis of dementia as a priority. One important element of this is supporting people to talk about their dementia diagnosis to whomever they want in the way the wish to. This step is crucial to receive appropriate support and resources after having received the diagnosis. However, many people living with dementia feel anxious or uncomfortable telling other people about the dementia diagnosis.

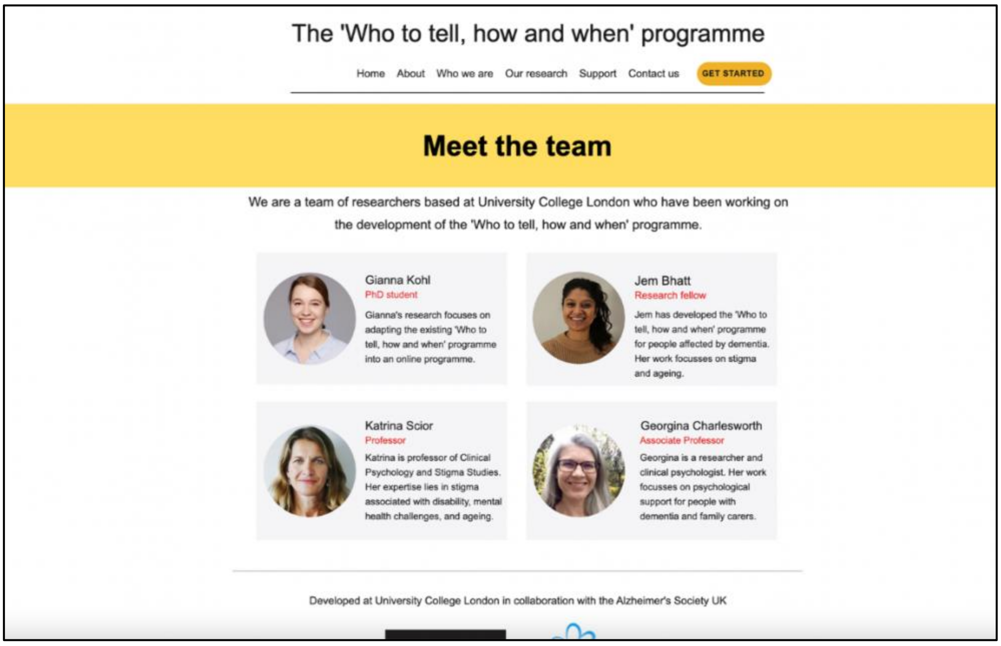
Development of the programme

The 'Who to tell, how and when' programme has been developed at University College London in collaboration with the Alzheimer's Society UK. It is based on an existing programme called 'Honest, Open, Proud' that was developed by Professor Patrick Corrigan and colleagues in the United States. 'Who to tell, how and when' supports people living with dementia and those who support or care for them in making decisions around who to tell, how and when to tell others about the dementia diagnosis. It was developed with people living with dementia, family carers and stakeholders such as other researchers and health professionals to make is as usable for those who might benefit from this programme.

The original programme consists of a booklet that people living with dementia and carers work through in three group sessions with a person facilitating the session. The booklet contains information and exercises accompanied with quotes from people living with dementia to support people with making decision around sharing the diagnosis that feels comfortable to them.

A page called ‘meet the team’ provides information and photos of the individuals who developed the intervention (see Figure 5.7).

Figure 5.7. ‘Meet the team’ page used in prototype v1



Meet the team

We are a team of researchers based at University College London who have been working on the development of the 'Who to tell, how and when' programme.

Gianna Kohl
PhD student
Gianna's research focuses on adapting the existing 'Who to tell, how and when' programme into an online programme.

Jem Bhatt
Research fellow
Jem has developed the 'Who to tell, how and when' programme for people affected by dementia. Her work focusses on stigma and ageing.

Katrina Scior
Professor
Katrina is professor of Clinical Psychology and Stigma Studies. Her expertise lies in stigma associated with disability, mental health challenges, and ageing.

Georgina Charlesworth
Associate Professor
Georgina is a researcher and clinical psychologist. Her work focusses on psychological support for people with dementia and family carers.

Developed at University College London in collaboration with the Alzheimer's Society UK

5.5 Step 2: Evaluating mock-ups of prototype v1

In step 2, I evaluated prototype v1 of the digital ‘Who to tell, how and when’ intervention through use of focus groups to gather feedback on its design and look and feel.

5.5.1 Methods for evaluation

5.5.1.2 Procedure

Individuals from the participant pool were contacted to assess their interest in participating in focus groups about the prototype design. Those who agreed to participate received a PDF document containing mock-ups of prototype v1 one week before the scheduled discussions (see Appendix U), allowing them time to review the design. A study reminder was sent two days before the scheduled meeting. The discussions were held on Zoom, and during these sessions, mock-ups were presented on Google Jamboard, a digital interactive whiteboard that was shared on the participants’ screens. An observer (PH) was present to take notes during each session, each of which lasted one hour.

As with step 1, a semi-structured topic guide was used based on ‘perceived usefulness’, ‘perceived ease of use’, and ‘credibility’. It included questions related to participants' thoughts on the overall design, use of photographs, and readability (see Appendix V). Participants willingly provided feedback, often answering questions from the guide without prompting.

5.5.1.3 Data analysis

As with recordings from the focus groups described in step 1, the discussions from step 2 focus groups were transcribed verbatim. Data were analysed using NVivo 12, employing qualitative content analysis as outlined in step 1 (Elo & Kyngäs, 2008; Erlingsson & Brysiewicz, 2017). Qualitative content analysis was also deemed appropriate for step 2 due to the ability to describe and categorise participants' feedback. The analysis was conducted independently by me and PH, with the final set of themes discussed with GC.

5.5.2 Results of evaluation

Three main themes (see Table 5.3) were identified to encapsulate participants' feedback on prototype v1 and their suggestions for its improvement. The first theme, 'design and accessibility', reflects participants' views on the prototype's design, ease of use, and recommendations for enhancing accessibility for people with dementia. While the focus of the discussions was not on these aspects, participants naturally engaged in discussions about potential future implementations of the intervention and the broader representation of people with dementia in society, which are reflected in the second theme, 'usefulness of intervention', and the third theme, 'representation', respectively. The second and third theme were generated in response to participants' comments that, while not directly addressing the mock-ups' design, were deemed essential to adequately represent their feedback. The third theme especially aligns with findings from Chapters 2 to 4 that discuss the stigma of dementia. As in step 1, quotes are followed by the participant's ID and their age.

Table 5.3. Overview of themes and categories from the prototype v1 evaluation

Themes	Categories
Design and accessibility	- Colour contrast - Language - Readability - Navigation
Usefulness of intervention	- Changes to content - Enhancing credibility
Representation	- Diversity - Stigma and stereotypes

5.5.2.1 Theme 1: Design and accessibility

Comments on design and accessibility fell into four categories of colour contrast, language, navigation, and readability.

Colour contrast: The website's colours and their contrast were discussed in all three focus groups. The mock-ups were presented in yellow, white, grey, and black (see also Figures 5.2-5.7). Generally, participants were positive about the colour contrast in the images and text. However, one participant noted difficulties in reading dark text on a grey background given their dementia type: "I do have some issues with some of the colouring where the black writing is on the grey box. The type of dementia I have I can't see that too easily" (PWD5, 49).

Language: Both people with dementia and family carers emphasised the importance of using simple and plain language on the website, recognising that some words might be difficult to understand for people with dementia or non-native English speakers. Participants stressed the need for dementia-friendly language that avoids causing offence unintentionally, acknowledging that this might not be easy: "… you can't always be totally aware of not offending anybody very inadvertently" (FC11, 68). One participant suggested incorporating an easy-read version of the website, accessible with a single click, to cater to individual preferences.

Readability: In all focus groups, participants highlighted the importance of improving text readability. Two main concerns were the font size, with several participants suggesting to increase it, and the amount of text on the pages. Participants believed that excessive text on the pages might deter people with dementia from using the website. One participant recommended using bullet points and concise summaries for improved layout: "I definitely am very much drawn to reading anything of the sort of bullet points and set out, sort of, very easily in summary" (FC10, 57).

Navigation: Even though participants were asked to respond to the design of the website mock-ups, many provided feedback aimed at streamlining navigation. They commented on the 'get started' button, which leads individuals to the start of the intervention. Some participants found it confusing when this button appeared both at the top and bottom of a page (see Figure 5.2, image A). Additionally, participants proposed allowing users to choose which session to start with instead of mandating session 1. A participant expressed this as follows: "If you think it works best for people to work through all of it, you can just put that as advice how to do it. But then give people [the choice] to jump around where they want to" (FC7, 60).

5.5.2.2 Theme 2: Usefulness of intervention

Several participants acknowledged the importance of having an intervention that would support individuals with their disclosure decisions, provided suggestions to improve the content of the intervention to enhance its future implementation, and discussed ways to advertise the intervention in the future:

> *… as soon as it is out there, whether it's on all the various dementia organisation, websites and/or … memory services or dementia assessment services … I think it will be networked through the network so to speak and become a go-to resource, I suspect, because it is such a key one.* (PWD2, 70)

Participants could relate to the difficulties that individuals might face regarding disclosure decisions and were supportive of the intervention and its aims: "I just think you've got a great opportunity here. If you're gonna [sic] use this programme and how to do it, at the same time you could tackle a lot of the stigmas and a few other things" (PWD5, 49). Another participant mentioned that their parents could have benefitted from the intervention: "I think she would have had more open conversations with my father earlier on and to a certain extent, I think that would have made his life a little bit easier" (FC10, 57).

Changes to content: Participants gave suggestions to improve the content of the website and, thereby, improve its usefulness and future implementation. One suggestion was to remove the 'our research' page (see Figure 5.2, image D), as the content was deemed too detailed and irrelevant for individuals. Alternatively, participants suggested adding a link which would lead individuals to more information about the intervention development on the university website.

In all focus groups, participants commented on the exercises shown in the intervention mock-ups (see Figure 5.2, image C for an example) which had been taken from the original paper manual. Some participants stated they did not understand the purpose of the exercise, suggesting that additional explanations on the website were necessary. Others provided suggestions how to improve the exercises shown in the mock-ups:

> *What about suggesting a range of words that people could click on to say 'these are the words that I've heard used about someone with a dementia'. So, rather than asking the open-ended question, you're given a range of answers. Possible answers. And when they click on certain ones, that automatically takes one to the next stage.* (FC8, 74)

Participants felt that psychoeducation was an important element of disclosing one's diagnosis and felt such an exercise would be a useful addition to the intervention: "So, in order to start talking to people openly, we first have to educate those want to speak … and then you can start to explain how you would go about telling somebody" (PWD5, 49). It was also suggested to signpost individuals to existing material and resources on other websites to get more specific examples about dementia, if these existed.

Enhancing credibility: As this intervention was developed in collaboration with the Alzheimer's Society, one participant suggested adding the names of individuals the researchers worked with to the website to enhance its credibility. Another participant stated it could be worthwhile to mention the user-centred design aspect of the intervention development on the website, so users were aware of the involvement of people affected by dementia: "… you could have a small PPI [Patient and Public Involvement] group going forward in this and put their photographs on one of the web pages [which] would let people see that you [have] incorporated PPI and you value PPI" (FC11, 68).

5.5.2.3 Theme 3: Representation

Throughout the discussions, participants reflected on the way people with dementia are represented in images or videos and in society, which they acknowledged was often negative and one of the barriers to disclosing one's dementia diagnosis. Similar to the previous theme, the third one was generated

Diversity: Several images were used in the first prototype that participants commented on, stating that they found it important that individuals with dementia are shown as "normal everyday people": "It sends out a message … it can affect anybody. So, that for me was the first reaction seeing those photos of the people" (FC6, 58). Equally important for the participants was the use of images on the website that showed younger people with dementia, as they found that the misconception exists that only older people have dementia. Similarly, they wished to see a larger representation of individuals from ethnically diverse backgrounds, with disabilities or single people in the photographs. In two focus groups, participants stated that they would like to see more photos that represent the 'ups and down' of living with dementia, as illustrated by the following quote:

> *… these pictures all show people with smiles on their faces as if everything's absolutely wonderful … If this programme is for people who just have recently had their diagnosis, they ain't [sic] going to be smiling all that much … although I don't want you to show miserable people all the time, I think there should be a reflection of a person just on their own, sort of looking, looking around or something …* (PWD2, 70)

Stigma and stereotypes: Reflecting on one of the photographs which showed two individuals with white hair holding hands, walking in a park with the sunset in the background and their backs facing the camera, participants started talking about the stigma that surrounds dementia, which they felt was represented in this photograph. While some participants found the photo "peaceful", others found it too much of a cliché: "… most of the websites that one looks at have bloody American stop [sic] people looking at, hand in hand, looking out at the sunset or looking across the waves. How wonderful life is with dementia. Not" (PWD2, 70). Participants also discussed the meaning of two individuals having their backs turned towards the camera and what that said about society's view about dementia: "It may not be the way it was designed, but I rather like the first picture of the people walking away from other people, because in many ways I think that's what society wants people with dementia to do" (FC8, 74).

5.5.2.4 Summary of findings from step 2

The aim of step 2 was to establish what participants thought of the design and look of prototype v1. In order to gather their feedback, I shared several mock-ups with participants, both before and during the focus group discussions. As outlined in section 5.5.2, participants in the three groups engaged in discussions on the design of prototype v1, potential intervention implementation avenues and the representation of people with dementia in images. Based on these discussions, I considered several points for creating the mid-fidelity prototype (prototype v2). Pages of the website should not contain a greyish background to enhance the colour contrast. It was desirable to only display one 'get started' button on the homepage, and it was requested that individuals should be able to access each session individually. The font size should be increased, and the amount of text decreased, if possible. Detailed information on how the intervention was developed was deemed unnecessary and linking to another website if more information was required should suffice. It would be helpful if the first exercise would contain more detailed instructions. An important aspect of self-disclosure that was described in this chapter as well as in Chapters 2 to 4 was the stigma associated with dementia. Participants in these chapters described awareness raising and the ability to educate others as empowering. Similarly, focus group participants from step 1 suggested to use the first exercise (see Figure 5.5) to enable individuals to learn more about dementia to educate others. They recommended signposting individuals to other websites for this kind of information. Regarding the photographs, they recommended that they should feature a more diverse group of people, including various ages, ethnicities, and physical abilities. Participants found the image on the main homepage inappropriate.

5.6 Step 3: Development of prototype v2

Findings from the focus groups in step 2 were used to adapt prototype v1 into prototype v2 (also referred to as 'the website').

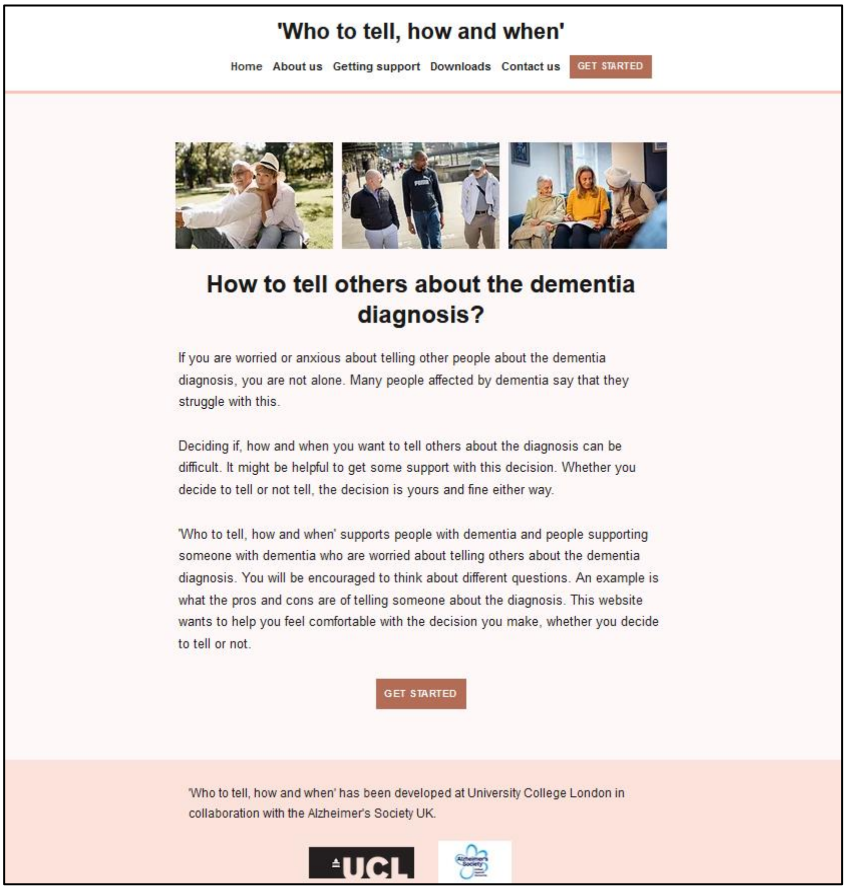
5.6.1 Development of prototype v2

I took the feedback and recommendations gathered in step 2 (see section 5.5.2.4 for a summary) to refine prototype v1 and create prototype v2. This version was designed as a mid-fidelity prototype, offering more detail, precision, and functionality compared to prototype v1. It featured clickable elements and content. For example, it enabled users to navigate the website, access the three intervention sessions, and visit websites of dementia support organisations linked within the intervention website. Compared to a high-fidelity prototype, however, its functionality was limited. For example, exercises were not interactive and video placeholders were used instead of actual videos. A mid-fidelity prototype was chosen for step 2 as I considered it a good balance between cost and value, presenting participants with a relatively functional website to gather feedback before a high-fidelity prototype could be developed in future research, including subsequent usability testing (McElroy, 2016).

A table presenting specific feedback from participants and the changes made to prototype v1 can be found in Table A3 in Appendix W. In the following, I will provide examples of changes I incorporated. I changed the overall design to a lighter colour palette, changed the grey background of the session pages to a lighter background to enhance readability, and increased the font size of all text. I added additional information to the homepage to clarify who this intervention is aimed at and what it entails, and I exchanged the main image on the homepage for three separate ones. As participants suggested developing an interactive website, I added video placeholders to the website to indicate where videos could introduce the intervention and its content in the future. Due to restraints of time and resources, I was not able to record these at the time of the study. I renamed the sessions into ‘modules’. In response to findings from Chapter 2 to 4 on stigma and advocacy, as well as insights from the focus group discussions within this chapter, I enriched the first exercise by incorporating additional information on dementia and its symptoms. This included a hyperlink to a dementia factsheet by the Alzheimer’s Society. As detailed in section 5.5.2.4, this adjustment aimed to address findings of this overall thesis, fostering a more comprehensive understanding of dementia among intervention participants, and to enable them to articulate its implications to others, thereby enhancing the feeling of being able to speak out against stigma. I carefully evaluated photographs used in the first prototype for their level of diversity (e.g., ethnic and age diversity), and replaced some by new photographs.

The exact changes are presented in the following section. The overall colour palette for prototype v2 was now a light red, and the homepage of the website showed three separate images (see Figure 5.8). Similar to prototype v1, this page contains a brief introduction to the intervention. The number of items shown in the top menu was scaled down. I added the item ‘downloads’ that would lead individuals to a page where they could download the manual. Contrary to participants’ feedback, I decided to keep the two ‘get started’ buttons on this page for two reasons. First, one would need to scroll down to read all of the text provided on this page, and I felt that a button at the end of the page clearly indicated that one would start with the intervention when clicking on it. Second, the button in the top menu would always be visible, even when someone was on a different page and not on the homepage.

Figure 5.8. Homepage used in prototype v2



'Who to tell, how and when'

How to tell others about the dementia diagnosis?

If you are worried or anxious about telling other people about the dementia diagnosis, you are not alone. Many people affected by dementia say that they struggle with this.

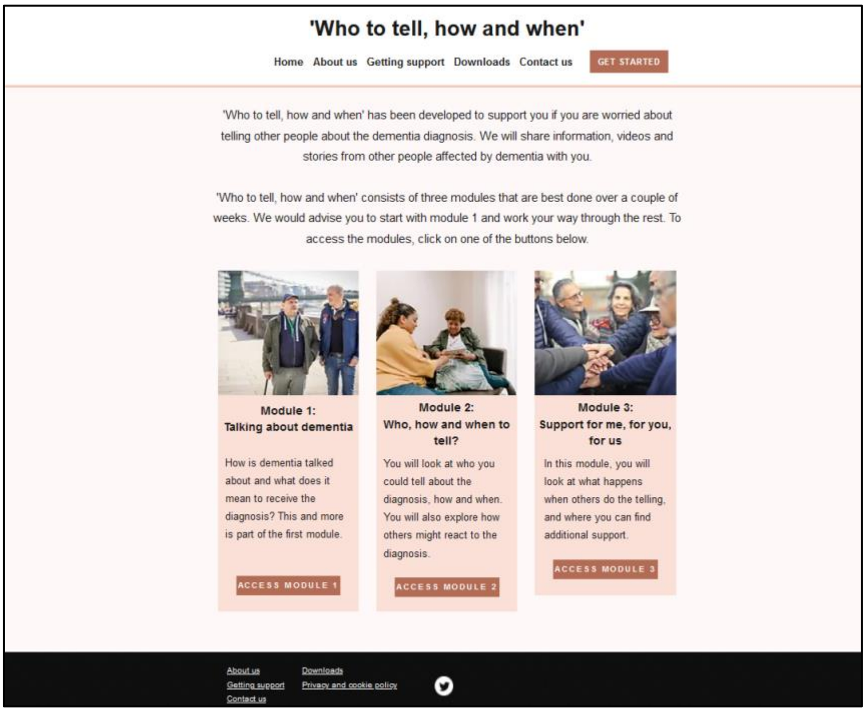
Deciding if, how and when you want to tell others about the diagnosis can be difficult. It might be helpful to get some support with this decision. Whether you decide to tell or not tell, the decision is yours and fine either way.

'Who to tell, how and when' supports people with dementia and people supporting someone with dementia who are worried about telling others about the dementia diagnosis. You will be encouraged to think about different questions. An example is what the pros and cons are of telling someone about the diagnosis. This website wants to help you feel comfortable with the decision you make, whether you decide to tell or not.

'Who to tell, how and when' has been developed at University College London in collaboration with the Alzheimer's Society UK.

By clicking on one of the ‘get started’ buttons, individuals are led to the session overview (see Figure 5.9). In line with participants’ feedback, the word ‘session’ was changed into ‘module’. For consistency purposes, I will keep using the word ‘session’ in this chapter. A brief overview of what each session entails is provided. Participants can access all of the sessions individually, though they are advised to follow them in order.

Figure 5.9. Overview of the modules used in prototype v2



'Who to tell, how and when'

'Who to tell, how and when' has been developed to support you if you are worried about telling other people about the dementia diagnosis. We will share information, videos and stories from other people affected by dementia with you.

'Who to tell, how and when' consists of three modules that are best done over a couple of weeks. We would advise you to start with module 1 and work your way through the rest. To access the modules, click on one of the buttons below.

Module 1:
Talking about dementia

How is dementia talked about and what does it mean to receive the diagnosis? This and more is part of the first module.

Module 2:
Who, how and when to tell?

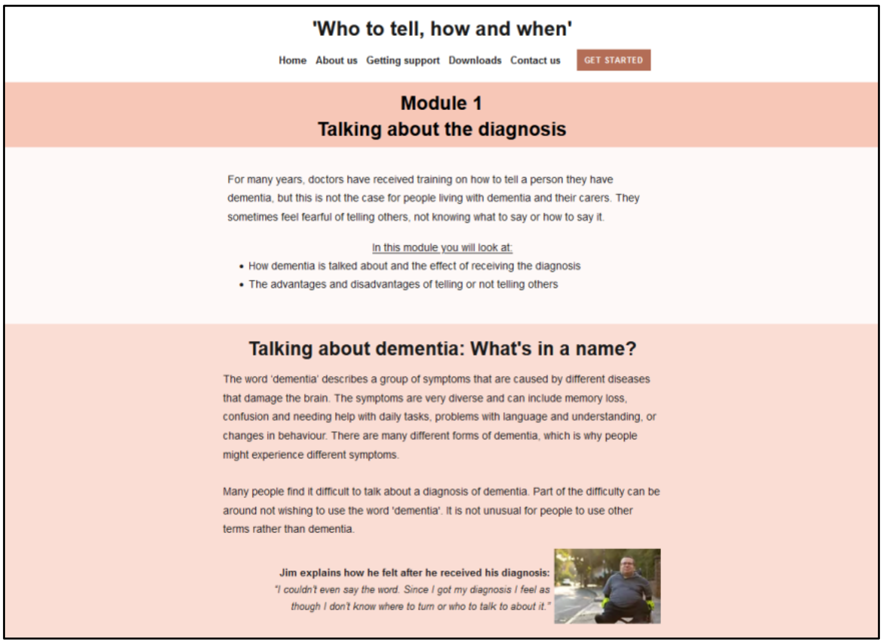
You will look at who you could tell about the diagnosis, how and when. You will also explore how others might react to the diagnosis.

Module 3:
Support for me, for you, for us

In this module, you will look at what happens when others do the telling, and where you can find additional support.

Figure 5.10 shows the main page of session 1, including information on what the session will be about.

Figure 5.10. Start page of session 1 used in prototype v2



'Who to tell, how and when'

Module 1
Talking about the diagnosis

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 and their carers. They sometimes feel fearful of telling others, not knowing what to say or how to say it.

In this module you will look 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?

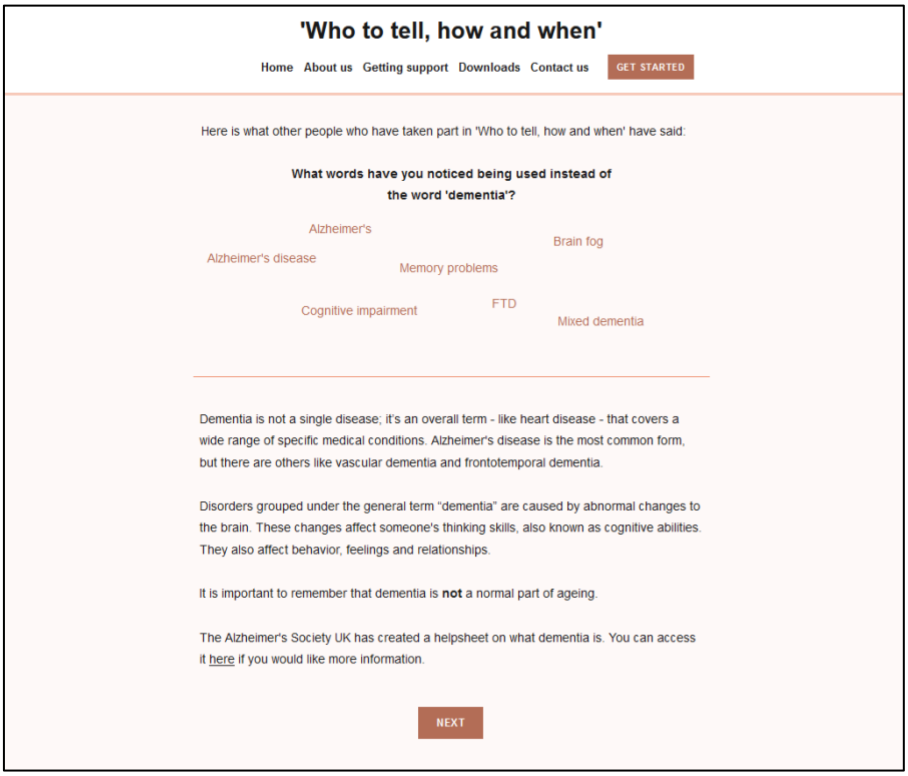
The word 'dementia' describes a group of symptoms that are caused by different diseases that damage the brain. The symptoms are very diverse and can include memory loss, confusion and needing help with daily tasks, problems with language and understanding, or changes in behaviour. There are many different forms of dementia, which is why people might experience different symptoms.

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.

Jim explains how he felt after he received his diagnosis:
"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."

Scrolling down this main page, participants are presented with the first exercise that was also shown in Figure 5.5. Once participants have submitted their response, they are led to a page showing possible responses by other intervention participants (see Figure 5.11). These responses were created by me as this was a prototype. Additional information below these responses describes what dementia is and also links individuals to a factsheet by the Alzheimer's Society.

Figure 5.11. Possible responses to exercise 1 as shown in prototype v2



Here is what other people who have taken part in 'Who to tell, how and when' have said:

What words have you noticed being used instead of the word 'dementia'?

Alzheimer's

Brain fog

Alzheimer's disease

Memory problems

FTD

Cognitive impairment

Mixed dementia

Dementia is not a single disease; it's an overall term - like heart disease - that covers a wide range of specific medical conditions. Alzheimer's disease is the most common form, but there are others like vascular dementia and frontotemporal dementia.

Disorders grouped under the general term "dementia" are caused by abnormal changes to the brain. These changes affect someone's thinking skills, also known as cognitive abilities. They also affect behavior, feelings and relationships.

It is important to remember that dementia is **not** a normal part of ageing.

The Alzheimer's Society UK has created a helpsheet on what dementia is. You can access it here if you would like more information.

5.6.2 Think-aloud interviews

Additionally, I used think-aloud interviews to gauge participants' overall impressions of the website, their interactions with it, and to identify any obstacles they may encounter. 'Think aloud' is a widely used approach in psychology and characterised by the simultaneous verbalisation of thoughts while performing a task (Ericsson &

Simon, 1993). It is often used in user-centred design approaches (Årsand & Demiris, 2008; Jaspers, 2009). In the development of internet- and computer-based health interventions, think aloud is used to test the design and uncover potential usability issues in prototypes and interventions (Jaspers, 2009). While navigating through the prototype or intervention, participants are asked to verbalise their actions, impressions, suggestions, and concerns. The data is then used to refine the product. This approach was chosen to gain real-time insights into how people affected by dementia interacted with the prototype and to obtain immediate feedback. Think-aloud was preferable to retrospective interviews, as these would have relied on participants' memory of their impressions of the prototype, or simply showing them mock-ups. Importantly, studies using think-aloud methodology do not require large sample sizes (Nielsen et al., 2002) and have successfully been applied in the development and testing of technological interventions for people with dementia (Kort et al., 2019; A. R. Lee, Csipke, et al., 2023), making it a suitable approach for this study.

5.6.3 Participants and procedure

I contacted members of the Research Network who had expressed interest in participating in the study but were either unavailable for the focus groups or had only participated in the first round of focus groups. Participants who had taken part in the second round of focus groups were not eligible, as they had previously seen mock-ups of prototype v1. The aim was to include participants who could evaluate the intervention with a fresh perspective.

Participants had the option to choose between in-person interviews held on the UCL campus or online interviews via Zoom. For in-person interviews, I reserved a testing room equipped with a computer for participants to access prototype v2. For Zoom interviews, I shared a link in the chat, giving participants access to the prototype on their own computers. At the start of each interview, I explained the think-aloud method and provided an example, checking with the participants if they understood the approach (see Appendix X for the topic guide). During online interviews, participants were asked to share their screens to observe their interactions with the website. As I wanted to observe participants' natural engagement with the website, the initial instruction was simply to 'use the website as you would explore any website for the first time', while verbalising their thoughts. Throughout the interviews, I encouraged them to keep verbalising their thoughts if they fell silent (e.g., by saying 'What is going through your head?'). Audio as well as screen recordings were conducted to capture participants' activities and interactions with the website. Participants received a study reminder via email two days before the interview. After the interviews, I sent a debrief email (see Appendix S) along with a £15 retail voucher to each participant.

The interviews were transcribed verbatim using Scrintal and checked for accuracy. Physical actions, such as participants reading out loud, were noted within the transcripts and identified with square brackets ([]), which are included in the quotes. Recordings served as a reference during analysis when needed. I applied a qualitative content analysis approach, as detailed in the methods of step 1 and 2. The analysis was conducted by myself in NVivo 12.

5.6.4 Findings from think-aloud interviews

One person with dementia and one family carer, both of whom were male, participated in the interviews. They were 72 and 60 years old, respectively. The person with dementia had previously participated in step 1 of the focus groups (i.e., has not commented or seen prototype v1), while the family carer had not taken part in any of the focus group discussions. Both participants were positive about the website, finding it straightforward and generally easy to navigate. Two themes were generated in the analysis: 1) presentation and navigation, and 2) content. Quotes are followed by the participant's ID and their age.

5.6.3.1 Theme 1: Presentation and navigation

Participants generally found the design and layout of the website suitable, including the colour palette, contrast, font, and font size (Arial 42 for headings and 24 for body text). One participant noted that the grey scroll bar on the right-hand side was not immediately visible. Regarding navigation, participants initiated their interaction by clicking on the 'Get started' button, which was positioned at both the top and bottom of the homepage (as shown in image A, Figure 2). The button at the top of the page had a different colour compared to the rest of the menu, which led to confusion for one participant: "Puzzled by the 'Get started' button at the end. It's out of context with the others, different colour, different standards etc., so I don't know what that's doing" (PWD3, 72). The participant also expressed confusion regarding the existence of two of these buttons. Upon clicking one of the buttons, participants were directed to a page introducing the modules and recommending they be completed in order (as illustrated in image B, Figure 2). One participant commented that they were less inclined to do so, saying, “Being the sort of guy I am, I'd access module 3 straight away [laughing]“ (PWD3, 72), and recommending the use of cookies to aid this kind of navigation. Subsequently, participants easily navigated through all modules in ascending order as well as the rest of the website by using either the ‘Next’ button or the top menu. A suggestion was made to have external links on the website, such as those leading to the homepages of dementia support organisations, open in new tabs or windows. This recommendation was based on the consideration that people with dementia may experience confusion when links replace the current page. Participants also proposed the inclusion of a progress bar, which would visually indicate the extent of content they had read to enhance the website’s navigation.

5.6.3.2 Theme 2: Content

Participants consistently expressed positive feedback regarding the general content of the website and the intervention content specifically. As they progressed through the pages of the website, they actively shared their thoughts and comments on the text, images, quotes, and exercises that constitute the intervention. They frequently responded to the content by sharing their own experiences with dementia, indicating a strong resonance with the material. Participants responded positively to the page introducing the people involved in creating the intervention: “I like this because I suddenly got people … I can now almost put a face to the voice” (PWD3, 72). Regarding the three modules of the intervention, the following paragraphs will provide detailed descriptions of the feedback and comments.

In module 1, after reading the initial three quotes from people with dementia, one participant indicated feeling saddened and suggested incorporating more positive perspectives on dementia: “Could we not have a little bit of light as well as dark? Maybe another one underneath said, ‘I've told people, I feel great!’” (PWD3, 72). The participant expressed concern that these quotes might deter people with dementia who are hesitant to disclose their diagnosis, emphasizing the need for a more balanced approach. Quotes within the section discussing the advantages and disadvantages of disclosing one’s diagnosis were generally well-received. These quotes included both positive and negative aspects of both disclosing and concealing a diagnosis. However, participants suggested adding context to some quotes to enhance clarity and revising certain words. For example, the quotes from Jane and Nicki were introduced with ‘below, Jane and Nicki talk’, which may have suggested the presence of a video instead of a quote. Furthermore, it was suggested to split this page into two separate pages as there was “a lot going on” (FC9, 60). The suggested split would be after the advantages and disadvantages of sharing one’s diagnosis with others.

Module 2 begins by addressing the spectrum of disclosure, ranging from telling no one to telling everyone about one’s diagnosis. The first exercise within this module encourages participants to reflect on this spectrum and enter their response into a form located at the end of the page. One participant proposed the idea of aggregating the responses provided by individuals for this exercise, as well as for other exercises within the intervention. This approach would allow researchers to gather valuable data that could be used to adapt the intervention based on participants' input. Additionally, it could provide people with dementia insight into the experiences and perspectives of others who completed the exercises. Overall, participants responded positively to the content on this page, finding it thought-provoking. On the next page, individuals are prompted to think about whom they would like to disclose to and whom they believe should not be informed. Feedback on this page was positive, with one participant noting, “This is really good. You're helping them in the process of coming to decisions” (FC9, 60). Following this, individuals are presented with a quote by Tobias, along with an exercise asking them to reflect on how he disclosed his diagnosis. One participant questioned the necessity of this exercise. The final page in module 2 explores the reactions of others and presents a vignette illustrating a situation in which Claire discloses her diagnosis to Geoff. After reading the vignette, one participant expressed a negative impression, saying: “I think if I was unsure whether to tell people and I saw and I read that little bit, that alone would really sort of worry me” (PWD3, 72). This participant suggested omitting the second half of the vignette to allow readers the opportunity to form their own opinions about how Geoff may have responded to Claire’s diagnosis. Upon completing module 2, one participant noted that the current intervention appears to primarily target individuals who have recently received their diagnosis. However, they pointed out that individuals who had been living with the diagnosis for a few years might also benefit from it, stating, “It would take very little work to say … as your diagnosis gets worse, you may need to tell more people, or your carer needs to tell more people … at the moment, you captured the one moment in time, post-diagnosis perfectly. But so much more you can do with it” (PWD3, 72).

In module 3, participants were prompted to reflect on the possibility of others sharing the diagnosis without their awareness. Overall, participant noted a lack of clarity in the content in this module. The text on the first page lacked clarity due to the phrasing of the sentences under the heading ‘Whose diagnosis is it?’. The confusion stemmed from the use of the term 'supporter of someone with a dementia diagnosis' instead of the more familiar term 'carer'. On subsequent pages, participants sought clarification for specific elements, including an exercise at the bottom of the third page and the introductory text at the top of the fourth page. Upon clarifying the text, one participant recommended a more direct and personalised approach to the content, suggesting “rewrite it like you were telling me … Imagine you’re talking directly to a person” (PWD3, 72). One of the last pages, which provided information on dementia support organisations, received positive feedback. The last page of module 3, contained contact information for the researchers, prompted a suggestion to replace personal email addresses with a generic one as employees may change over time.

5.6.3.3 Summary of findings from think-aloud interviews

The aim of step 3 was to gather feedback on prototype v2 through think-aloud interviews while participants interacted with it. Their comments highlighted considerations for further adaptations to prototype v2 to enable the development of a high-fidelity prototype that can be tested further. Despite my decision to keep the two ‘get started’ buttons, confusion by one participant indicates a need for reconsidering this choice. To optimise usability, I recommend that any links to external websites open in a new tab or window and to incorporate a progress bar to simplify module navigation. While some quotes displayed in throughout the intervention were perceived as slightly negative, it is important to note that they represent actual responses from people with dementia gathered in previous research (Bhatt et al., 2020). To address a desire for increased positivity, I suggest adding new, positive quotes in addition to the ones already existing. Additional recommendations include providing more context for certain quotes and splitting the discussion of advantages and disadvantages into separate pages. One participant proposed potentially saving individuals' responses for future research as a form of data collection. Furthermore, I advise to shorten the vignette by Geoff and Claire. Expanding the website's scope to include individuals who have been living with their diagnosis for an extended period, and who have not just recently been diagnosed, is recommended. Lastly, participants expressed concerns about the clarity of the third module, suggesting improvements in language use, particularly regarding terms like 'supporter' and the simplification of complex sentences.

5.7 Discussion

This chapter describes the adaptation of the ‘Who to tell, how and when’ intervention for digital delivery. A three-step iterative process was undertaken as part of a user-centred design approach, focusing on the development and subsequent testing of both low- and mid-fidelity prototypes.

5.7.1 Principal findings

Findings from the focus groups and think-aloud interviews revealed the importance of adapting the intervention into a format that is not only user-friendly but also accessible and easy to use, both in terms of content and mode of delivery. This became particularly apparent during the focus group discussions, where participants suggested having a variety of formats for digitally delivering the intervention (e.g., downloadable PDF manuals) to cater to different preferences and needs. This aligns with previous research findings that highlight user preferences for tailored delivery modes in internet-based interventions and providing choices in accessing information (Hoffman et al., 2021; Yardley et al., 2010). Specific suggestions were raised for the exercises. Aligning with the findings on awareness raising and advocacy from Chapters 2, 3, and 4, it was suggested to enrich exercises with an element of psychoeducation. This enhancement aimed to bolster individuals' confidence and knowledge, thereby increasing understanding among others about dementia. As described previously, these concepts reflect the first and third domains of the social health framework.

This chapter affirmed the value of peer support, especially in the realm of self-disclosure, as described in Chapters 3 and 4. Peer support is valuable for social health, especially for the third domain of the framework. It is also an important aspect of the original HOP programme and the 'Who to tell, how and when' intervention is peer support (Bhatt et al., 2020; Scior et al., 2019). While it was not feasible to develop a peer support option in this chapter due to time and resource restraints, participants discussed their preferences for integrating it into the digital adaptation. One suggested option was the use of Zoom calls. As noted in previous research (Gerritzen et al., 2023; Talbot & Briggs, 2022), participants became well-acquainted with this approach during the COVID-19 pandemic and generally enjoyed using it. This suggests it might be a viable option for the adaptation as well, though Zoom facilitators would be required. Another suggestion was the inclusion of a discussion forum. Though some participants expressed hesitation, incorporating an established platform like ‘Talking Point’ by the Alzheimer’s Society could be beneficial due its positive reception among people with dementia in prior research (Talbot & Coulson, 2023). Given the abundance of existing online communication tools, developing a peer support tool solely for this intervention might be unnecessary.

Findings from the study described in this chapter underscored the stigma of dementia, as was also found in Chapters 2 to 4. In particular, while this chapter focuses on the digital adaptation of the intervention, participants naturally engaged in sharing their personal experiences of living with dementia. This included difficulties related to their perceptions that people with dementia are being portrayed negatively in society and media (Gerritsen et al., 2018). These challenges were reflected in their observations about the photographs and images initially used in the adaptation process. While their reflections on stigma were not part of the immediate aims of this study, participants sharing these experiences underlined the importance of the intervention for them and the difficulties they encounter in their daily lives. They also reaffirmed the relevance of findings from previous chapters. As part of these discussions, participants shared their views on the necessity of using photographs on the website that represented a diverse group of people in terms of ethnicity, physical impairments, and age. The latter seemed especially important to the participants, potentially because dementia is often associated with older people (Pipon-Young et al., 2012). Participants also discussed potential implementation avenues and ways to enhance future access to the intervention. Discussions like these may reflect the varying quality and availability of post-diagnostic support for people affected by dementia in the UK (Frost et al., 2021; Stamou et al., 2021). Therefore, utilising digital interventions like the one developed in this study to support people with dementia may be an important addition to existing face-to-face support in dementia care (Knapp et al., 2022).

5.7.2 Strengths and limitations

One of the strengths of this study is the user-centred design approach. It allowed end users to be fully involved in all phases of the design and build process of the two prototypes. Their involvement ensured that the intervention was tailored to the preferences of this population and minimised future discrepancies or problems between user needs and the final product (van Gemert-Pijnen et al., 2011). This approach has also been recommended in the development of digital technologies for people affected by dementia (Robillard et al., 2018). In addition, starting the digital adaptation of the intervention with a low-fidelity prototype followed by a mid-fidelity prototype offered the advantages of being cost-effective and having relative quick development cycles, compared to developing a fully functional high-fidelity prototype from the start (Walker et al., 2002).

Limitations of the work presented include the self-selection bias observed in the participant pool. All participants seemed to be comfortable sharing their diagnosis or family carer status with others. Thus, the participants differed considerably from the target group of ‘Who to tell, how and when’, that is, individuals who may feel uncomfortable disclosing their diagnosis. The recruitment of participants from the Research Network, which is known for its research-engaged members, likely played a contributing factor. A similar bias, namely studies exploring disclosure among stigmatised identities attracting participants who are open about their identity, has been observed in previous disclosure research (e.g., Pembroke et al., 2017), including the qualitative interview study described in Chapter 3. Despite this, the participants in this study provided valuable feedback for the digital adaptation. The involvement of the Research Network may also have revealed findings that might have otherwise gone unnoticed due to its members' research experience. Future research should pay particular attention to recruiting a diverse range of participants in terms of their disclosure status. A second limitation stems from the sample predominantly comprising White British participants. Consequently, the findings and conclusions drawn from this research, as well as the digital adaptation itself, may not be readily generalisable to individuals who do not identify as White or who represent a more diverse range of ethnicities. This may especially be the case as the stigma of dementia, and potentially the disclosure of one's diagnosis, can present itself differently in other cultures (Herrmann et al., 2018), which was also discussed by PPI contributors in Chapter 2. It is therefore advisable to culturally adapt the adaption of 'Who to tell, how and when' as opposed to having one intervention for everyone (Barrera et al., 2013), which was also noted by the focus group participants. A third limitation is the small sample size of the think-aloud interviews. The decision to only recruit two participants was made due to time constraints and the notion that it would not be possible to conduct a full usability study with a mid-fidelity prototype. Therefore, potential issues with prototype v2 may have been missed. Nevertheless, the feedback from participants in step 3 was beneficial and can support the development of a high-fidelity prototype in future research as well as its subsequent usability testing. For this kind of study, a small sample of five participants would be sufficient to uncover approximately 80% of usability issues (Jaspers, 2009). Finally, the website was primarily designed for desktop computer use and not optimised for smartphones. Given the increasing prevalence of mobile internet usage across all age groups in the UK (Ofcom, 2023), this limitation could affect the future accessibility and user experience of the website. It is therefore advisable to adapt the website for mobile device compatibility in future research to ensure broader accessibility and usability.

5.7.3 Recommendations for future intervention development

The focus groups and interviews provided a valuable basis for the development of the mid-fidelity prototype and its evaluation. Further refinements are required to develop a fully functional and usable prototype that can be tested. In the following, I will provide recommendations for future developments, building on findings from this chapter as well as Chapters 2 to 4.

First, it is recommended that future research evaluates if and how the manual of the intervention can be developed into a self-guided one, as it was suggested to have a variety of options regarding how the intervention content is delivered. This could be made available to download from the website. Second, similar to a mixed-methods study developing a health information website for older adults (Fink & Beck, 2015), participants recommended developing an intervention that would be interactive to elicit interest and engagement. To address this, placeholders were added to the website to indicate where interactive elements could be placed, including videos, fillable forms, and interactive exercises, which participants in the study reacted positively towards. As noted, videos to introduce the intervention and its content have not yet been produced due to time restraints. As an existing meta-analysis suggests that using interactive elements in web-based health interventions also positively influences efficacy and user experience (Lustria et al., 2013), it is recommended to implement fully functioning features in future research. Third, participants in the interviews commented on the vignettes, quotes, and exercises used in the adaptation, and suggested to add or select alternative vignettes or quotes as some were thought to be too off-putting for people with dementia who are hesitant to disclose their diagnosis. To address these suggestions, it is advisable to review existing content further with participants or PPI contributors ensure suitability for the online intervention. Where feasible, exercises or vignettes could be enriched, or quotes added, with content focused on raising awareness and education, which was identified as beneficial for self-disclosure in Chapters 2 to 5. This could potentially increase empowerment, which was found to be relevant in HOP (Klein et al., 2023), and add to all domains of the social health framework. Additionally, incorporating strategies supporting self-disclosure which were discussed in Chapter 3, such as the use of a disability lanyard or 'I have dementia' card, could be valuable additions currently not included in the digital adaptation.

Fourth, findings from Chapters 2 to 4 as well as the current chapter highlight the value of peer support in the disclosure process. Peer support is also a valuable component of the paper-based 'Who to tell, how and when' intervention (Bhatt et al., 2020) as well as HOP, and beneficial for the third domain of the social health framework. In this chapter, time restraints did not allow me to test a peer support element. Therefore, it is worthwhile to explore options how to incorporate digital peer support into the future intervention. This is relevant as Chapters 3 and 4 found that social media can be valuable for peer support, as was found in previous research (Gerritzen et al., 2023). Finally, research has recommended the creation of a business model and involving financial gatekeepers early in the development of internet-based health interventions, as this enhances their implementation (Christie et al., 2019; van Limburg et al., 2011). This task was not undertaken in this study, as the focus was on the development of low- and mid-fidelity prototypes. However, it is a recommended to explore in the next stage.

5.8 Chapter summary and conclusion

The use of digital technologies has become an integral part of people's everyday lives. This also applies to people with dementia, including supporting their decision to disclose their dementia identity, as highlighted in Chapters 2 to 4. To cater to the growing number of people using digital technologies, and to enhance accessibility to self-disclosure support that can enhance social health, this chapter aimed to adapt the 'Who to tell, how and when' intervention for digital delivery. I conducted the adaptation using an iterative user-centred design approach, including relevant findings from Chapters 2 to 4 where applicable. This process resulted in the development of an intervention that was endorsed by people affected by dementia, potentially benefitting their social health. Further refinements to the adaptation are required to make the intervention suitable for wider testing and evaluation, including its contribution to social health.

Chapter 6: General discussion

6.1 Chapter overview

Due to the stigma associated with dementia, people with the condition can hesitate to disclose their diagnosis, leading to increased social withdrawal and decreased social health. Recognizing the importance of both in-person and online disclosure avenues and considering the growing adoption of digital technologies in all age cohorts, this thesis aimed to enhanced accessibility to support for people with dementia regarding disclosure. Specifically, this thesis sought to explore how the manualised, face-to-face intervention 'Who to tell, how and when' can be adapted for digital delivery. To adapt the intervention, I conducted a series of studies:

1) To bring together, for the first time, existing research on the topic, I undertook a systematic review on factors associated with self-disclosure of a dementia diagnosis in people with dementia, focusing on qualitative studies.
2) To address gaps identified in the review and to get a better understanding of self-disclosure, I conducted a qualitative study using a narrative approach, which specifically focused on changes over time and the use of social media for self-disclosure.
3) To learn more about whether and how people with dementia use social media for self-disclosure purposes, I carried out a cross-sectional online survey with people with dementia.
4) To adapt the intervention in a user-friendly and person-centred manner, I adopted a user-centred design approach, utilising focus groups and think-aloud interviews.

In the following, I first present the key findings and their interpretations in relation to the aim of the thesis. This is followed by an exploration of the strengths and limitations of the research conducted in this thesis. Subsequently, I provide a critical reflection and suggest avenues for future research, before concluding this thesis.

6.2 Key findings

For an overview of study aims, key findings, and implications for the digital adaptation of ‘Who to tell, how and when’, see Table 6.1. In the following, I will summarise the key findings and implications for the digital adaptation to answer the thesis’s research question.

6.2.1 Study findings

The aim of the first study (a systematic review) described in Chapter 2 was to explore factors associated with disclosure by people with dementia. The review found that research on the specific topic of self-disclosure in people with dementia was limited: Of 23 qualitative studies included, only three had self-disclosure as their primary study aim. Research on online self-disclosure was also scarce, with only one study identified that described self-disclosure in an online context. Factors identified in the review predominantly related to facilitators and barriers of self-disclosure. It was found that awareness-raising efforts, wishes to explain dementia-related symptoms, and perceived stress reduction were facilitators of self-disclosure. Barriers included active concealment to shield oneself and others from the impact of the diagnosis, as well as experiences with stigma and a fear of being stigmatised.

Table 6.1. Key findings of thesis, including implications for digital adaptation of 'Who to tell, how and when'

Chapter 2

Aims:

To explore factors associated with disclosing a diagnosis of dementia by people with dementia

Key findings:

- Research focusing on both offline and online self-disclosure is limited
- Advocacy, explaining symptoms, and stress reduction can facilitate self-disclosure
- Concealment and (fear of) stigma can impede self-disclosure

Implications for digital adaptation:

- Psychoeducation is a valuable addition to learn about dementia and educate others

Chapter 3

Aims:

- To explore how people with dementia experience disclosing their condition to other people
- To explore how disclosure changes over time

Key findings:

- Disclosure decisions evolve with time
- Participants disclose in person and on social media to raise awareness and engage in peer support
- Empathy and social support, or lack thereof, can influence disclosure decisions over time

Implications for digital adaptation:

- Disclosure on social media can be a valuable addition to in-person disclosure
- Strategies such as a disability lanyard can support in-person disclosure
- Disclosure decisions are made throughout the dementia journey

Chapter 4

Aims:

- To describe how people with dementia use social media and establish cohort differences
- To describe motivations for people with dementia posting dementia-related content

Key findings:

- Both younger and older internet-using people with dementia use social media
- Younger and older people with dementia disclose on social media to raise awareness, engage in peer support, and share their lives with dementia

Implications for digital adaptation:

- Disclosure on social media can facilitate peer support, provide new opportunities, and enable opportunities for advocacy

Chapter 5

Aims:

- To describe preferences for a digital adaptation of 'Who to tell, how and when'
- To develop, and undertake preliminary evaluation, of prototypes

Key findings and implementation:

- Different formats and modes of delivery enhance accessibility
- Images need to be carefully evaluated for stigma and should portray a diverse group of people

Implications for further development:

- Adding an option for digital peer support
- Adapting or adding content for disclosure at later dementia stages
- Adding non-verbal strategies as disclosure options

The second study, in Chapter 3, focused on exploring how people with dementia experience disclosing their diagnosis and how their disclosure decisions change over time. The study showed that self-disclosure is multifaceted and can resemble a 'journey', as disclosure levels are not stable but evolve over time. The 'what', 'how much', and 'to whom' someone discloses is often influenced by the empathy and support shown by others. Experiencing a lack of support or non-empathetic responses can lead to a reduction in openness over time. The study found that disclosure can occur both in person and online on social media. In both settings, reasons for sharing one's diagnosis included a desire to live life normally, raise awareness, educate others about dementia, and give and receive support, including peer support.

The third study, described in Chapter 4, aimed to explore the use of social media in more depth, particularly for self-disclosure, through an online survey. The study showed that a large proportion of internet-using people with dementia, both those aged below 65 and those aged 65 and older, use social media. Echoing findings from Chapter 3, this study found people with dementia also disclose their dementia identity on social media. Those aged 65 and younger predominantly disclosed their identity to raise awareness, educate others, and engage in peer support, while those aged 65 and older mainly shared their lives with the diagnosis.

The aim of the final study was to adapt 'Who to tell, how and when' for digital delivery, with the adaptation consisting of three steps. Findings from the first step, exploring adaptation preferences, showed that a website was preferred, but making the intervention available in different formats (e.g., PDF workbook) can enhance its accessibility. Furthermore, corroborating existing work on ‘Who to tell, how and when’ (Bhatt et al., 2020) as well as findings from Chapters 3 and 4, implementing peer support elements would be valuable for participants. Finally, credibility of the adaptation is important and can be achieved by providing information on the intervention’s developers and funders. These findings supported the development of the first prototype, and its evaluation highlighted two important aspects. Firstly, the design needed to be clear with appropriate colour contrast and font size to cater to the diverse forms of dementia. Secondly, images had to be carefully evaluated for diversity and non-stigmatizing attitudes. Evaluation of the second prototype showed that the intervention was well-received. Further suggestions for content improvement made by participants are described in section 6.2.3.

6.2.2 Implications of findings for digital adaptation and further development

This thesis was guided by the overall research question *how* the ‘Who to tell, how and when’ intervention can be adapted for digital delivery. As such, findings from Chapter 2 to 5 have informed the adaptation of the original intervention. This resulted in additional content that was not included in the original intervention, as well as recommendations for further development of the digital intervention. Additionally, using a user-centred design ensured that the adaptation was built according to the preferences of people with dementia.

Findings from all studies revealed that educating others about dementia and awareness raising are important factors in the decision to share one’s diagnosis, leading to the expansion of existing exercises and content, such as including

Alzheimer's Society UK factsheet. These factors are closely linked to the stigma of dementia, which was a central theme throughout this thesis.

While Chapters 2 to 4 mainly describe experiences of stigma within personal relationships, findings from Chapter 5 underscore stigmatising attitudes of people with dementia in a broader context, including their portrayal in images and photographs. As the original intervention is conducted face-to-face, the adaptation includes photographs to enhance the visual appeal of the digital platform. Discussions with participants in Chapter 5 prompted a careful evaluation and replacement of photographs initially deemed sufficiently dementia friendly and respectful. Negative depictions of people with dementia in commercial stock images (Harvey & Brookes, 2019), the British press (Brookes et al., 2018), and advertisements (Vermeer et al., 2022) have previously been described. The current research contributes to the existing body of literature by emphasising the importance of also considering negative portrayals of people with dementia in the development of digital interventions.

Finally, Chapter 5 emphasised the importance of incorporating format variety and options to enhance accessibility of the digital intervention, similar to findings discussed by Hoffman et al. (2021) and Yardley et al. (2010). Therefore, the adaptation consisted not only of a workable website, but also included the option of downloading a PDF workbook or requesting a physical option that would be sent to one's address.

Moreover, this thesis highlights several refinements recommended for future developments of the digital platform. Firstly, since Chapters 3 and 4 show the usefulness of social media for disclosure and peer support, the content of the platform can be enhanced by providing additional information on disclosing online and the usefulness of social media for peer support. Secondly, Chapter 3 highlights that disclosing a dementia diagnosis is an evolving journey, with disclosure decisions not limited to the early stages but extending throughout life with dementia. This was further emphasised in the evaluation of the final prototype in Chapter 5. Therefore, future developments benefit from including content aimed at people who have been living with dementia for a while, such as a separate session on 'disclosure throughout the dementia journey'. Finally, Chapter 3 provides evidence for the usefulness of disclosure strategies that do not rely on verbal communication, such as the use of cards stating 'I have dementia' or a lanyard that identifies someone as living with a disability. It is advised that future developments incorporate these non-verbal disclosure options into the platform to cater to diverse communication preferences and specific needs, which can form part of dementia (Banovic et al., 2018). Future testing of the digital adaptation can benefit from including measures exploring aspects such as internalised shame due to self-stigma and efforts to keep the diagnosis secret considering their relationship with feeling comfortable disclosing (Bhatt et al., 2023).

6.3 Findings in the context of existing literature and implications

6.3.1 Self-disclosure of a dementia diagnosis

The results of the systematic review in Chapter 2 and the empirical studies in Chapters 3, 4, and 5 highlight the complexity of self-disclosure, which is often guided by the stigma associated with dementia that people with dementia experience (Alzheimer's Disease International, 2019; Swaffer, 2014). Chapter 2 specifically provided evidence that while individuals may conceal their diagnosis due to experiencing actual unfair treatment, the anticipation of negative treatment appears to have a greater influence on their decision. Both factors, however, can lead to social withdrawal and decreased social activities. The importance of anticipated stigma as a factor influencing self-disclosure has also been described in other concealable stigmatised conditions (Abbott & Mollen, 2018; Cook et al., 2016). While the stigma of dementia has been well-established in dementia research, studies specifically exploring anticipated stigma among people with dementia, using either quantitative or qualitative measures, seem to be limited.

Chapter 2 revealed that research on self-disclosure, particularly in an online context, was lacking. Research has found that the use of digital technologies can be useful for people with dementia to engage in social and leisure activities (Astell et al., 2019) or to support self-management (A. R. Lee, Csipke et al., 2023). The limited number of studies for both self-disclosure and self-disclosure in the online context reveal an important limitation. Chapter 3 and 4 built on these limitations to gather novel insights.

Chapter 3 employed a novel narrative approach to explore self-disclosure in people with dementia. The findings revealed that individuals disclose their diagnosis in spite of or because of stigma, which can enable social support and positively influence their social health. Disclosure on social media is also not uncommon. Individuals may also opt to make themselves visibly known as a person living with dementia, for example, by wearing the hidden disability sunflower lanyard. Chapters 2 and 3 provided evidence that self-disclosure is a multifaceted construct and not a simple ‘yes or no’ question, as has been described in other conditions

(Corrigan, 2005). The decision to disclose was one that needed to be considered continuously. The findings contribute to the existing literature by highlighting that disclosure decisions can evolve over time. Only one longitudinal study was identified in the review in Chapter 2, which did not report any self-disclosure changes over time. Different models aiming to explain how individuals with concealable stigmatised identities construct disclosure decisions have been established (Chaudoir & Fisher, 2010; Greene, 2009; Omarzu, 2000). While comprehensive, none of them consider the duration an individual has held stigmatising attitudes in their disclosure decision-making process.

Findings from Chapter 4 reveal that a large percentage of internet-using people with dementia use social media (54%), and almost half of those (48%) also disclose their diagnosis or share dementia-related information on their accounts, corroborating findings from Chapter 3. While previous research has explored the use of specific social media platforms by people with dementia, such as Facebook (D. Craig & Strivens, 2016), Twitter (Talbot et al., 2020a), or discussion forums (Johnson et al., 2020), the research in Chapter 4 is unique as it represents the largest sample to date to explore the use of a variety of platforms and self-disclosure among people with dementia. Both younger and older individuals use and acknowledge their diagnosis on social media, with younger users seeming to primarily focus on peer support and awareness raising. Similar findings have been reported by other studies acknowledging the value of peer support, including online peer support, and advocacy and awareness raising for people with young-onset dementia (Broders & Wiersma, 2022; Gerritzen et al., 2023; Rabanal et al., 2018).

This suggests that social media is a helpful tool to complement the existing post-diagnostic support for people with dementia.

6.3.2 Social health and disclosure in people with dementia

The social health framework provides the conceptual basis for this thesis, particularly that the development of user-friendly and person-centred technology can enhance participation in meaningful and social activities (domain three of the social health framework). In the course of conducting the research included in this thesis, however, additional pathways have been mapped between self-disclosure and the other two domains of the social health framework, namely 'the capacity to fulfil one's potential and obligations' and 'ability to manage life despite the disease'. Disclosing the diagnosis facilitates opportunities for advocacy and awareness raising, both in-person and online, as revealed in Chapters 2, 3, and 4. These activities can empower individuals to assert their rights abilities as well as foster new connections with like-minded people (Seetharaman & Chaudhury, 2020), thus influencing the individual's capacity to fulfil their potential and obligations. Furthermore, both the systematic review in Chapter 2 and the qualitative study in Chapter 3 highlighted the important role of disclosure in enabling individuals to take control over the narrative surrounding dementia. By openly acknowledging their diagnosis, individuals foster a sense of autonomy, enabling them to make decisions that align with their values and preferences. This aligns with discussions around agency and 'active citizenship' in people with dementia, which suggests that talking about the diagnosis acts as tool to enable opportunities for adjustment (Birt et al., 2017). As such, self-disclosure can also be linked to the ‘the ability to manage life despite the disease’.

While the original description of the social health framework focuses on domains at the individual level (Dröes et al., 2017), recent expansions have included domains on the social environment level to provide a more tangible definition (Vernooij-Dassen et al., 2022). The social environment level focuses on a person’s social context and comprises the following three domains: (1) structure, which pertains to the social ties between individuals in a network; (2) functions, involving actual exchanges between individuals such as emotional support; and (3) appraisal, which relates to the perceived quality of the relationships and interactions. Under this newly-expanded concept of social health, it becomes apparent that a person with dementia’s functioning is contingent not only on their individual capabilities but also on the dynamics of their social environment, which can support or hinder their capacities. The current research underscores the importance of expanding the social health framework to include the social environment level. For example, findings from Chapters 2 and 3 highlight that, while disclosure is often met positively, reactions can also be negative, leading to feelings of rejection and social isolation. This indicates that disclosure is not a precursor for optimal social health, but also relies on the person’s social environment. It is therefore important to consider both levels in the context of self-disclosure of a dementia diagnosis in promoting social health in people with dementia.

6.3 Strengths and limitations

6.3.1 Involvement of people with dementia

As noted in Chapter 1, including the voices of people with dementia was central to this thesis. Each chapter involved people with dementia as either research participants or PPI contributors. In the case of Chapter 4, people with dementia were included as both. The involvement of people with dementia as research participants contributed to a more comprehensive, holistic, and nuanced understanding of their experiences regarding disclosure of a diagnosis for Chapters 3 and 4. In Chapter 5, it ensured that the prototypes were built with end users in mind to enhance their usability and user-friendliness for this population (Rodgers, 2018). Besides involving individuals as research participants, I aimed to enhance the robustness and relevance of this thesis by involving individuals as PPI contributors. Speaking with and hearing from people with dementia about their personal and lived experiences has been an important and valuable contribution to this research for two reasons. Firstly, it adds to the credibility and validity of the research findings by incorporating the perspectives of individuals affected by the subject matter (Gove et al., 2018). Secondly, it contributes to a more comprehensive understanding of the experiences of people with dementia regarding disclosure of a diagnosis.

6.3.2 Internet-mediated research

The online data collection methods that were employed in Chapters 3, 4, and 5 can be considered both a strength and a weakness of this thesis. Compared to face-to-face methods of data collection, the online methods used for the qualitative and quantitative studies enabled the participation of a large number of people with a wide range of experiences. In Chapter 4 in particular I recruited one of the largest samples of people with dementia to date to participate in an online survey to explore their social media use and online self-disclosure. A large sample such as this one contributed to the collection of a wide spectrum of perspectives, especially when it contains a qualitative data collection element (Braun et al., 2021). The online survey also encouraged candid responses as it was anonymous, contributing to the richness of the data. A final strength of conducting internet-mediated research using methods outlined in Chapters 3, 4, and 5 are accessibility and efficiency. Conducting the studies online facilitated overcoming geographical barriers, and participants could complete data collection in their own home and in their own time, adding to a level of convenience. This likely enhances data quality (Braun et al., 2021). However, there are some limitations to conducting research online. The choice of online recruitment and data collection methods likely meant that only a subset of people with dementia was able to participate. While the COVID-19 pandemic and its UK-wide restrictions on in-person contact meant that collecting data online was a requirement (Binder et al., 2023; Sherrington, 2022), it likely presented a barrier for individuals who are unfamiliar or uncomfortable with these methods. As a result, it is likely that some individuals may not have heard about study recruitment or if they did, may have decided against participating.

6.3.3 Diversity

In the course of this thesis, it became evident that recruiting diverse and representative study samples posed a challenge. Unfortunately, the findings, as is often the case in dementia research (Bhatt et al., 2023; Birt et al., 2019; Giebel et al., 2021), are not generalisable to individuals from non-White ethnic backgrounds. Despite efforts to enhance ethnic diversity in Chapter 4 by directly contacting individuals on JDR who identified as being from an ethnic background other than ‘White British’, diversity remained limited. Lack of ethnic diversity is especially relevant considering that stigmatising attitudes may present themselves differently among individuals from ethnic minorities (Eylem et al., 2020), including individuals affected by dementia (Alzheimer’s Disease International, 2019; Herrmann et al., 2018). Differing experiences regarding self-disclosure among ethnic minorities and the importance of including a diverse set of participants were also highlighted by the PPI contributors in Chapter 2.

I also aimed to include a diverse range of participants with varying degrees of openness regarding their diagnosis. Though some participants described changes over time regarding their openness, as described in Chapter 3, all participants in the qualitative studies (Chapters 3, 4, and 5) were comfortable disclosing their diagnosis to others. As a result, the voices of individuals who experience discomfort sharing their diagnosis or actively aim to conceal it and would therefore potentially benefit from the ‘Who to tell, how and when’ intervention, were likely missed. Recognising the limitations outlined in this section, future research would benefit from adopting a more diverse range of strategies for recruitment and data collection to reach a broader range of participants. This could include working with local dementia organisations to advertise studies or including researchers from an ethnic minority background on the research team to enhance ethnic diversity of participants (Brijnath et al., 2022).

Finally, it must be acknowledged that people with dementia who participated in this thesis as research participants and PPI contributors possessed the necessary linguistic abilities and understanding of their impairments to contribute to this research, such as answering questions or sharing their opinions. Given the nature of the research topic, which required individuals to reflect on and express their experiences verbally, those with more severe dementia-related impairments – such as speech and cognitive impairments – or those who have difficulties accepting or discussing their diagnosis were unable to contribute to this research. While the findings hold value in contributing to existing research on self-disclosure of a dementia diagnosis and the development of digital technologies, they are likely only relevant for people in the early to mid-stages of their dementia diagnosis.

6.4 Critical reflections

6.4.1 Involvement of people with dementia

Motivated by the principle that no research *for* people with dementia should be conducted *without* their involvement and drawing from my prior experiences working as a research assistant, it was important to me to include people with dementia as much as possible in this thesis. Consequently, I involved them either as study participants, PPI contributors, or in both capacities, across all chapters. This not only contributes to the limited existing literature on self-disclosure in people with dementia but is also unique since including the voices of people with dementia is often overlooked in research (Morbey et al., 2019). Including the voices of such a large number of people with dementia in this thesis was partly made possible by the online methods for recruitment and data collection that I employed. While these methods were largely a result of the COVID-19 pandemic, their inclusion can be a valuable addition to dementia research as it overcomes geographical barriers and showed that people with dementia were able and confident regarding their internet use, among other things. Reflecting on the involvement of people with dementia, I realised that individuals not only contributed to answering the research questions but also generated ideas that I had not considered. For example, participants in the focus groups engaged in discussions regarding the future implementation of the intervention, improving exercises, or the representation of people with dementia in society, thereby providing novel insights. While their contributions have been invaluable, I acknowledge that the individuals who were able to participate in this thesis only represent a small portion of the existing population of people with dementia and the findings are likely not generalisable (see also section 6.3.3). As the involvement of people with dementia in research is still relatively new (Murphy et al., 2015), and to make sure that people in later stages of their condition are also included, research needs to adapt more diverse methodologies to engage with these groups. These could include the use of communication tools, art- or music-based approaches, and observations to ensure that the voices of people with all forms and stages of dementia are heard (Collins et al., 2022, 2023).

6.4.2 Informed consent

As noted previously, I only involved people with dementia in this thesis who understood the study aims and were able to provide informed consent. While the thesis and research findings show that people with dementia can contribute valuable insights to both qualitative and quantitative studies, I am aware that contributing to research can pose challenges for individuals. This is especially the case in the later stages of dementia when dementia-related impairments affect decision-making, meaningful participation, and capacity to provide informed consent more strongly. As such, I implemented strategies for meaningful inclusion of people with dementia throughout this thesis (Murphy et al., 2015). For example, I provided flexibility regarding the informed consent process: participants in Chapters 3, 4, and 5 were given the option to provide consent online through the Qualtrics platform, print a PDF document to sign and email or post back, or receive a consent form via post with a prepaid return envelope. Additionally, they were able to choose the interview setting, allowing for flexibility in conducting interviews online, over the phone, or in person. I conducted a PPI discussion with members of the EWGPWD to ensure that the study described in Chapter 4, including the Participant Information Sheet and Informed Consent form, were comprehensible for people with cognitive impairments. While UCL provides templates for these forms that are thorough and fulfil the university’s requirements, they can be difficult to read and contain jargon that individuals may not be familiar with. This can be especially challenging for people with dementia. Feedback from the PPI contributors led me to amend the forms, which required approval from the UCL ethics committee. This was granted and I was able to incorporate easier-to-read forms in all subsequent studies, which enhanced the studies’ accessibility. As mentioned previously, a large portion of people with dementia may not be able to provide informed consent; their voices are therefore, unfortunately, excluded from this research.

6.4.3 Aim of ‘Who to tell, how and when’

During the course of this thesis, I was prompted to reflect on the aim of the ‘Who to tell, how and when’ intervention, partly due to questions posed by participants. One question I received from participants in Chapter 5 was if the intervention aimed for complete openness. ‘Who to tell, how and when’ is based on the HOP programme and, as noted in the introductory chapter, the theory of change behind HOP is that supporting disclosure decision-making can alleviate stigma-related stress and self-stigma, which positively affects wellbeing (Scior et al., 2019). Although the theory underpinning this thesis is that reducing self-stigma enhances social health through increasing social participation, this is likely applicable for ‘Who to tell, how and when’, considering the relationship between internalised shame due to stigma and self-stigma and feelings of comfort regarding self-disclosure (Bhatt et al., 2023). The name chosen for the dementia-related version moved away from the original name of ‘Honest, Open, Proud’, as the goal was not to persuade people with dementia to share their diagnosis with everyone but feel empowered in making a disclosure decision that felt comfortable to them. This distinction was not always clear to participants in this thesis. In addition, some people with dementia who took part in the study outlined in Chapter 5 expressed dissatisfaction with the name chosen due to its length. This might require further consideration in the future.

Another question posed by participants was if the intervention required people with dementia and carers to take part in the intervention together. Development of the face-to-face intervention showed joint participation was valuable to both people with dementia and carers (Bhatt et al., 2020). Participants in this thesis seemed to be comfortable with this as well. However, considering that family carers also experience dementia-related stigma (Bhatt et al., 2022), developing a version for family carers might be worth considering.

6.5 Avenues for future research

6.5.1 Stigma resistance

While findings from all Chapter 2 to 5 endorsed the stigma of dementia, it also became apparent that participants disclosed their diagnosis despite these stigmatising perceptions. This thesis suggests varied reasons for self-disclosure, including using it as a means to explain dementia-related symptoms or difficulties and to raise awareness. While advocacy and awareness-raising efforts have been well-documented in dementia research (e.g., Knauss & Moyer, 2006; Seetharaman & Chaudhury, 2020; Weetch et al., 2021), the findings prompt an exploration of questions about additional intrapersonal factors influencing the ability to disclose a dementia diagnosis. A concept that aims to explain how individuals may come to resist stigmatising attitudes is stigma resistance. A conceptual model proposed by Firmin et al. (2017) describes stigma resistance requiring skills and knowledge on a personal, peer, and public level. While the authors do not posit stigma resistance as an innate ability, they do acknowledge that these levels appear sequential, with stigma resistance at the personal level often serving as a prerequisite for resistance at the peer and public level. While stigma resistance has been explored among people with mental health difficulties (Firmin et al., 2016), the concept remains unexplored among people with dementia. With O’Connor et al. (2018) suggesting that acts of disclosure are similar to stigma resistance, and Bhatt et al. (2023)

finding a relationship between self-stigma and disclosure-related comfort, further research on the ability of people with dementia to resist stigma and its correlation with disclosure is warranted.

6.5.2 Digital peer support

A central element of both HOP and the manualised ‘Who to tell, how and when’ intervention is peer support (Bhatt et al., 2020; Scior et al., 2019). In HOP, sessions are group-based and peer-led, with the facilitator having lived experience of mental health difficulties. In ‘Who to tell, how and when’, groups consist of people with dementia and family carers, where peer support was described as comforting and valuable. The importance of peer support for people with dementia was also endorsed in the chapters of this thesis. As the manualised intervention is group-based, it is necessary to consider how the peer support element can be transitioned to an online environment. This aspect was touched upon in Chapter 5, where participants shared their experiences with Zoom and the Alzheimer’s Society’s discussion forum ‘Talking Point’ (https://forum.alzheimers.org.uk/). The findings suggested that offering a variety of options was preferable to cater to a range of needs. Despite the increase in research on online peer support for people with dementia during the COVID-19 pandemic (Gerritzen et al., 2023; Talbot & Coulson, 2023), studies remain limited. Therefore, it is recommended that future research further explores ways in which peer support can be administered, both in the context of ‘Who to tell, how and when’ and in web-based interventions in general.

6.5.3 Digital delivery of ‘Who to tell, how and when’

This thesis proposes low- and mid-fidelity prototypes of a digitalised version of ‘Who to tell, how and when’. As this is the first digitalised version of this intervention and no high-fidelity prototype was developed, it is necessary to develop and evaluate it further. It is recommended that future research incorporates a user-centred design for this development, potentially including a person with dementia as co-researcher who can accompany the process. This could include their input on the development of videos or ensuring that study details, including Participant Information Sheet and Informed Consent form, are comprehensible for people with dementia. While using a free-to-use website creator resulted in the development of usable prototypes, collaborating with an existing software company is advised, as that would result in the development of a fully functioning prototype or product.

6.5.4 Disclosure support for people with dementia in employment

People with concealable stigmatised conditions face particular challenges in the workplace (Brohan et al., 2012). This is also applicable to people with dementia in employment, encompassing issues such as job retention, the impact of symptoms at work, and resulting work performance (Ritchie et al., 2015). Employers may also lack awareness and understanding concerning dementia (Egdell et al., 2021). Due to these unique difficulties, it was decided that this thesis would focus on self-disclosure outside of the workplace. Consequently, the digital adaptation of ‘Who to tell, how and when’ does not include information or support specific to employment-related self-disclosure. Given that a considerable number of individuals receiving the diagnosis are of working age, it is imperative that this population receives adequate support. This involves both training for employers and support with disclosure decision-making. ‘Who to tell, how and when’ could be a valuable resource for the latter. Therefore, careful adaptation of ‘Who to tell, how and when’ for use by this population is advisable. Given the flexibility that delivering an intervention digitally provides, it is recommended that the adaptation for employees should be applicable for both face-to-face and digital delivery.

6.6 Conclusion

This is the first research to explore how the manualised, paper-based ‘Who to tell, how and when’ intervention can be adapted for digital delivery, in the process considerably furthering current understanding of in-person and digital self-disclosure in people with dementia and its relationship with social health. Findings suggest that self-disclosure is a multifaceted and evolving process guided by several factors, including stigma, advocacy, and social support. The research shows that social media are a useful platform for sharing one’s life with dementia, making it a valuable option for post-diagnostic support and enhancing social health. Complementing these findings, a website was developed showcasing a working prototype of the digital version of ‘Who to tell, how and when’. An iterative user-centred design process resulted in an intervention that was endorsed by people affected by people affected by dementia. Further refinements of the digital adaptation should focus on emphasising the value of social media for disclosure, how living with dementia can influence disclosure decisions, and additional strategies for non-verbal disclosure.

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Appendices

Appendix A: Database search strategies

Database: Embase Classic + Embase, from 1947

Search strategy:

1 exp dementia/ (366865)

2 exp Alzheimer disease/ (200000)

3 exp motor neuron disease/ (47547)

4 exp amyotrophic lateral sclerosis/ (39095)

5 exp Huntington chorea/ (27492)

6 exp Parkinson disease/ (157334)

7 exp multiple sclerosis/ (134778)

8 exp traumatic brain injury/ (50462)

9 exp epilepsy/ (257283)

10 exp migraine/ (66397)

11 (dement* or Alzheimer* or "Pick's disease" or "cognitive disorder*" or "vascular dementia" or "Lewy bod* disease*" or "Creutzfeldt–Ja?ob" or "mixed dement*" or "frontotemporal dement*").ti,ab,kw. (321789)

12 ("motor neuron disease*" or "motor neuron disorder*" or "amyotrophic lateral scleros*" or "Lou Gehrig* disease").ti,ab,kw. (38325)

13 Huntington*.ti,ab,kw. (24932)

14 Parkinson*.ti,ab,kw. (175270)

15 "multiple scleros*".ti,ab,kw. (121247)

16 "traumatic brain injur*".ti,ab,kw. (55646)

17 epilep*.ti,ab,kw. (216215)

18 migraine*.ti,ab,kw. (56559)

19 exp self disclosure/ (4618)

20 (diagnosis adj3 (disclos* or conceal* or shar* or communicat* or tell* or talk* or notif* or inform*)).ti,ab,kw. (13992)

21 (disclos* or self-disclos* or non-disclos* or "coming out" or conceal* or self-conceal* or secrecy).ti,ab,kw. (129450)

22 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 (1151511)

23 19 or 20 or 21 (143947)

24 22 and 23 (8078)

Database: Emcare 1995 to present

Search strategy:

1 exp dementia/ (101357)

2 exp Alzheimer disease/ (51065)

3 exp motor neuron disease/ (7765)

4 exp amyotrophic lateral sclerosis/ (6195)

5 exp Huntington chorea/ (3685)

6 exp Parkinson disease/ (27200)

7 exp multiple sclerosis/ (22801)

8 exp traumatic brain injury/ (20347)

9 exp epilepsy/ (34214)

10 exp migraine/ (17569)

11 (dement* or Alzheimer* or "Pick's disease" or "cognitive disorder*" or "vascular dementia" or "Lewy bod* disease*" or "Creutzfeldt–Ja?ob" or "mixed dement*" or "frontotemporal dement*").ti,ab,kw. (88629)

12 ("motor neuron disease*" or "motor neuron disorder*" or "amyotrophic lateral scleros*" or "Lou Gehrig* disease").ti,ab,kw. (5308)

13 Huntington*.ti,ab,kw. (3061)

14 Parkinson*.ti,ab,kw. (27923)

15 "multiple scleros*".ti,ab,kw. (18760)

16 "traumatic brain injur*".ti,ab,kw. (17576)

17 epilep*.ti,ab,kw. (22566)

18 migraine*.ti,ab,kw. (12822)

19 exp self disclosure/ (2045)

20 (diagnosis adj3 (disclos* or conceal* or shar* or communicat* or tell* or talk* or notif* or inform*)).ti,ab,kw. (3611)

21 (disclos* or self-disclos* or non-disclos* or "coming out" or conceal* or self-conceal* or secrecy).ti,ab,kw. (28511)

22 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 (236898)

23 19 or 20 or 21 (31856)

24 22 and 23 (1506)

Database: APA PsycInfo (Ovid), from 1806

Search strategy:

1 exp dementia/ (76947)

2 exp alzheimer's disease/ (46556)

3 exp picks disease/ (276)

4 exp creutzfeldt jakob syndrome/ (722)

5 exp amyotrophic lateral sclerosis/ (3845)

6 exp huntingtons disease/ (3233)

7 exp parkinson's disease/ (24814)

8 exp multiple sclerosis/ (12774)

9 exp traumatic brain injury/ (19546)

10 exp epilepsy/ (27501)

11 exp migraine headache/ (9166)

12 (dement* or Alzheimer* or "cognitive disorder*" or "Pick's disease*" or "vascular dementia" or "Lewy bod* disease*" or "dementia with Lewy bod*" or "Creutzfeldt-Ja#ob" or "mixed dement*" or "frontotemporal dement*").mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (110564)

13 ("motor neuron disease*" or "motor neuron disorder*" or "amyotrophic lateral scleros*" or "Lou Gehrig* disease").mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (6293)

14 Parkinson*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (35735)

15 Huntington*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (5115)

16 "multiple scleros*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (16310)

17 "traumatic brain injur*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (21764)

18 epilep*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (44559)

19 migraine*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (12886)

20 exp self-disclosure/ (7452)

21 exp privacy/ (2575)

22 exp Secrecy/ (599)

23 exp "Sharing (Social Behavior)"/ (1584)

24 (disclos* or self-disclos* or "coming out" or conceal* or self-conceal* or secrecy).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (41987)

25 (diagnosis adj3 (disclos* or conceal* or shar* or communicat* or tell* or talk* or notif* or inform*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] (2457)

26 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 (233294)

27 20 or 21 or 22 or 23 or 24 or 25 (47310)

28 26 and 27 (1716)

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily, from 1946

Search strategy:

1 exp Dementia/ (164554)

2 exp Alzheimer Disease/ (93051)

3 exp Motor Neuron Disease/ (27635)

4 exp Amyotrophic Lateral Sclerosis/ (18743)

5 exp Parkinson Disease/ (66073)

6 exp Huntington Disease/ (12034)

7 exp Multiple Sclerosis/ (58449)

8 exp Brain Injuries, Traumatic/ (14328)

9 exp Epilepsy/ (110763)

10 exp Migraine Disorders/ (27070)

11 (dement* or Alzheimer* or "Pick's disease" or "cognitive disorder" or "vascular dementia" or "Lewy bod*" or "dementia with Lewy bod*" or "Creutzfeldt–Ja?ob" or "mixed dement*" or "frontotemporal dementia").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (244651)

12 ("motor neuron disease*" or "motor neuron disorder*" or "amyotrophic lateral scleros*" or "Lou Gehrig* disease").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary

concept word, rare disease supplementary concept word, unique identifier, synonyms] (32335)

13 Huntington*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (19472)

14 Parkinson*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (128585)

15 "multiple scleros*".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (83016)

16 "traumatic brain injur*".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (37535)

17 epilep*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (162646)

18 migraine*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (39490)

19 exp Self Disclosure/ (7101)

20 exp Disclosure/ (31933)

21 exp Confidentiality/ (52856)

22 (disclos* or self-disclos* or non-disclos* or "coming out" or conceal* or self-conceal* or secrecy).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (113010)

23 (diagnosis adj3 (disclos* or conceal* or shar* or communicat* or tell* or talk* or notif* or inform*)).mp. (8653)

24 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 (707360)

25 19 or 20 or 21 or 22 or 23 (144914)

26 24 and 25 (5236)

Database: CINAHL

Search strategy:

#	Query	Limiters/Expanders	Results
S10	S8 AND S9	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	1,944
S9	S5 OR S6 OR S7	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	51,618
S8	S1 OR S2 OR S3 OR S4	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	249,552
S7	(diagnosis N3 (disclos* OR conceal* OR shar* OR communicat* OR tell* OR talk* OR notif* OR inform*))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	5,266
S6	disclos* OR self-disclos* OR "coming out" OR conceal* OR self-conceal* OR secrecy	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	47,241
S5	(MH "Truth Disclosure") OR (MH "Self Disclosure")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	17,085
S4	Huntington* OR Parkinson* OR "multiple scleros*" OR "traumatic brain injur*" OR epilep* OR migraine*	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	117,167
S3	"motor neuron disease*" OR "motor neuron disorder*" OR "amyotrophic lateral scleros*" OR "Lou Gehrig* disease"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	6,535
S2	dement* OR Alzheimer* OR "Pick's disease" OR "cognitive disorder*" OR "vascular dementia" OR "dementia with Lewy bod*" OR "Lewy bod* disease*" OR Creutzfeldt-Ja?ob OR "mixed dement*" OR "frontotemporal dementia"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	113,356

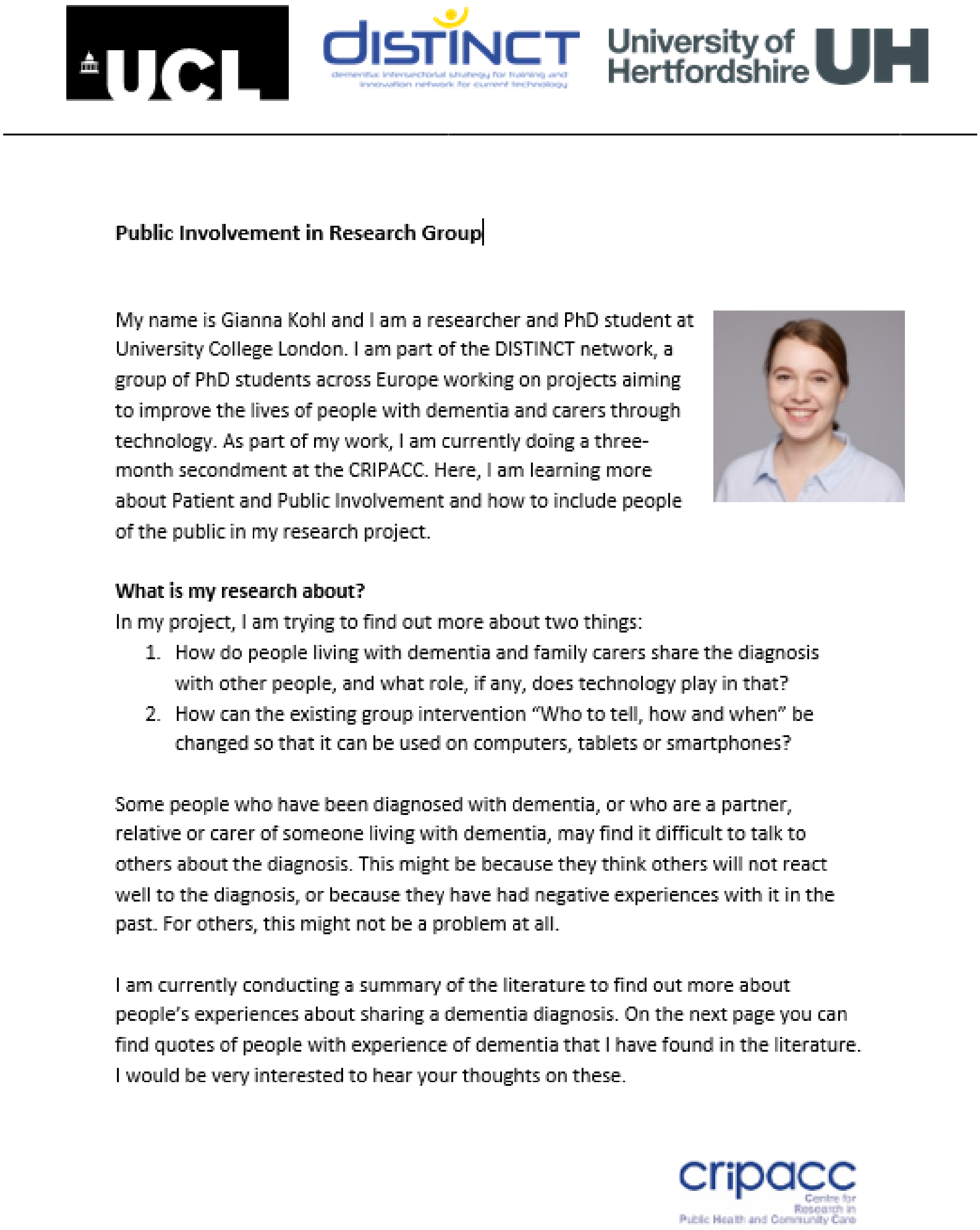
S1	(MH "Dementia+") OR (MH "Motor Neuron Diseases+") OR (MH "Huntington's Disease") OR (MH "Multiple Sclerosis") OR (MH "Brain Injuries+") OR (MH "Epilepsy+") OR (MH "Migraine")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	172,116

Database: SCOPUS

Search strategy:

((TITLE-ABS-KEY(dement* OR Alzheimer* OR "Pick's disease" OR "cognitive disorder" OR "vascular dementia" OR "dementia with Lewy bod*" OR "Lewy bod* disease" OR Creutzfeldt-Ja?ob OR "mixed dementia" OR "frontotemporal dement*")) OR (TITLE-ABS-KEY("motor neuron disease*" or "motor neuron disorder*" or "amyotrophic lateral scleros*" or "Lou Gehrig")) OR (TITLE-ABS-KEY(Huntington*)) OR (TITLE-ABS-KEY(Parkinson*)) OR (TITLE-ABS-KEY("multiple scleros*")) OR (TITLE-ABS-KEY("traumatic brain injur*")) OR (TITLE-ABS-KEY(epilep*))) AND ((TITLE-ABS-KEY(disclos* or self-disclos* or non-disclos* or "coming out" or conceal* or self-conceal* or secrecy)) OR (TITLE-ABS-KEY(diagnosis W/3 (disclos* or conceal* or shar* or communicat* or tell* or talk* or notif* or inform*)))

Appendix B: Information material for PPI groups for Chapter 2



Public Involvement in Research Group

My name is Gianna Kohl and I am a researcher and PhD student at University College London. I am part of the DISTINCT network, a group of PhD students across Europe working on projects aiming to improve the lives of people with dementia and carers through technology. As part of my work, I am currently doing a three-month secondment at the CRIPACC. Here, I am learning more about Patient and Public Involvement and how to include people of the public in my research project.

What is my research about?

In my project, I am trying to find out more about two things:

1. How do people living with dementia and family carers share the diagnosis with other people, and what role, if any, does technology play in that?
2. How can the existing group intervention "Who to tell, how and when" be changed so that it can be used on computers, tablets or smartphones?

Some people who have been diagnosed with dementia, or who are a partner, relative or carer of someone living with dementia, may find it difficult to talk to others about the diagnosis. This might be because they think others will not react well to the diagnosis, or because they have had negative experiences with it in the past. For others, this might not be a problem at all.

I am currently conducting a summary of the literature to find out more about people's experiences about sharing a dementia diagnosis. On the next page you can find quotes of people with experience of dementia that I have found in the literature. I would be very interested to hear your thoughts on these.

1. “I don’t go round telling people I’ve got it because it’s got a horrible sounding name anyhow, Alzheimer’s disease you know, it can make you sound as if you’re very gnarled.” (Person living with dementia)

2. “Veronica said we must tell them at the club … that I have dementia. But I won’t tell them anything […] I think they may yap, yap, yap with everybody that I have dementia.” (Person living with dementia)

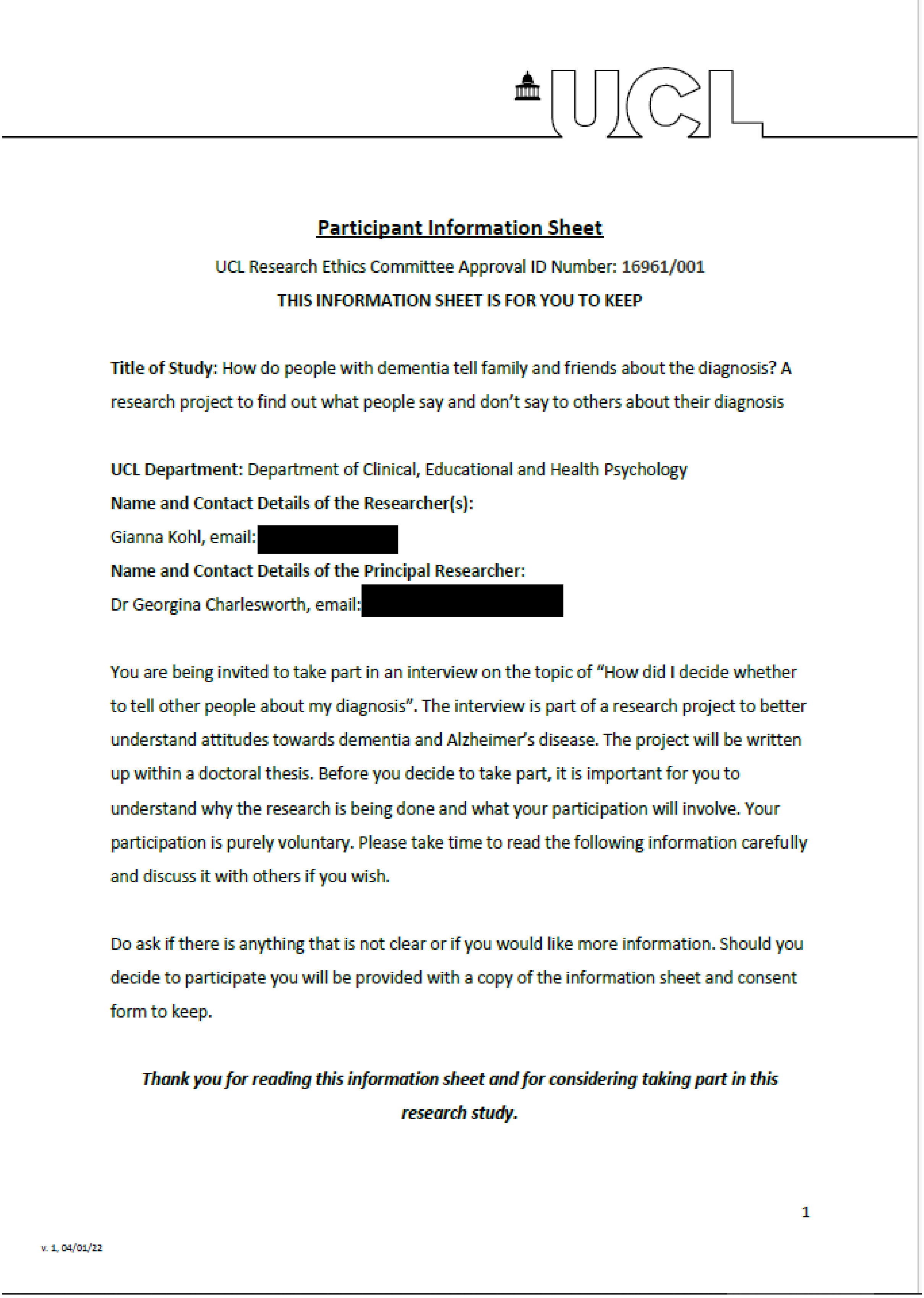
3. “The difficult thing is that no one notices anything … people don’t notice that something is wrong.” (Partner)

4. “My friend, he said, “Should I mention this [diagnosis] to Donnie?” who was a mutual friend. I said, “Oh, that's quite alright.” I said, “Anyone in [local area] that was a friend of mine that you bump into, you can say, “by the way, did you know?” But he wanted to know the parameters too. Who do we tell? Who do we just say we're going to shop?” (Person living with dementia)

5. “I feel it is quite important [to tell] in the sense if they notice that I am doing something that I ought not to be doing, or if I have forgotten something they know it is not deliberate, but something which I have no control over.” (Person living with dementia)

6. I find this very helpful and I put this [badge] on my chest because, as you said, “You don't look like you are a disabled person.” So what I do is, when I go to the banks, because when I talk to strangers I get stressed and I cannot express myself. So with this, automatic when I'm having the problem–I just go–and they seem to be very understanding–clerks, cashiers, and stuff. Once they know that you have difficulty in communication, once you show them that it is not that you're under the influence of something–it's something else–and I show them the card and I find them very helpful.” (Person living with dementia)

Appendix C: Participant information sheet for Chapter 3



Participant Information Sheet

UCL Research Ethics Committee Approval ID Number: 16961/001

THIS INFORMATION SHEET IS FOR YOU TO KEEP

Title of Study: How do people with dementia tell family and friends about the diagnosis? A research project to find out what people say and don't say to others about their diagnosis

UCL Department: Department of Clinical, Educational and Health Psychology

Name and Contact Details of the Researcher(s):

Gianna Kohl, email: [redacted]

Name and Contact Details of the Principal Researcher:

Dr Georgina Charlesworth, email: [redacted]

You are being invited to take part in an interview on the topic of "How did I decide whether to tell other people about my diagnosis". The interview is part of a research project to better understand attitudes towards dementia and Alzheimer's disease. The project will be written up within a doctoral thesis. Before you decide to take part, it is important for you to understand why the research is being done and what your participation will involve. Your participation is purely voluntary. Please take time to read the following information carefully and discuss it with others if you wish.

Do ask if there is anything that is not clear or if you would like more information. Should you decide to participate you will be provided with a copy of the information sheet and consent form to keep.

Thank you for reading this information sheet and for considering taking part in this research study.

1. What is the project's purpose?

The aim of this study is to better understand how people with a diagnosis of dementia decide whether to conceal (hide) or reveal their health status to wider family and social networks. We are also seeking to better understand the consequences of these decisions on the wellbeing of people with dementia.

2. Who can take part?

We would like to interview people who have been diagnosed with an illness associated with dementia, such as Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia or any of the rarer forms of dementia. The interviews are carried out in English, so participants need to be confident enough in the English language to hold a conversation about their decisions, views and attitudes.

3. Do I have to take part?

Participation is entirely voluntary and it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep, and you will be asked to fill out a consent form. You can withdraw from the study at any time without giving a reason why. If you decide to withdraw, you will be asked what you wish to happen to the data you have provided up to that point.

4. What will happen to me if I take part?

If you decide to take part you will be asked to sign a consent form, giving your consent to participate in the study. You will then take part in a one-off interview which will last up to an hour. This will take place over a remote online video call via Zoom or Microsoft Teams in order to comply with COVID-19 regulations. Instructions and advice on accessing and using Zoom or Microsoft Teams will be provided if required. If conducting the interview online proves difficult, the option of a telephone call will be offered. The researcher will conduct the interview, which will be audio-recorded. You will be asked questions about whether, and how, you have chosen to tell others about the dementia diagnosis, and why. You will also be asked how recent the diagnosis is, your gender and ethnicity. At the interview you will be asked whether you would like to receive a preliminary copy of the findings when these are available, and, if so, how you would like to receive this information.

You will be offered a £12 gift card as a token of appreciation for your time following the interview. This will be sent to you via email as an online voucher code. Alternatively, you can request that this is posted to you.

5. Will I be recorded and how will the recorded media be used?

Your interview will be audio recorded so that the researcher captures all the details of what you wish to say. The recording will be typed out ('transcribed'), and the original recording will be deleted. The information that you provide will be used only for the purposes of this project. No other use will be made of it without your written permission, and no one outside the project will be given access to the original recording. Your data will be appropriately anonymised, with care taken to ensure there is no identifying information included in the write-up. Recordings will be kept on a secure UCL server on a password protected account, and will only be kept as long as they are required (likely to be up to two weeks following interview to allow them to be transcribed).

6. What are the possible disadvantages and risks of taking part?

No disadvantages or risks are expected. However, the interviews will include questions about your personal experience of living with dementia which can be an emotional topic. Any unexpected discomfort which arises during the interview should be brought to the researcher's attention. You do not have to answer questions if you would rather not, and interviews can be paused, suspended or ended according to your preference.

7. What are the possible benefits of taking part?

Whilst there are no immediate benefits to taking part in the interviews, we hope that the findings will help increase understanding of the experience of people with dementia. Little is currently known about why people with a dementia diagnosis choose to reveal or conceal their diagnosis.

8. What if something goes wrong?

Should you wish to make a complaint about any aspect of the research study you can do so by contacting the principal investigator Dr Georgina Charlesworth via email at [redacted] If you feel that this complaint has not been handled to your satisfaction, you can contact the chair of the UCL Research Ethics Committee via [redacted]

9. Will my taking part in this project be kept confidential?

Yes, all the information that we collect about you during the course of the research will be kept strictly confidential. Direct quotes from the interviews may be included in reports but there will not be any identifying information. You are free to talk about your participation in the study, should you wish.

10. Limits to confidentiality

The only time when confidentiality is breached is if there is evidence of actual or potential harm to yourself or another. In such cases the University may be obliged to contact relevant statutory bodies/agencies. If this was the case we would inform you of any decisions that might limit your confidentiality. Thus, confidentiality will be respected unless there are compelling and legitimate reasons for this to be breached.

11. What will happen to the results of the research project?

Findings from this research will be written up as part of educational qualifications (a PhD thesis) and will also be submitted for publication in an academic journal(s). A lay summary of findings will be produced, a final version of which will be made available on the UCLUS website (www.ucl.ac.uk/pals/research/clinical-educational-and-health-psychology/research-groups/ucl-unit-stigma-research-uclus).

12. Who is organising and funding the research?

Funding and sponsorship for the research is provided by University College London.

Contact for further information

If you require any more information before deciding on whether to participate in the research, please contact the main researcher:

Ms Gianna Kohl, Email [redacted]

Appendix D: Informed consent form for Chapter 3

Department of Clinical, Educational and Health
Psychology

CONSENT FORM

UCL Research Ethics Committee approval ID: 16961/001

Please ensure that you have read the Participant Information Sheet for the study before completing this form.

Title of study: How do people with dementia tell family and friends about the diagnosis? A research project to find out what people say and don't say to others about their diagnosis

Name and contact details of the researchers:
Main researcher: Gianna Kohl, email: g.kohl@ucl.ac.uk
Principal investigator: Dr Georgina Charlesworth, email [redacted]
Name and contact details of the UCL Data Protection Officer:
Alexandra Potts [redacted]

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 provided with a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking each box below I am consenting to this element of the study. I understand that it will be assumed that unticked 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.

	Tick box
1. I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider this ask questions and have had these answered satisfactorily.	☐
2. I understand that my personal information including age, gender, ethnicity and details disclosed in the interview will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing, and, 'research purposes' will be the lawful basis for processing special category data.	☐

3. I understand that my data will be stored anonymously and securely on a password protected UCL server, that everything I say will remain confidential and that my data will be appropriately pseudonymised to ensure there no identifying information included in any write-up. I understand that confidentiality will be maintained as far as possible, unless during communication the researcher hears anything which makes them concerned that someone might be in danger of harm. If this is the case they might have to inform relevant agencies of this.	☐
4. I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without it affecting any benefits to which I am entitled. 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. I understand that I will be able to withdraw my interview data up to 1 August 2022.	☐
6. I understand the potential risks of participating and the support that will be available to me should I become distressed during the research. I also understand the indirect benefits of participating (to increase knowledge around people with dementia's decision to share the diagnosis and support future people affected by dementia).	☐
7. 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.	☐
8. I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	☐
9. I consent to my interview being audio recorded and transcribed. Direct quotes from the interview may be used in the write-up, but these will not contain any personally identifiable information.	☐
10. I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher: - I have been diagnosed with dementia - I am willing to talk about my experience in an audio-recorded interview in English.	☐
11. I am aware of who I should contact if I wish to lodge a complaint.	☐
12. I understand that my data will be stored in the following timeframes: Recordings: two weeks after they have been taken to allow time for transcription (exact time depends on when data is collected)	☐

Transcripts: up to two years after transcription has taken place to allow for thesis corrections and the possibility of publication; data will be pseudonymised. Personal data (i.e. name and contact details) – September 2022 should you decide to see the preliminary results. If you decide you do not want to see these results, your personal data will be deleted after your interview has taken place. The Information Sheet and Consent Form will be stored electronically on the UCL server. UCL requirements are that data is stored securely for 10 years. There will be no paper records after the project.	
13. I voluntarily agree to take part in this study.	☐

Please tick the box below, if you would like to receive a copy of the study findings:

☐ **I would like to be sent a copy of the preliminary results**

____________________ ______________ ________________

Participant Date Signature

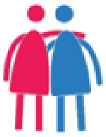
____________________ ______________ ________________

Researcher Date Signature

Appendix E: Participant debrief information for Chapter 3

Participant debriefing

How do people with dementia tell family and friends about the diagnosis? A research project to find out what people say and don't say to others about their diagnosis



Thank you for taking part in this research project.

We hope that you have enjoyed taking part in the interview. There is a possibility it may have got you thinking more about your feelings around the dementia diagnosis and the responses of those around you. If you would like further information, support or advice, you can reach out to the organisations listed below.

Alzheimer's Society UK	Website: https://www.alzheimers.org.uk/ Email: [redacted] Phone: [redacted] (Dementia Connect support line)
Age UK	Website: https://www.ageuk.org.uk/ Email: [redacted] Phone
Dementia UK	Website: https://www.dementiauk.org/get-support/ Dementia Helpline: [redacted]
DEEP - Peer support network	Website: https://www.dementiavoices.org.uk/ Email: [redacted] email address)

Young Dementia Network	Website: https://www.youngdementianetwork.org
Rare Dementia Support	Website: https://www.raredementiasupport.org/ Email: [redacted]
Alzheimer's Research UK	Website: https://www.alzheimersresearchuk.org/ Infoline: [redacted]
CarePlace - Source for care and community services, information and guidance	Website: https://www.careplace.org.uk/ Phone [redacted]
Pathways Through Dementia - Legal and financial support	Website: https://pathwaysthroughdementia.org/ Email: [redacted] Phone
NHS	**Website:** https://www.nhs.uk/conditions/dementia/
Psychological support	If you are feeling worried or low, you can access psychological support through your local Improving Access to Psychological Therapies (IAPT) "Talking Therapies" service. You can find your local IAPT service via the link below where you self-refer online, or you can ask your GP to refer you. https://www.nhs.uk/service-search/psychological-therapies-(IAPT)/locationsearch/10008

If you have any further questions or concerns following your participation in the study, please contact Gianna Kohl via [redacted] or the Principal Researcher, Dr Georgina Charlesworth at [redacted]

Thanks once again for giving up your time to participate.

Appendix F: Demographics questionnaire for Chapter 3

Demographic details' record sheet

How do people with dementia tell family and friends about the diagnosis? A research project to find out what people say and don't say to others about their diagnosis

Thank you for expressing an interest in taking part in this study. We need to collect some information from you.

Age: ……………………………………………………….

Gender: ☐ male ☐ female ☐ other, please specify…………. ☐ rather not say

Ethnicity: ☐ white British ☐ white other ☐ Black British ☐ Asian
☐ other (please specify) …………………

Type of dementia:
……………………………………………………………………………………………………

How long ago were you diagnosed?
☐ 0-6 months ☐ 6 months-1 year ☐ 1-2 years ☐ 2-5 years ☐ more than 5 years

Living situation:

………

To be filled in by researcher:

Would like to receive a summary of the findings: Yes ☐ No ☐

How to receive summary of findings: …………………………..

ID number (for administrative use only): ………………………

The study has been reviewed and approved by the UCL Research Ethics Committee [16961/001]. Any information you provide will only be used for this project. For further information about UCL's privacy notice click here.

Appendix G: Interview topic guide for Chapter 3

1. Since you were told you had dementia, what kinds of conversations do you and people who are close to you, for example, your partner/spouse or friends, have about the diagnosis, between yourselves?

2. Have you told other people about your diagnosis?
    - Have you mentioned your diagnosis on social media? If yes, what information you share? If not, would this be something you would consider?

3. Have you ever decided not to tell others about your dementia? What was the impact of this?
    - When in the company of others, is there anything you (or your partner) do to ‘cover up’ or hide your diagnosis of dementia? Why?

4. What has influenced your decision to tell others/not tell others about your dementia?
   Prompts: Who to tell? How to tell them? When to tell them?
    - What was your view on this?
    - Why did you decide to tell others about your dementia?

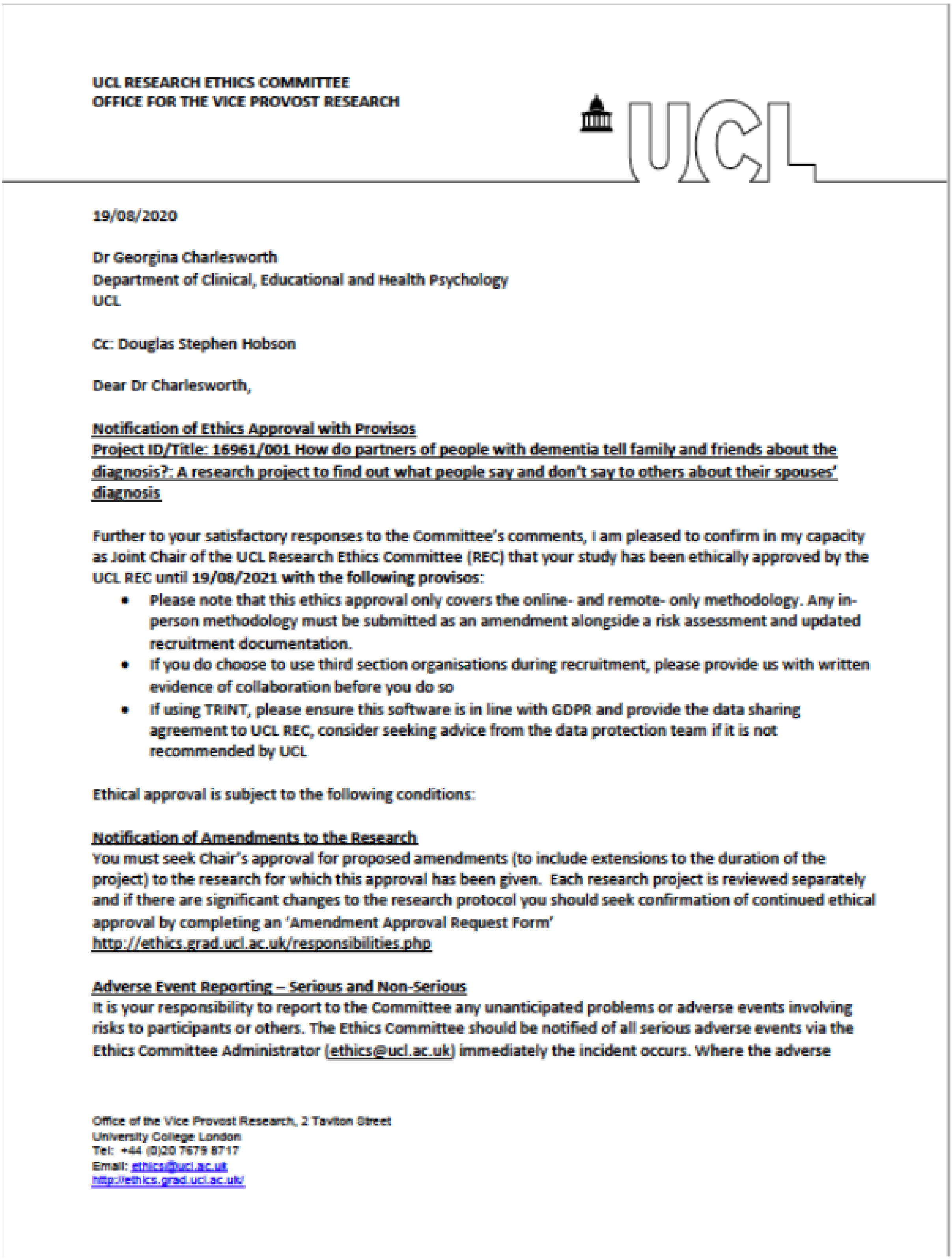
5. What was your experience with telling other people about your dementia?
    - What concerns did you have?
    - What reactions have you had from others?
        a) What were advantages of disclosing the diagnosis in this way?
        b) What were disadvantages of disclosing the diagnosis in this way?

6. How has telling others affected your own wellbeing?
    - How has this affected your day-to-day routine or levels of support?
    - How has telling others affected your partners wellbeing?

7. What kind of support have you had around making the decision to tell others or not tell others?

8. How has your decision to tell others changed over time?

Appendix H: Ethics approval letter for Chapter 3



UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

19/08/2020

Dr Georgina Charlesworth
Department of Clinical, Educational and Health Psychology
UCL

Cc: Douglas Stephen Hobson

Dear Dr Charlesworth,

Notification of Ethics Approval with Provisos
Project ID/Title: 16961/001 How do partners of people with dementia tell family and friends about the diagnosis?: A research project to find out what people say and don't say to others about their spouses' diagnosis

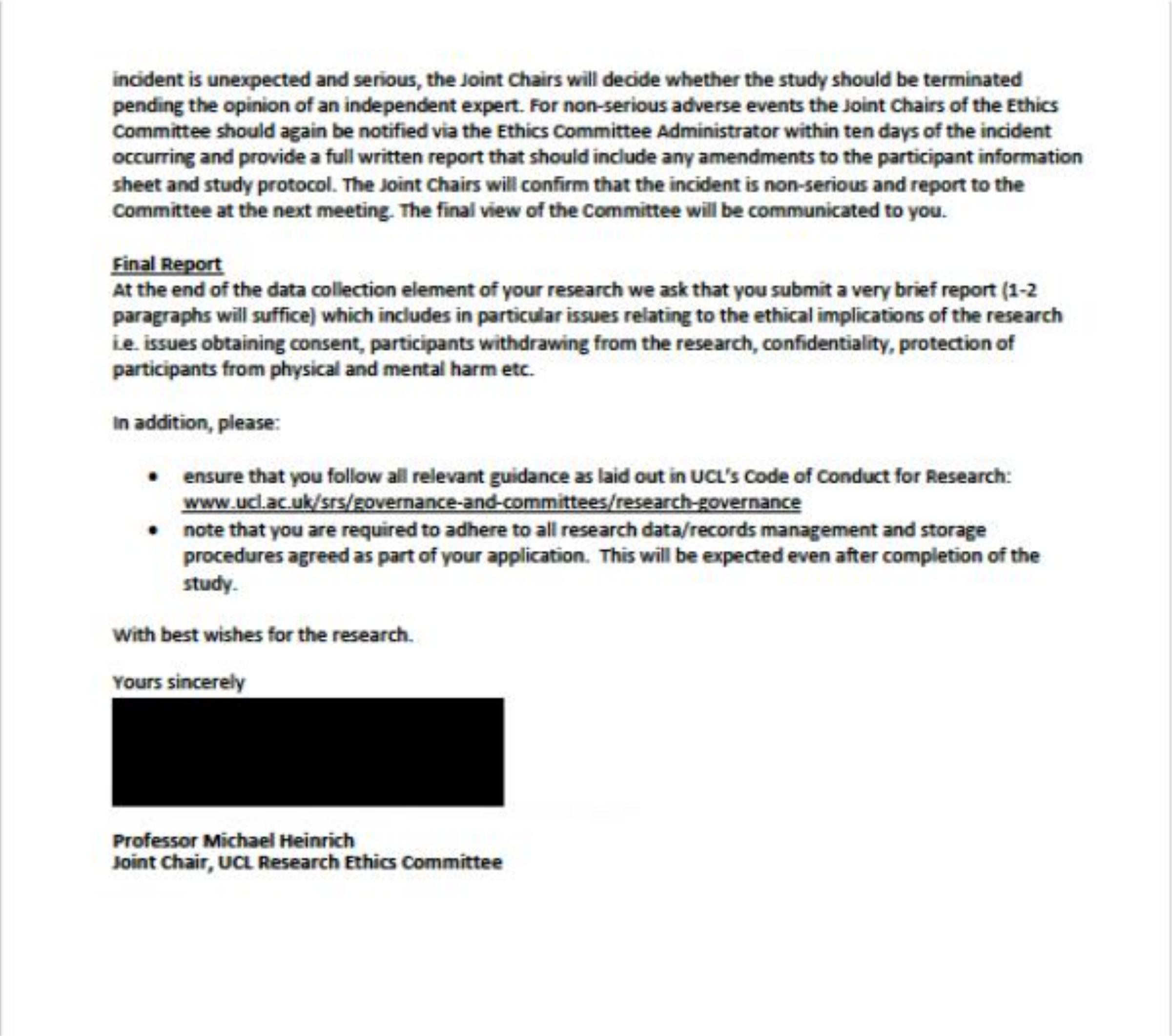
Further to your satisfactory responses to the Committee's comments, I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **19/08/2021 with the following provisos**:

- Please note that this ethics approval only covers the online- and remote- only methodology. Any in-person methodology must be submitted as an amendment alongside a risk assessment and updated recruitment documentation.
- If you do choose to use third section organisations during recruitment, please provide us with written evidence of collaboration before you do so
- If using TRINT, please ensure this software is in line with GDPR and provide the data sharing agreement to UCL REC, consider seeking advice from the data protection team if it is not recommended by UCL

Ethical approval is subject to the following conditions:

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) 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.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: www.ucl.ac.uk/srs/governance-and-committees/research-governance
- 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.

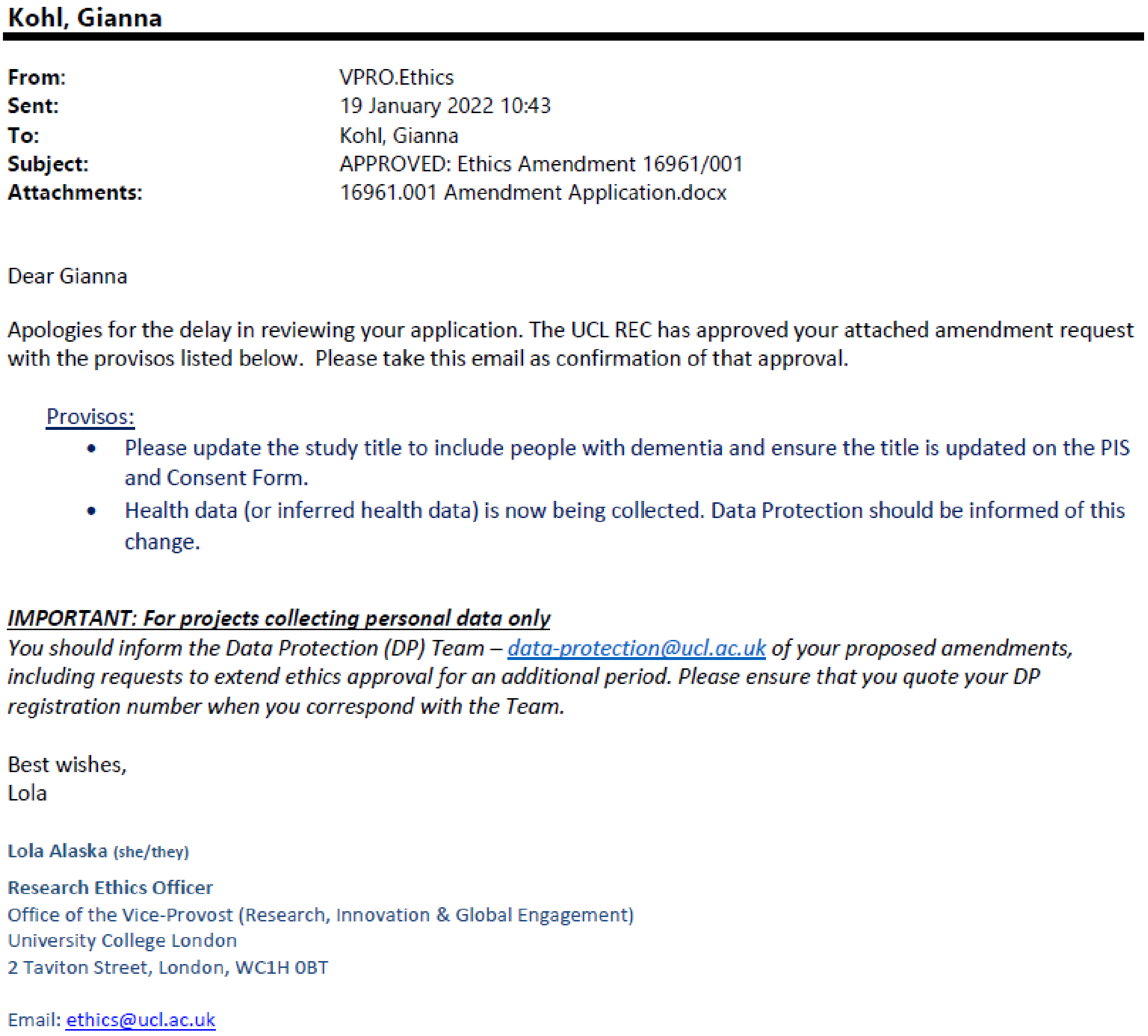
With best wishes for the research.

Yours sincerely

[redacted]

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Appendix I: Ethics amendments approval letter for Chapter 3



Kohl, Gianna

From:	VPRO.Ethics
Sent:	19 January 2022 10:43
To:	Kohl, Gianna
Subject:	APPROVED: Ethics Amendment 16961/001
Attachments:	16961.001 Amendment Application.docx

Dear Gianna

Apologies for the delay in reviewing your application. The UCL REC has approved your attached amendment request with the provisos listed below. Please take this email as confirmation of that approval.

Provisos:

- Please update the study title to include people with dementia and ensure the title is updated on the PIS and Consent Form.
- Health data (or inferred health data) is now being collected. Data Protection should be informed of this change.

IMPORTANT: For projects collecting personal data only
You should inform the Data Protection (DP) Team – data-protection@ucl.ac.uk of your proposed amendments, including requests to extend ethics approval for an additional period. Please ensure that you quote your DP registration number when you correspond with the Team.

Best wishes,
Lola

Lola Alaska (she/they)

Research Ethics Officer
Office of the Vice-Provost (Research, Innovation & Global Engagement)
University College London
2 Taviton Street, London, WC1H 0BT

Email: ethics@ucl.ac.uk

Appendix J: Overview of studies exploring social media use for Chapter 4

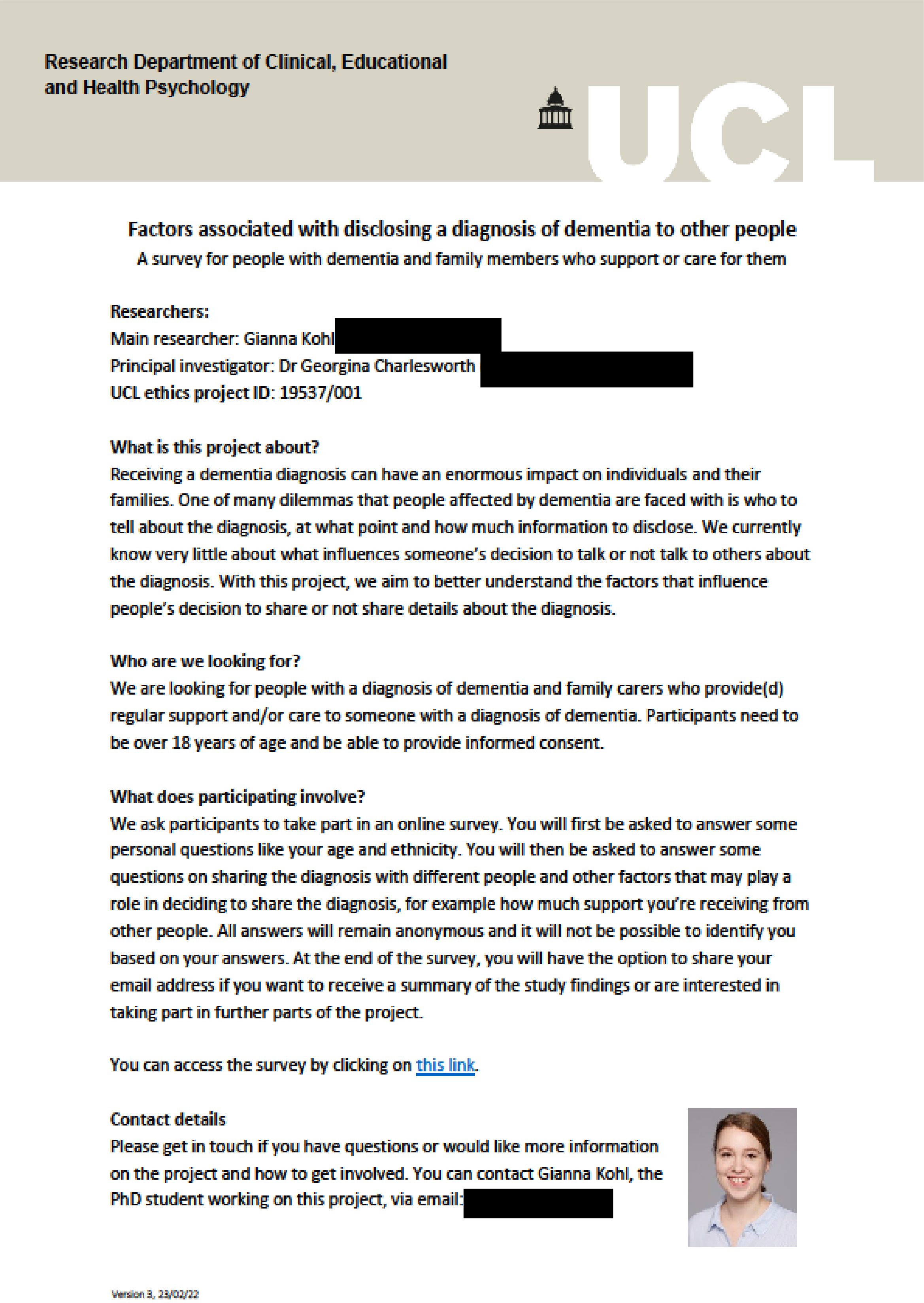
Table A1

Overview of studies exploring social media use by people with dementia

Author and year	Study aims	Design and methods	Participant characteristics
D. Craig and Strivens (2016)	To highlight the usefulness of a Facebook support group for people with young-onset dementia	Descriptive study using secondary data	Group consisted of more than 900 members 80% female; 44% aged 35 to 54, 16% aged 55 to 64; number of people with dementia unknown, large number of care providers likely
Johnson et al. (2022)	To explore how people with dementia and carers provide and receive social support in online spaces	Qualitative study using semi-structured interviews	Four people with dementia, 3 men and 1 woman. Mean age of 62 (range: 50-72)
Johnson et al. (2020)	To explore who posts in an online forum for people with dementia, and what kind of support posters seek to gain	Descriptive study using secondary data	No information about sample size, gender or age
Kannaley et al. (2019)	To thematically analyze blogs written by people with dementia to increase understanding of their experiences	Explorative study using secondary data	19 people with dementia, 12 male, 6 female, and 1 person’s gender unknown; no information about age
Mehta et al. (2020)	To summarize characteristics of Twitter and an online forum to inform recommendations for researchers interested in using these platforms	Mixed-methods study using secondary data	No information about sample size, gender or age of forum and Twitter users

Rodriquez (2013)	To explore how people with young-onset dementia use illness narratives to create community	Descriptive study using secondary data	Post written by 32 users. Gender and age unknown.
Talbot & Coulson (2023)	To explore the content of messages posted on an online discussion forum	Descriptive study using secondary data	Posts written by 251 forum users. Gender and age unknown
Talbot et al. (2020a)	To determine if and how many people with dementia use Twitter and examine their demographic characteristics	Descriptive study using secondary data	30 people with dementia, 17 men and 12 women; one person’s gender unknown. Mean age of 59 (range: 37-88 years)
Talbot et al. (2020b)	To identify how people with dementia use Twitter and the illness identities they create and promote on the platform	Descriptive study using secondary data	12 people with dementia, 8 men and 4 women. Age of four people known (mean age: 60; range: 58-65 years)
Talbot et al. (2021)	To explore why people with young-onset dementia use Twitter and which challenges they face on the platform	Qualitative study using repeated interviews	11 people with young-onset dementia, 8 men and 3 women. Mean age of 60 (range: 48-66 years)
Thomas (2017)	To explore the everyday accounts of two people with dementia on Twitter	Descriptive study using secondary data	One man and one woman diagnosed with young-onset dementia; age unknown

Appendix K: Study information for recruitment for Chapter 4



Research Department of Clinical, Educational
and Health Psychology

UCL

Factors associated with disclosing a diagnosis of dementia to other people

A survey for people with dementia and family members who support or care for them

Researchers:
Main researcher: Gianna Kohl [redacted]
Principal investigator: Dr Georgina Charlesworth [redacted]
UCL ethics project ID: 19537/001

What is this project about?

Receiving a dementia diagnosis can have an enormous impact on individuals and their families. One of many dilemmas that people affected by dementia are faced with is who to tell about the diagnosis, at what point and how much information to disclose. We currently know very little about what influences someone's decision to talk or not talk to others about the diagnosis. With this project, we aim to better understand the factors that influence people's decision to share or not share details about the diagnosis.

Who are we looking for?

We are looking for people with a diagnosis of dementia and family carers who provide(d) regular support and/or care to someone with a diagnosis of dementia. Participants need to be over 18 years of age and be able to provide informed consent.

What does participating involve?

We ask participants to take part in an online survey. You will first be asked to answer some personal questions like your age and ethnicity. You will then be asked to answer some questions on sharing the diagnosis with different people and other factors that may play a role in deciding to share the diagnosis, for example how much support you're receiving from other people. All answers will remain anonymous and it will not be possible to identify you based on your answers. At the end of the survey, you will have the option to share your email address if you want to receive a summary of the study findings or are interested in taking part in further parts of the project.

You can access the survey by clicking on this link.

Contact details

Please get in touch if you have questions or would like more information on the project and how to get involved. You can contact Gianna Kohl, the PhD student working on this project, via email: [redacted]

Version 3, 23/02/22

Appendix L: Email sent to JDR volunteers for Chapter 4

Dear XXX,

My name is Gianna Kohl and I am a PhD student and researcher at University College London. I am getting in touch with you as you have been matched to my study on Join Dementia Research called ‘Factors associated with sharing a diagnosis of dementia with other people’. This study is an online survey through which I am exploring which factors might play a role in someone’s decision to share or not share the dementia diagnosis with other people.

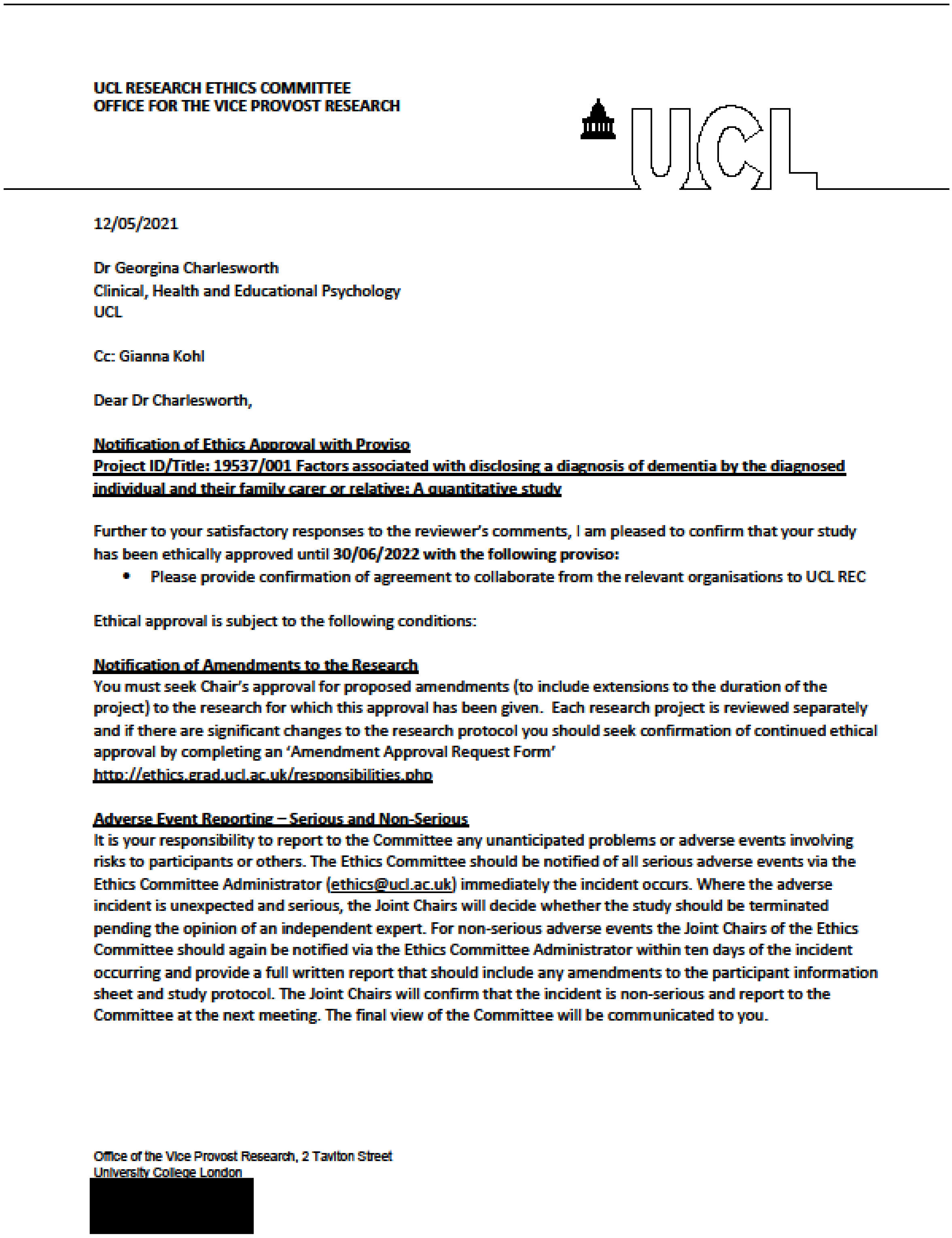
I am especially looking for people with a diagnosis of dementia to take part in the survey. The survey consists of different questionnaires. You can fill it in at home using your computer, mobile phone or tablet, and it takes around 20 minutes to complete. You have the option of pausing the survey and returning to it later. If this interests you or you would like more information, you can access the survey and read more about it by clicking on this link: https://bit.ly/TalkingAboutDementia

Of course, your support would be very valuable to my work but participation is completely voluntary. Please don’t think you have to take part if you don’t want to. If you have taken part already, thank you very much; you don’t have to complete it again.

If you prefer sharing your experiences on this topic in a conversation with me, you can also take part in a remote interview. Please contact me if you would like more information about the interview, or if you have any questions or comments about the survey. Thank you.

Kind regards,
Gianna Kohl

Appendix M: Ethics and amendments approval letters for Chapter 4



UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

12/05/2021

Dr Georgina Charlesworth
Clinical, Health and Educational Psychology
UCL

Cc: Gianna Kohl

Dear Dr Charlesworth,

Notification of Ethics Approval with Proviso
Project ID/Title: 19537/001 Factors associated with disclosing a diagnosis of dementia by the diagnosed individual and their family carer or relative: A quantitative study

Further to your satisfactory responses to the reviewer's comments, I am pleased to confirm that your study has been ethically approved until **30/06/2022 with the following proviso:**

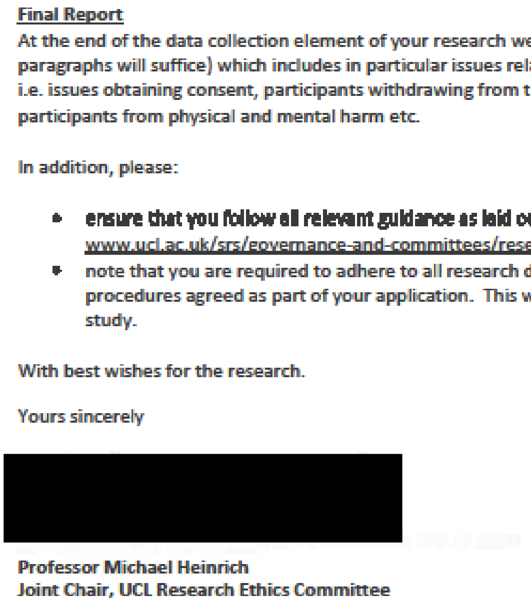
- Please provide confirmation of agreement to collaborate from the relevant organisations to UCL REC

Ethical approval is subject to the following conditions:

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) 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.

Office of the Vice Provost Research, 2 Taviton Street
University College London
[redacted]



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.

In addition, please:

- **ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research:** www.ucl.ac.uk/srs/governance-and-committees/research-governance
- 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

[redacted]

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Kohl, Gianna

From:	VPRO.Ethics
Sent:	30 July 2021 14:50
To:	Kohl, Gianna
Cc:	Charlesworth, Georgina
Subject:	APPROVED: Ethics Amendment 16961/001
Attachments:	Ethics amendments_time_16961-001_signed by GC.docx

Dear Gianna,

Your attached extension request has been approved and has therefore been extended to **19/08/2022.** Please take this email as confirmation of that approval.

IMPORTANT: For projects collecting personal data only
You should inform the Data Protection Team – [redacted] *of your proposed amendments, including requests to extend ethics approval for an additional period.*

Best wishes,

Sagal Elmi

Research Ethics Officer
Office of the Vice-Provost (Research)
University College London
2 Taviton Street, London, WC1H 0BT

[redacted]

Kohl, Gianna

From:	VPRO.Ethics
Sent:	19 January 2022 10:49
To:	Kohl, Gianna
Subject:	APPROVED: Ethics Amendment 19537/001
Attachments:	19537.001 Amendment Application V.2.doc

Dear Gianna

Apologies for the delay in reviewing your application. The UCL REC has approved your attached amendment request with the proviso below. Please take this email as confirmation of that approval.

- Proviso: Please ensure the same title is used across the Participant Information Sheet, consent forms, and recruitment materials.

IMPORTANT: For projects collecting personal data only
You should inform the Data Protection (DP) Team – [redacted] *of your proposed amendments, including requests to extend ethics approval for an additional period. Please ensure that you quote your DP registration number when you correspond with the Team.*

Best wishes,
Lola

Lola Alaska (she/they)

Research Ethics Officer
Office of the Vice-Provost (Research, Innovation & Global Engagement)
University College London
2 Taviton Street, London, WC1H 0BT

[redacted]

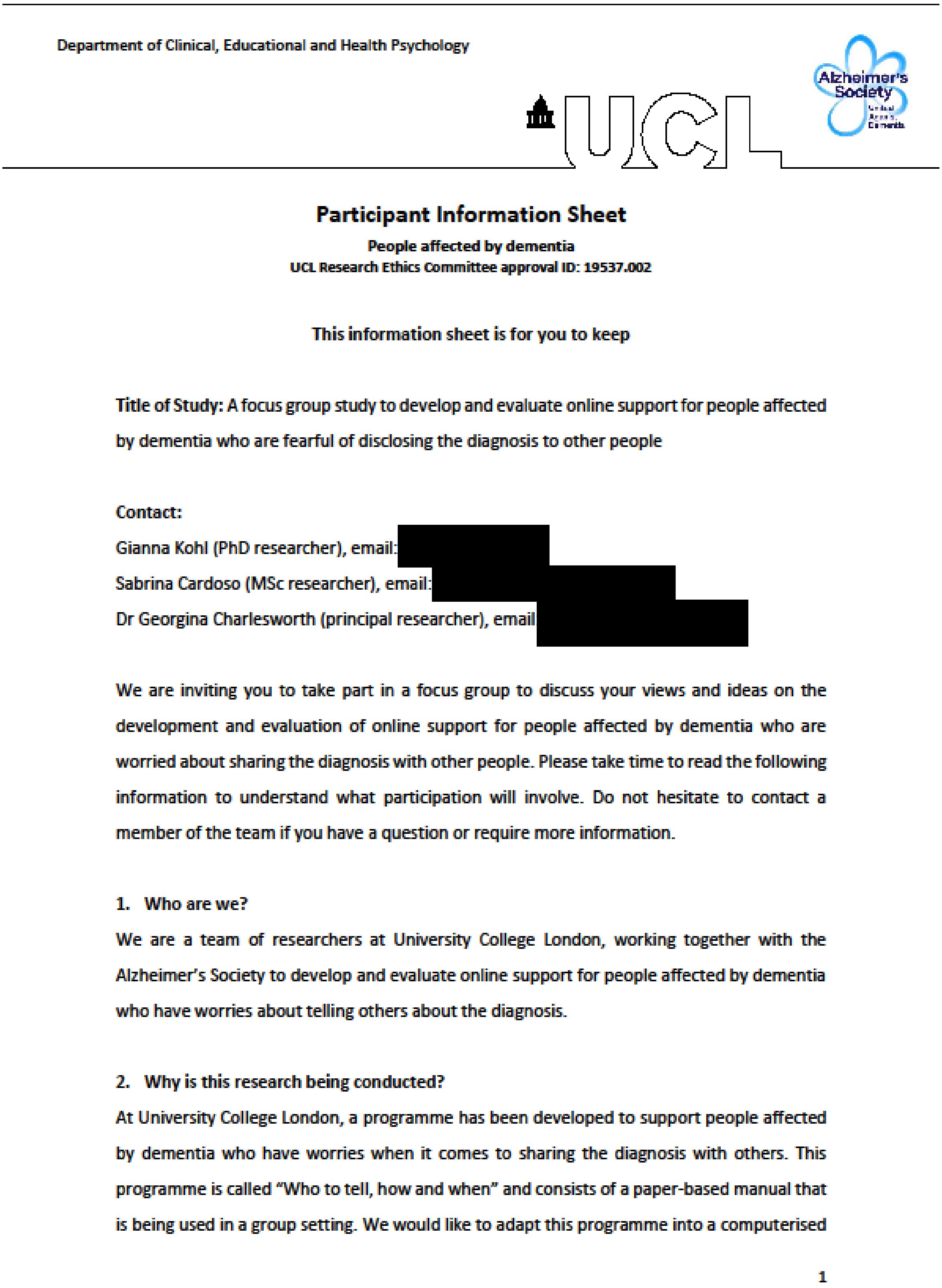
Appendix N: Examples quotes from survey respondents for Chapter 4

Table A2

Examples of quotes from survey respondents ($n = 37$)

Disclosure purpose	Quotes
Advocacy and awareness	
Dementia in general	*"Anything around Dementia"*
Personal advocacy work	*"As I am an active advocate, on various dementia-related committees & have made many presentations, I am an open book, so to speak. This is the only way to combat stigma."*
Fundraising	*"I've shared when people are raising money for it to help find a cure for it"*
Dementia events	*"events and taking part opportunities"*
Awareness campaigns	*"awareness raising videos, video clips"*
Research findings	*"Information about dementia and research"*
Research opportunities	*"research opportunities"*
Answering questions	*"Answered questions on Dementia"*
News	*"news items"*
Thoughts on stigma	*"I've shared … my thoughts on issues such as stigma"*
The dementia journey	
Living with dementia	*"Things that I am doing and sometimes the difficulties I have"*
Own diagnosis	*"Private Facebook page, I advised extended friends of my diagnosis (ie relatives & close friends were advised by my wife in person or by phone)"*
Explaining symptoms	*"Declare my dementia to help people understand I may be a little slow on uptake or forget or need facts repeated"*
Mental state	*"My own mental condition and mental state"*
Living well with dementia	*"also positive things about what I can still do!"*
Poetry	*"I write Poems about Living/Coping with Dementia"*
Crafts	*"I like to craft, so I have shared my skills on different platforms"*
Peer support	
Support group information	*"Meeting details, Discussion Groups around Dementia"*
For others affected by dementia	*"support for others"*
For oneself	*"people i regularly talk to on social media know i have dementia and help me with any problems I might have"*

Appendix O: Participant information sheet for Chapter 5



Department of Clinical, Educational and Health Psychology

Participant Information Sheet

People affected by dementia
UCL Research Ethics Committee approval ID: 19537.002

This information sheet is for you to keep

Title of Study: A focus group study to develop and evaluate online support for people affected by dementia who are fearful of disclosing the diagnosis to other people

Contact:
Gianna Kohl (PhD researcher), email: [redacted]
Sabrina Cardoso (MSc researcher), email: [redacted]
Dr Georgina Charlesworth (principal researcher), email [redacted]

We are inviting you to take part in a focus group to discuss your views and ideas on the development and evaluation of online support for people affected by dementia who are worried about sharing the diagnosis with other people. Please take time to read the following information to understand what participation will involve. Do not hesitate to contact a member of the team if you have a question or require more information.

1. Who are we?

We are a team of researchers at University College London, working together with the Alzheimer's Society to develop and evaluate online support for people affected by dementia who have worries about telling others about the diagnosis.

2. Why is this research being conducted?

At University College London, a programme has been developed to support people affected by dementia who have worries when it comes to sharing the diagnosis with others. This programme is called "Who to tell, how and when" and consists of a paper-based manual that is being used in a group setting. We would like to adapt this programme into a computerised

Optional:

If you would like to receive a summary of the study findings, please tick this box: ☐

Optional

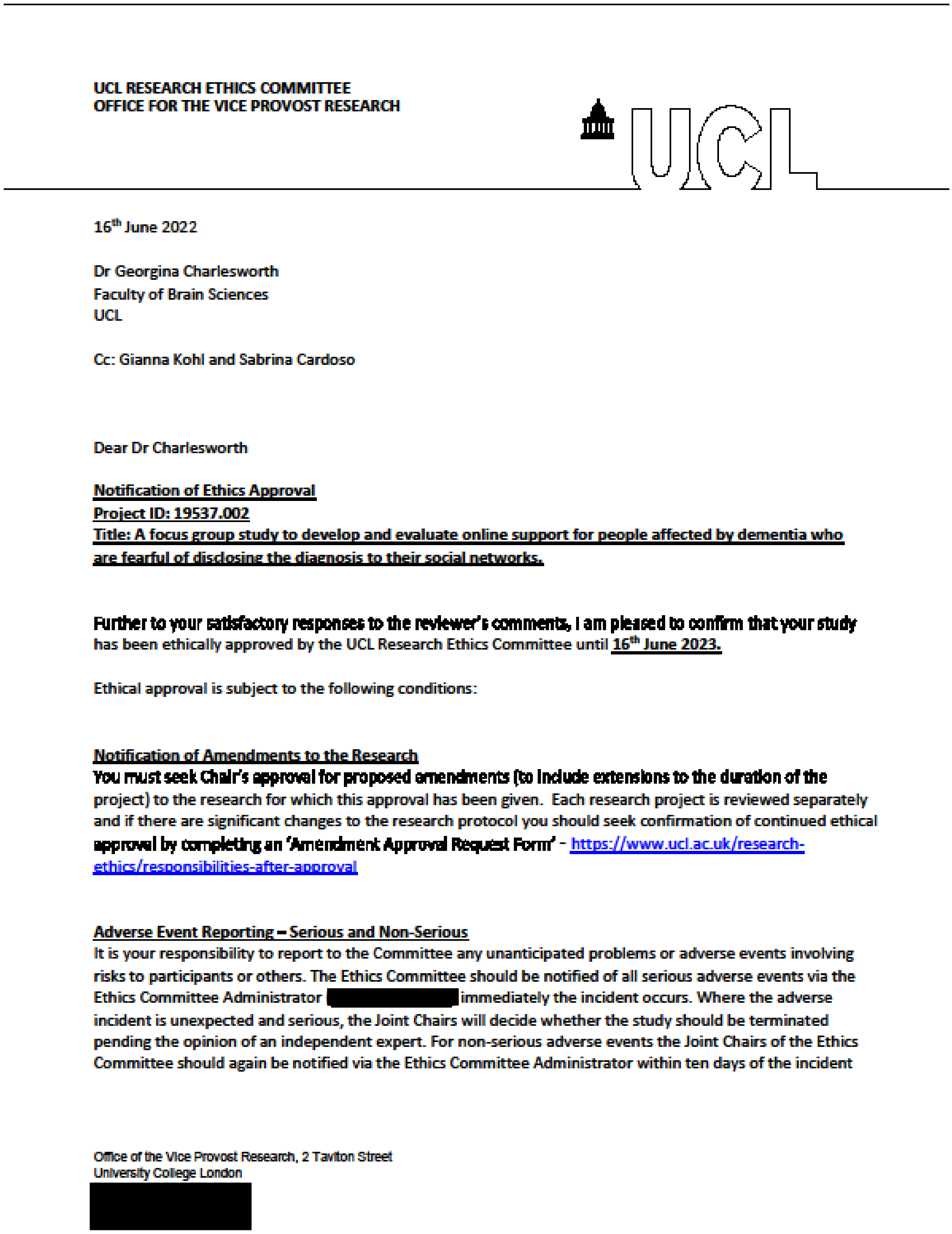
You can let us know below if you are interested in being contacted again by UCL researchers to take part in a follow-up focus group for this project or in future studies of a similar nature:

☐ Yes, I would be happy to be contacted in this way.

☐ No, I would not like to be contacted.

____________________	____________	_________________
Name of participant	Date	Signature
____________________	____________	_________________
Name of researcher	Date	Signature

Appendix P: Ethics approval letter for Chapter 5



UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

16th June 2022

Dr Georgina Charlesworth
Faculty of Brain Sciences
UCL

Cc: Gianna Kohl and Sabrina Cardoso

Dear Dr Charlesworth

Notification of Ethics Approval
Project ID: 19537.002
Title: A focus group study to develop and evaluate online support for people affected by dementia who are fearful of disclosing the diagnosis to their social networks.

Further to your satisfactory responses to the reviewer's comments, I am pleased to confirm that your study has been ethically approved by the UCL Research Ethics Committee until **16th June 2023.**

Ethical approval is subject to the following conditions:

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'** – https://www.ucl.ac.uk/research-ethics/responsibilities-after-approval

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 [redacted] 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

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University College London
[redacted]

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.

In addition, please:

- **ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for 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.

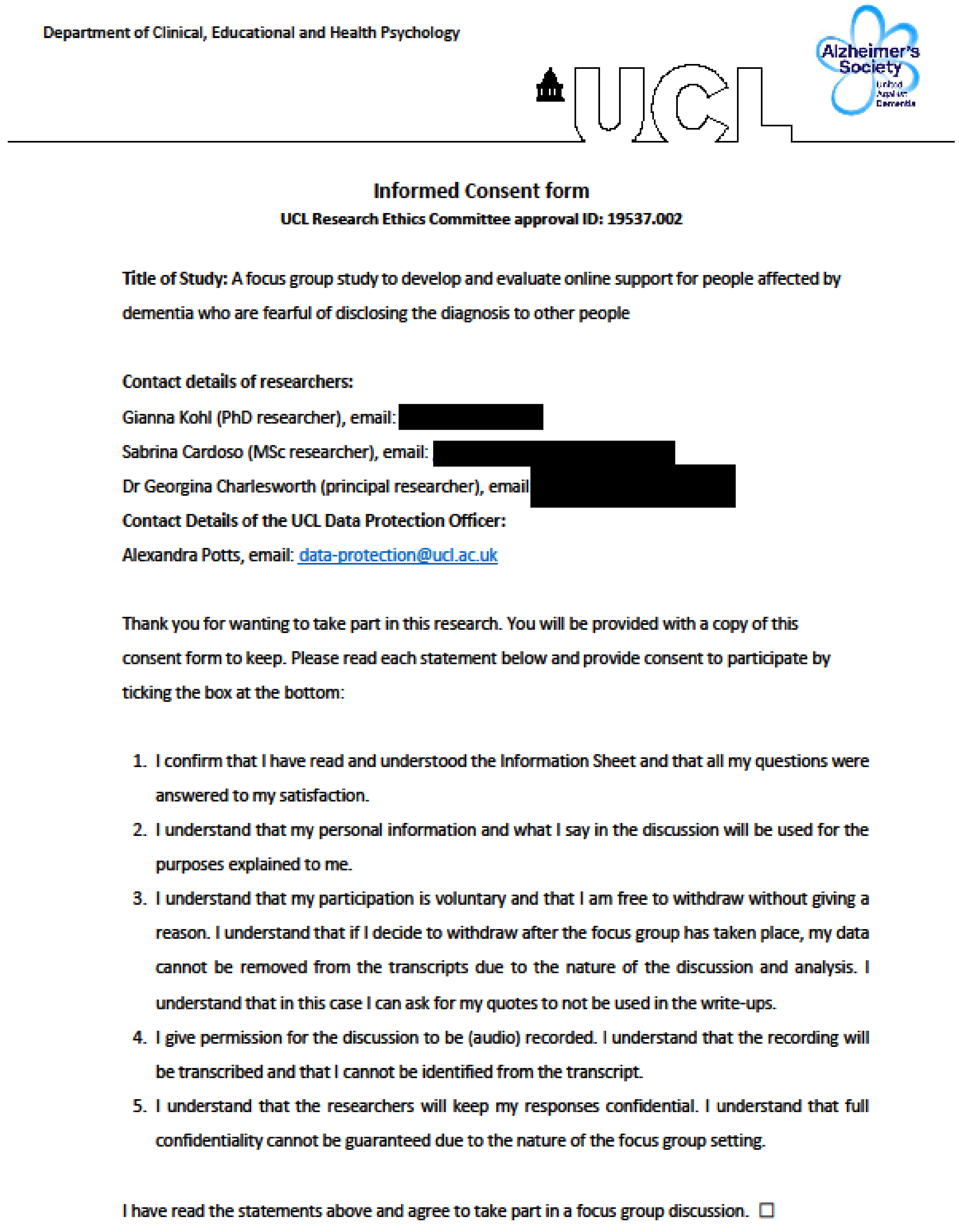
Yours sincerely

[redacted]

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Office of the Vice Provost Research, 2 Taviton Street
University College London
[redacted]

Appendix Q: Informed consent form for Chapter 5



Department of Clinical, Educational and Health Psychology

Informed Consent form

UCL Research Ethics Committee approval ID: 19537.002

Title of Study: A focus group study to develop and evaluate online support for people affected by dementia who are fearful of disclosing the diagnosis to other people

Contact details of researchers:

Gianna Kohl (PhD researcher), email: [redacted]
Sabrina Cardoso (MSc researcher), email: [redacted]
Dr Georgina Charlesworth (principal researcher), email [redacted]
Contact Details of the UCL Data Protection Officer:
Alexandra Potts, email: data-protection@ucl.ac.uk

Thank you for wanting to take part in this research. You will be provided with a copy of this consent form to keep. Please read each statement below and provide consent to participate by ticking the box at the bottom:

1. I confirm that I have read and understood the Information Sheet and that all my questions were answered to my satisfaction.
2. I understand that my personal information and what I say in the discussion will be used for the purposes explained to me.
3. I understand that my participation is voluntary and that I am free to withdraw without giving a reason. I understand that if I decide to withdraw after the focus group has taken place, my data cannot be removed from the transcripts due to the nature of the discussion and analysis. I understand that in this case I can ask for my quotes to not be used in the write-ups.
4. I give permission for the discussion to be (audio) recorded. I understand that the recording will be transcribed and that I cannot be identified from the transcript.
5. I understand that the researchers will keep my responses confidential. I understand that full confidentiality cannot be guaranteed due to the nature of the focus group setting.

I have read the statements above and agree to take part in a focus group discussion. ☐

Optional:

If you would like to receive a summary of the study findings, please tick this box: ☐

Optional

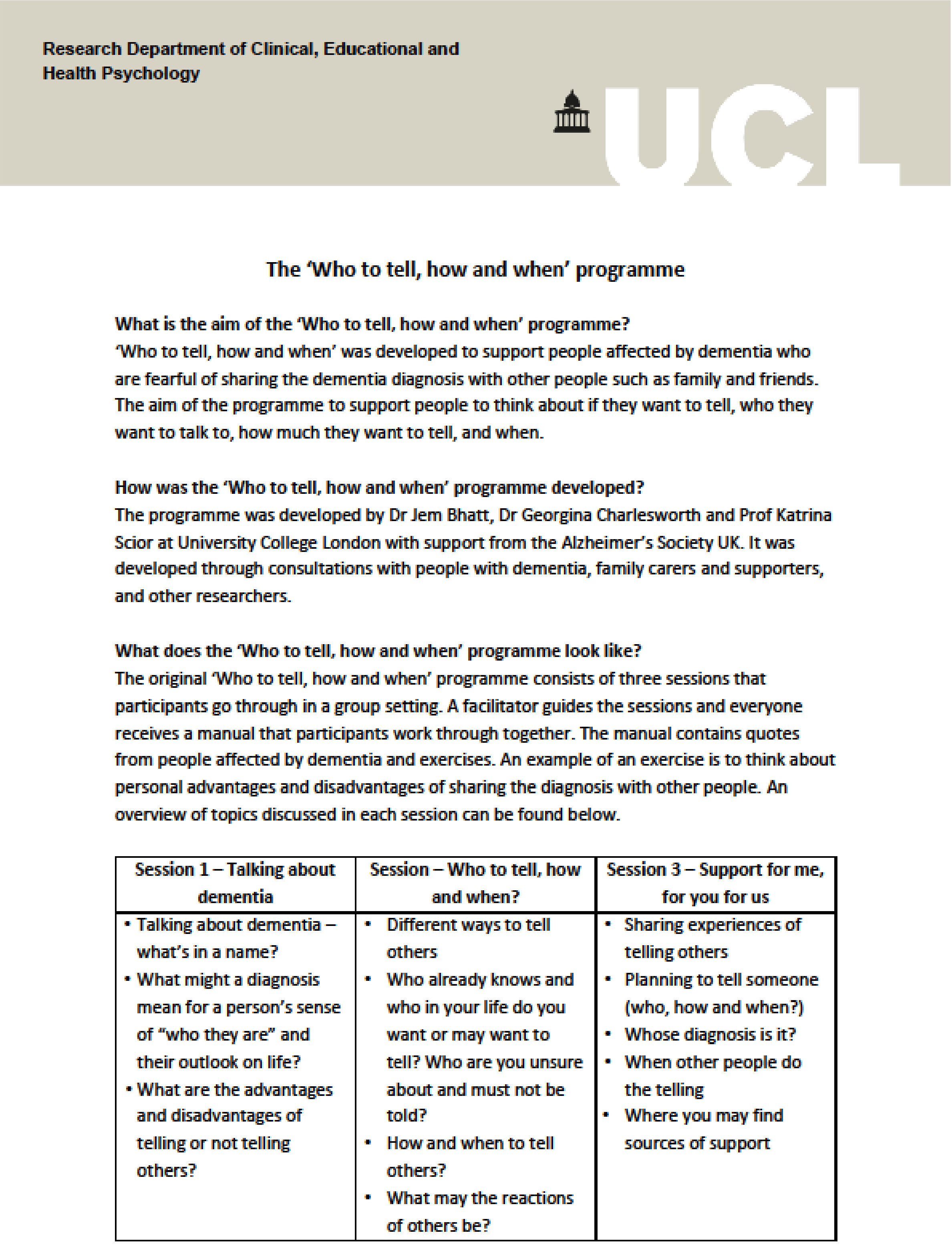
You can let us know below if you are interested in being contacted again by UCL researchers to take part in a follow-up focus group for this project or in future studies of a similar nature:

☐ Yes, I would be happy to be contacted in this way.

☐ No, I would not like to be contacted.

Name of participant	Date	Signature
Name of researcher	Date	Signature

Appendix R: ‘Who to tell, how and when’ information for Chapter 5



Research Department of Clinical, Educational and
Health Psychology

The ‘Who to tell, how and when’ programme

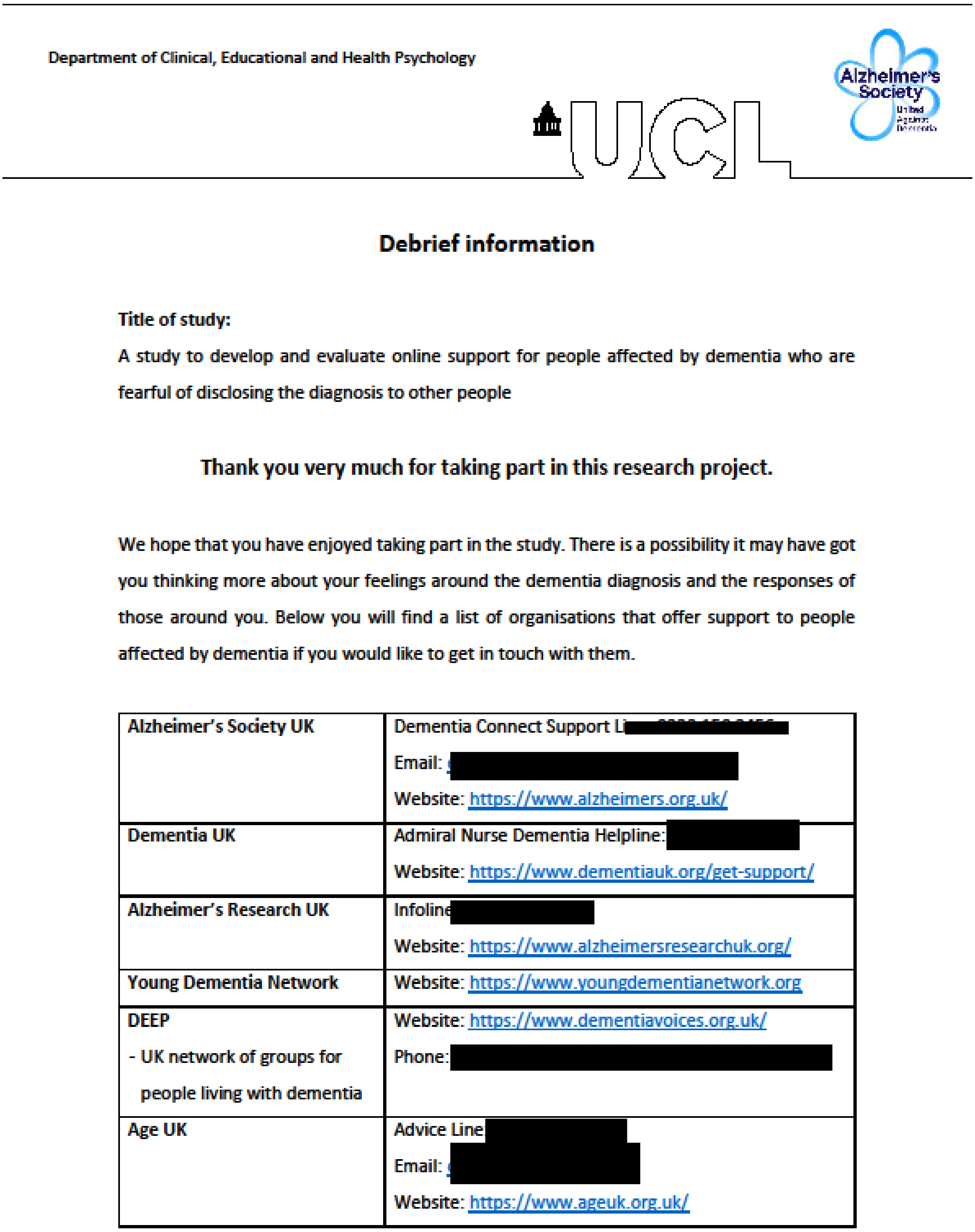
What is the aim of the ‘Who to tell, how and when’ programme?
‘Who to tell, how and when’ was developed to support people affected by dementia who are fearful of sharing the dementia diagnosis with other people such as family and friends. The aim of the programme to support people to think about if they want to tell, who they want to talk to, how much they want to tell, and when.

How was the ‘Who to tell, how and when’ programme developed?
The programme was developed by Dr Jem Bhatt, Dr Georgina Charlesworth and Prof Katrina Scior at University College London with support from the Alzheimer’s Society UK. It was developed through consultations with people with dementia, family carers and supporters, and other researchers.

What does the ‘Who to tell, how and when’ programme look like?
The original ‘Who to tell, how and when’ programme consists of three sessions that participants go through in a group setting. A facilitator guides the sessions and everyone receives a manual that participants work through together. The manual contains quotes from people affected by dementia and exercises. An example of an exercise is to think about personal advantages and disadvantages of sharing the diagnosis with other people. An overview of topics discussed in each session can be found below.

Session 1 – Talking about dementia	Session – Who to tell, how and when?	Session 3 – Support for me, for you for us
• Talking about dementia – what’s in a name? • What might a diagnosis mean for a person’s sense of “who they are” and their outlook on life? • What are the advantages and disadvantages of telling or not telling others?	• Different ways to tell others • 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? • How and when to tell others? • What may the reactions of others be?	• Sharing experiences of telling others • Planning to tell someone (who, how and when?) • Whose diagnosis is it? • When other people do the telling • Where you may find sources of support

Appendix S: Participant debrief information for Chapter 5



Department of Clinical, Educational and Health Psychology

Debrief information

Title of study:

A study to develop and evaluate online support for people affected by dementia who are fearful of disclosing the diagnosis to other people

Thank you very much for taking part in this research project.

We hope that you have enjoyed taking part in the study. There is a possibility it may have got you thinking more about your feelings around the dementia diagnosis and the responses of those around you. Below you will find a list of organisations that offer support to people affected by dementia if you would like to get in touch with them.

Alzheimer's Society UK	Dementia Connect Support Li[redacted] Email: [redacted] Website: https://www.alzheimers.org.uk/
Dementia UK	Admiral Nurse Dementia Helpline: [redacted] Website: https://www.dementiauk.org/get-support/
Alzheimer's Research UK	Infoline[redacted] Website: https://www.alzheimersresearchuk.org/
Young Dementia Network	Website: https://www.youngdementianetwork.org
DEEP - UK network of groups for people living with dementia	Website: https://www.dementiavoices.org.uk/ Phone: [redacted]
Age UK	Advice Line[redacted] Email: [redacted] Website: https://www.ageuk.org.uk/

CarePlace - Information on care and community services	The Silver Line [redacted] Website: https://www.careplace.org.uk/
Pathways Through Dementia - Legal and financial support	Legal Helpline [redacted] Email: [redacted] Website: https://pathwaysthroughdementia.org/

Where can I find information on the results of this study?

If you have provided your email address to be informed about the findings of this study, we will contact you after the study has been completed. In addition, you can learn more about the study results by visiting the University College London Unit for Stigma research (UCLUS) website at https://www.ucl.ac.uk/stigma-research

Thank you again for your participation.

Appendix T: Topic guide for step 1 of Chapter 5

Introduction

- Thank you for agreeing to take part in this focus group discussion.
- Repeat main points of consent form. Ask: You have all read the consent form and are still happy to take part?
- The aim of today's focus group is to have a discussion around using technology and the development of technology to support people affected by dementia in sharing the diagnosis with other people
- Sabrina and I will lead the discussion. There are no right or wrong answers. We are just interested in your ideas and opinions.
- We would like to record this session to make sure we get an accurate record of what was said. Then it will be transcribed and deleted. Everything you say will remain anonymous – all names will be removed and it won't be possible to identify you in the write-ups
- We want to remind you to please respect everyone's privacy and not repeat what is discussed to people outside of the group. Also, we ask that everyone please speak one at a time so we can hear what each person is saying.
- Does anyone have any questions before we start? Is everyone okay with having the session recorded?

Introducing ourselves:

Let's start by introducing ourselves. If you could tell us your name and maybe where you are based if you want.

Description of research

To start, we would like to tell you a bit about the research we are doing. I'll be sharing one slide for this. So, we are in the process of developing an online version of the "Who to tell, how and when" programme.

Over the next few months, we will be testing out this online programme with people with dementia and their informal carers as part of a focus group study. We hope this online programme will be a useful alternative to face-to-face for people affected by dementia who feel uncomfortable participating in a group-based intervention or who would like to take part in the comfort of their own home.

Perceived usefulness

1. Do you see any value in having a digital version of the 'Who to tell, how and when' intervention?

Format/platform

1. What are your thoughts on a website where you can download a PDF manual (all in one document)?
    - Would this be helpful or unhelpful?
2. What are your thoughts on a website where you can access the manual by clicking on different tabs instead of a PDF manual?
    - Would this be helpful or unhelpful?
3. What are your thoughts on a PDF manual sent via email instead of accessing a website?
    - Would this be helpful/unhelpful?
4. What are your thoughts on having an app on a smartphone where you can access the manual?
    - Would this be helpful/unhelpful?
5. What are your thoughts on having a hybrid version of the 'Who to tell, how and when' intervention? E.g., having both Zoom group sessions and some in-person group sessions?
    - Would this be helpful/unhelpful?

Peer support

1. Do you see any value in having discussions with other people affected by dementia who are also wary of disclosing the diagnosis?
2. What are your thoughts on using Zoom for this (with a facilitator)?
    - If so…
    - With cameras on or off?
    - Using your real name or a fictitious name? (pseudonym)
        - Is remaining anonymous important to you?
3. What are your thoughts on a discussion website (forum) where you can talk to other people affected by dementia about disclosing the diagnosis?

- Would this be helpful/unhelpful?

4. What are your thoughts on having the option of online peer support meetings?
5. Would you like to have the option of going through the intervention individually without the peer support?

Perceived ease of use

When the pandemic initially hit, how did you find using video call technologies like Zoom?

- Were there any challenges?
- Were there any benefits?

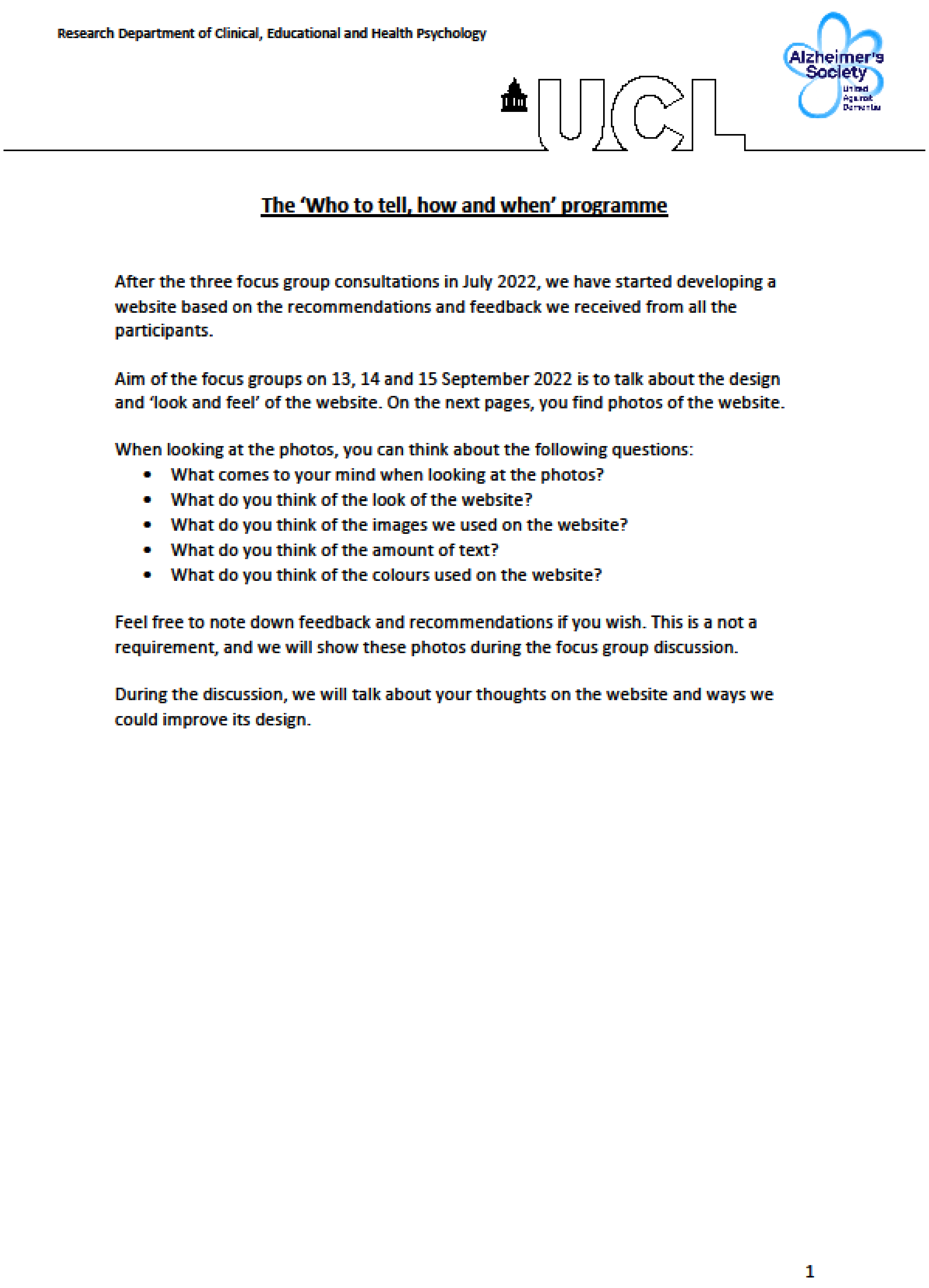
1. What are your thoughts on creating a profile with an email address and password to access the content on a website?

    - Could this be complicated for people with dementia who might forget their log-in information?
    - What about anonymity? E.g., creating a profile name

Credibility

1. Would it make a difference if a digital intervention was created in collaboration with the Alzheimer’s Society/any other dementia organisation?
    - (i.e., Would a collaboration with a dementia organisation make you more likely to trust/use the digital intervention?)
        - What about being on the NHS website?
        - What about being on the UCL website?

Appendix U: Mock-ups for participants of step 2 of Chapter 5



Research Department of Clinical, Educational and Health Psychology

UCL

Alzheimer's Society
United Against Dementia

The 'Who to tell, how and when' programme

After the three focus group consultations in July 2022, we have started developing a website based on the recommendations and feedback we received from all the participants.

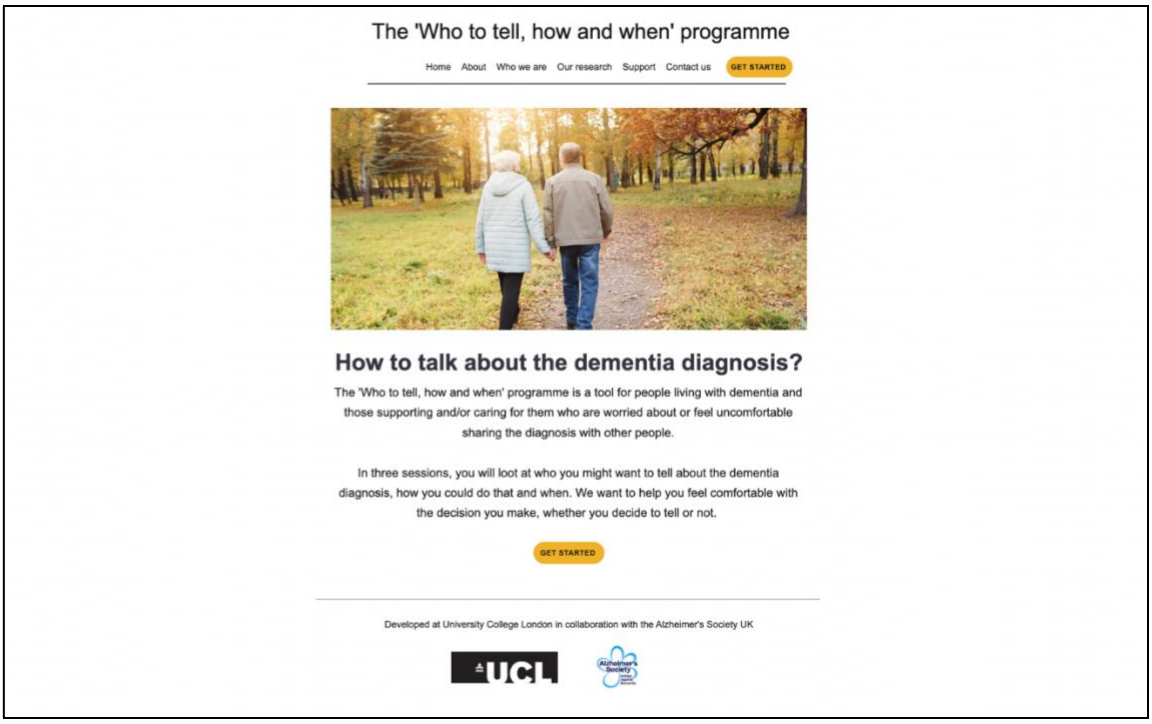
Aim of the focus groups on 13, 14 and 15 September 2022 is to talk about the design and 'look and feel' of the website. On the next pages, you find photos of the website.

When looking at the photos, you can think about the following questions:
- What comes to your mind when looking at the photos?
- What do you think of the look of the website?
- What do you think of the images we used on the website?
- What do you think of the amount of text?
- What do you think of the colours used on the website?

Feel free to note down feedback and recommendations if you wish. This is a not a requirement, and we will show these photos during the focus group discussion.

During the discussion, we will talk about your thoughts on the website and ways we could improve its design.

This is the main homepage:



The 'Who to tell, how and when' programme

How to talk about the dementia diagnosis?

The 'Who to tell, how and when' programme is a tool for people living with dementia and those supporting and/or caring for them who are worried about or feel uncomfortable sharing the diagnosis with other people.

In three sessions, you will loot at who you might want to tell about the dementia diagnosis, how you could do that and when. We want to help you feel comfortable with the decision you make, whether you decide to tell or not.

Developed at University College London in collaboration with the Alzheimer's Society UK

This 'About' page contains brief information on what the programme entails:


About the programme

The 'Who to tell, how and when' programme has been designed for people affected by dementia who are worried or anxious about sharing the diagnosis with other people. It consists of three sessions:

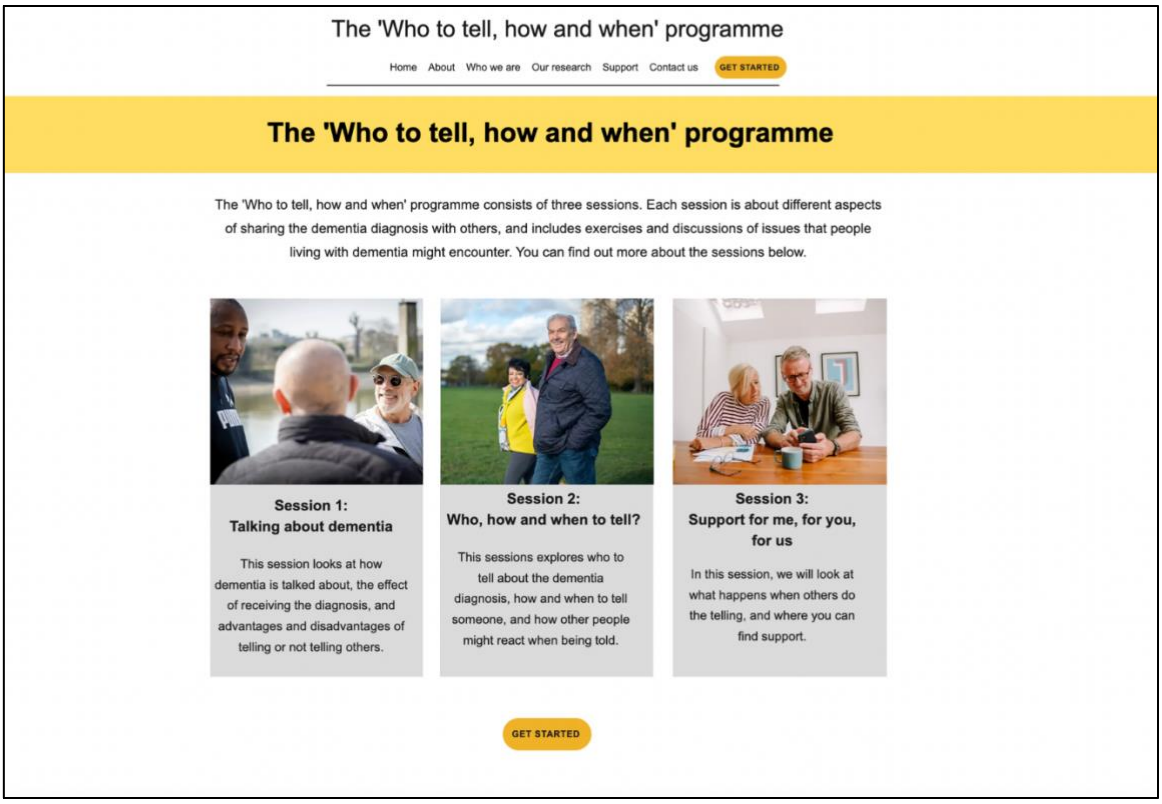
1. Talking about dementia
2. Who to tell, how and when?
3. Support for me, for you, for us

Each session will include information on relevant issues, quotes and videos from people affected by dementia and exercises to help you think about your ideas and thoughts on these issues.

Learn more about the programme in the video below:

For further information on the programme, please contact the principal investigator Dr Georgina Charlesworth: g.charlesworth@ucl.ac.uk

Developed at University College London in collaboration with the Alzheimer's Society UK



The 'Who to tell, how and when' programme

The 'Who to tell, how and when' programme consists of three sessions. Each session is about different aspects of sharing the dementia diagnosis with others, and includes exercises and discussions of issues that people living with dementia might encounter. You can find out more about the sessions below.

Session 1:
Talking about dementia

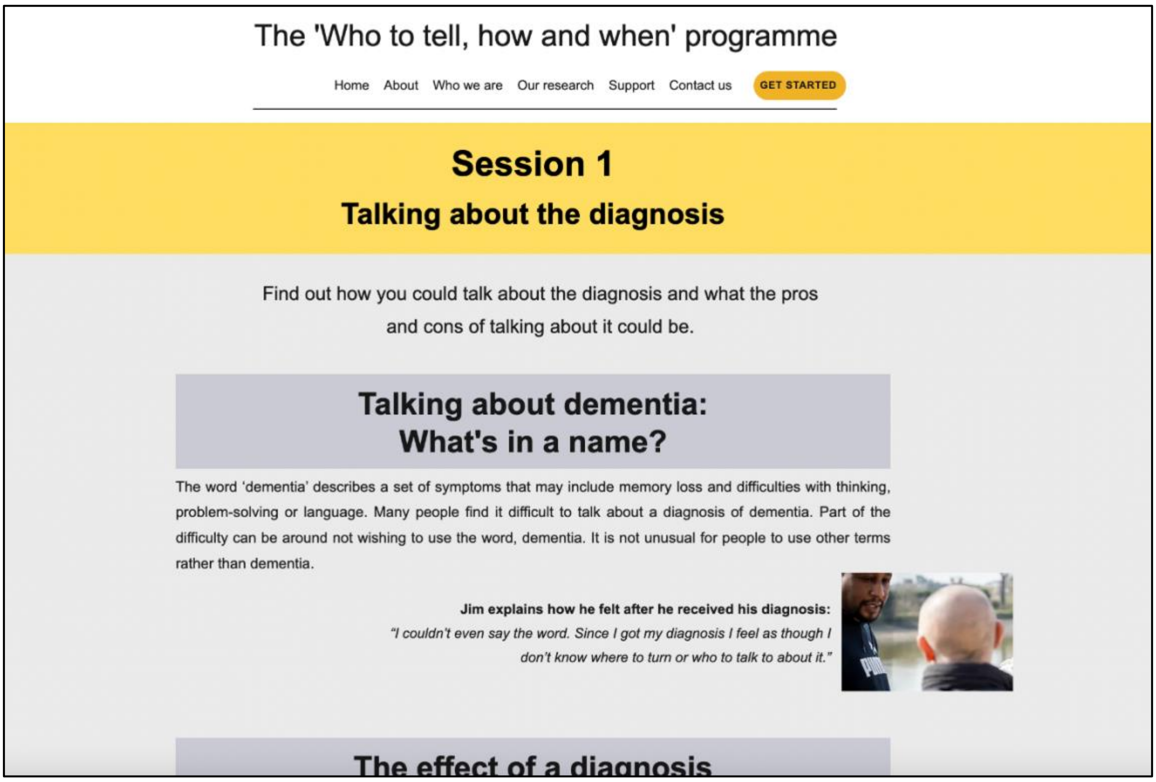
This session looks at how dementia is talked about, the effect of receiving the diagnosis, and advantages and disadvantages of telling or not telling others.

Session 2:
Who, how and when to tell?

This sessions explores who to tell about the dementia diagnosis, how and when to tell someone, and how other people might react when being told.

Session 3:
Support for me, for you, for us

In this session, we will look at what happens when others do the telling, and where you can find support.



Session 1

Talking about the diagnosis

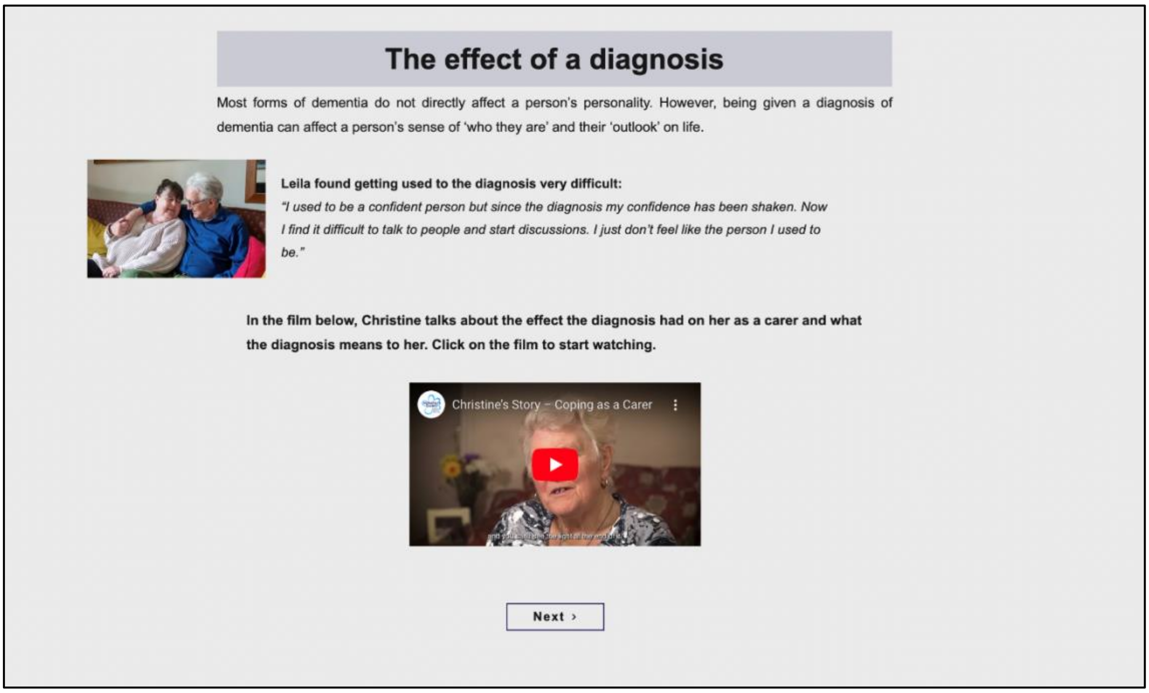
Find out how you could talk about the diagnosis and what the pros and cons of talking about it could be.

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.

Jim explains how he felt after he received his diagnosis:
"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."

The effect of a diagnosis



The effect of a diagnosis

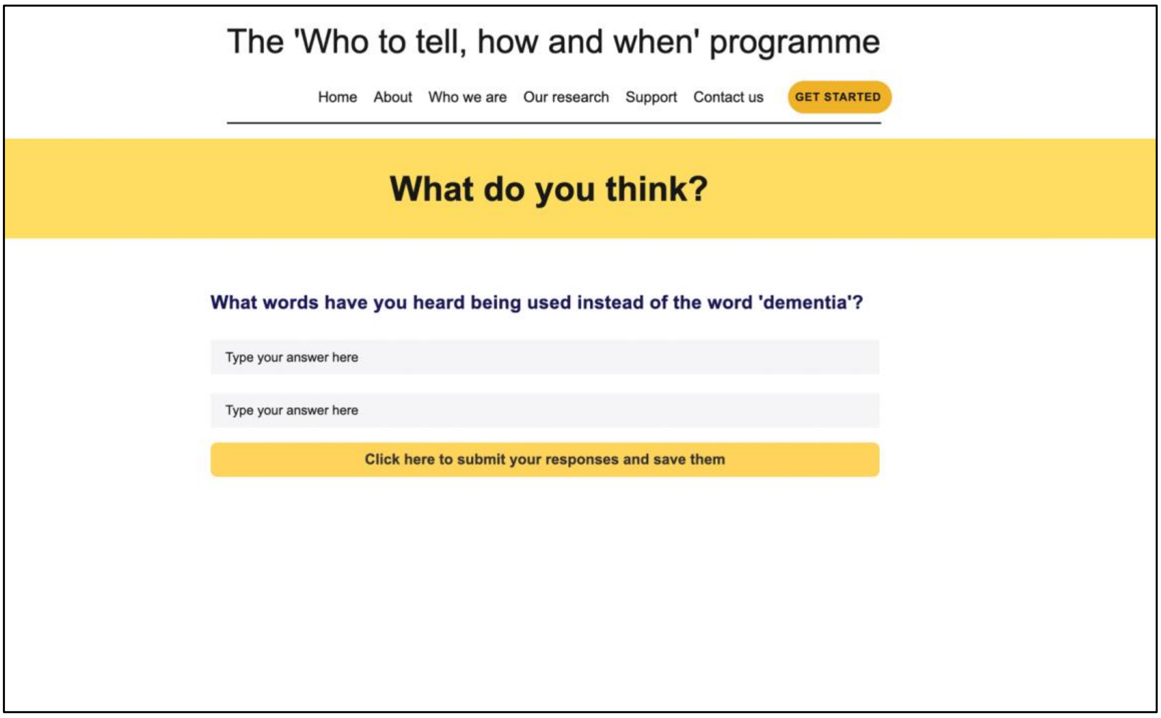
Most forms of dementia do not directly affect a person's personality. However, being given a diagnosis of dementia can affect a person's sense of 'who they are' and their 'outlook' on life.

Leila found getting used to the diagnosis very difficult:

"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."

In the film below, Christine talks about the effect the diagnosis had on her as a carer and what the diagnosis means to her. Click on the film to start watching.

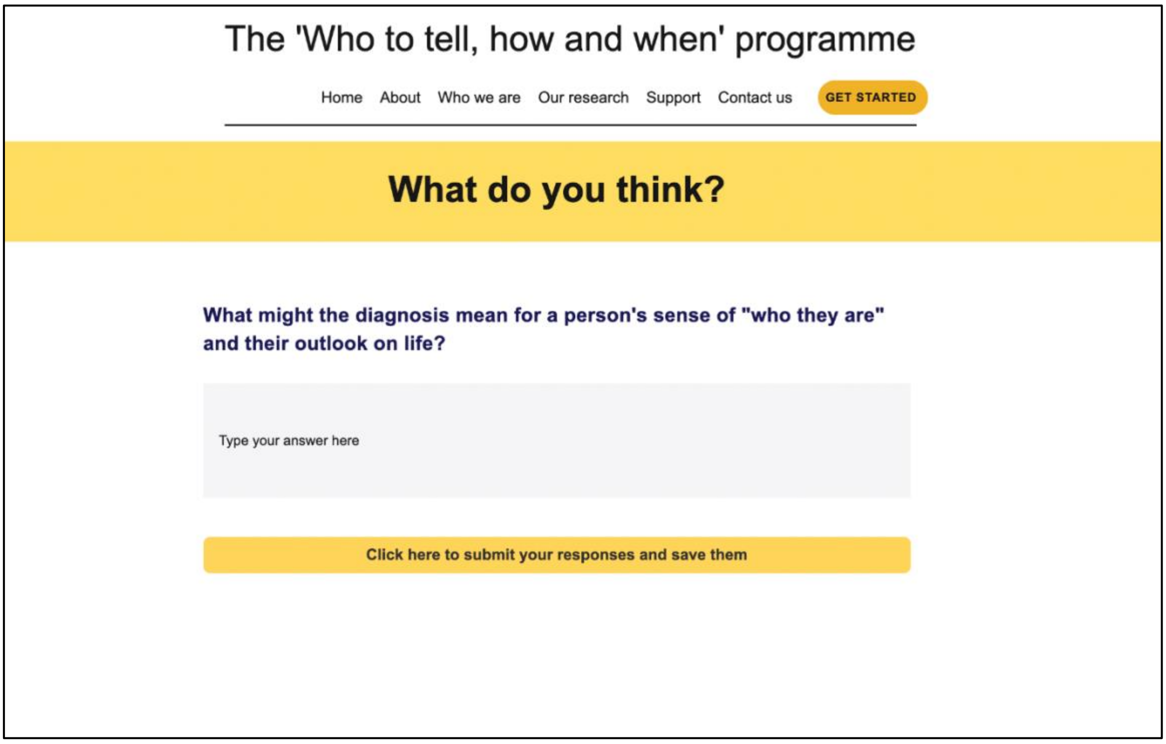
This page contains the first two exercises of session 1:



The 'Who to tell, how and when' programme

What do you think?

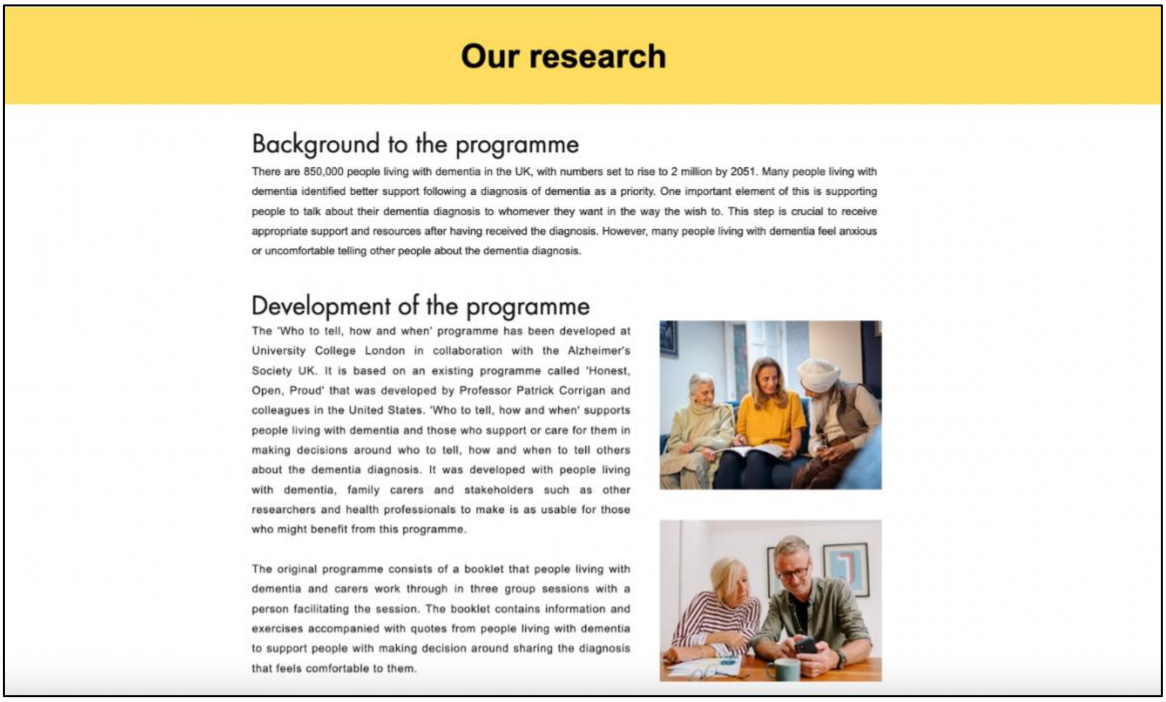
What words have you heard being used instead of the word 'dementia'?



What do you think?

What might the diagnosis mean for a person's sense of "who they are" and their outlook on life?

The ‘Our research’ page contains information on the development of ‘Who to tell, how and when’:



Our research

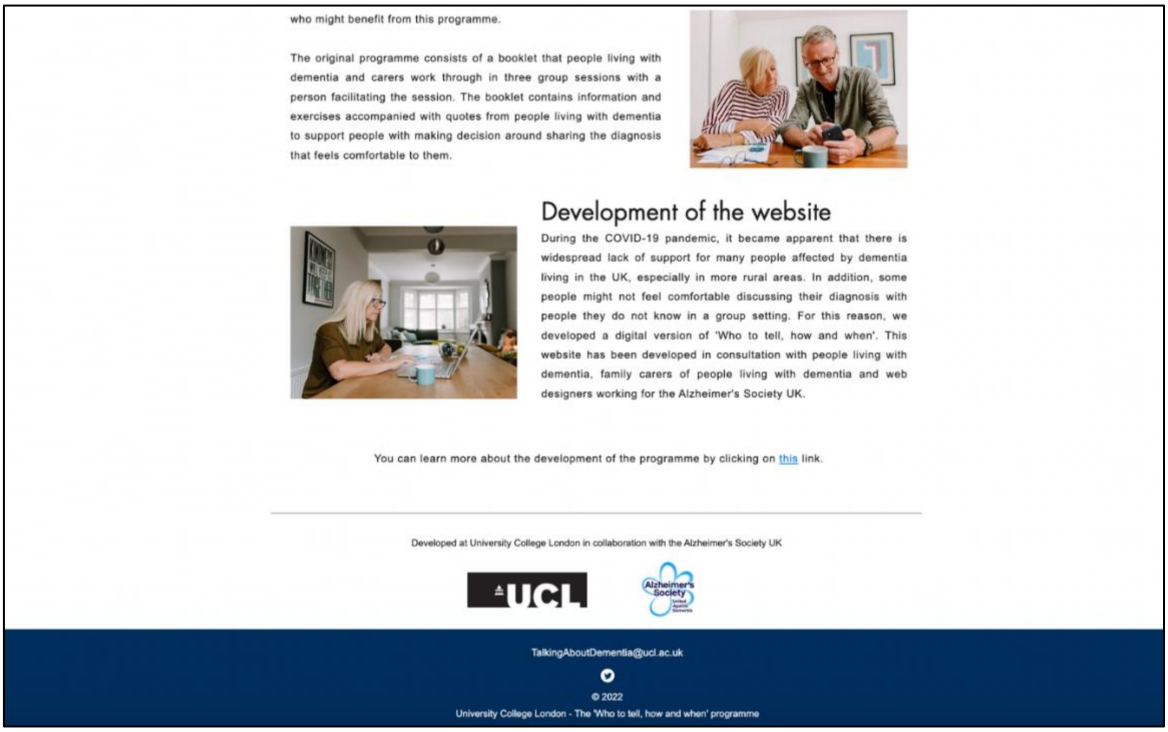
Background to the programme

There are 850,000 people living with dementia in the UK, with numbers set to rise to 2 million by 2051. Many people living with dementia identified better support following a diagnosis of dementia as a priority. One important element of this is supporting people to talk about their dementia diagnosis to whomever they want in the way the wish to. This step is crucial to receive appropriate support and resources after having received the diagnosis. However, many people living with dementia feel anxious or uncomfortable telling other people about the dementia diagnosis.

Development of the programme

The 'Who to tell, how and when' programme has been developed at University College London in collaboration with the Alzheimer's Society UK. It is based on an existing programme called 'Honest, Open, Proud' that was developed by Professor Patrick Corrigan and colleagues in the United States. 'Who to tell, how and when' supports people living with dementia and those who support or care for them in making decisions around who to tell, how and when to tell others about the dementia diagnosis. It was developed with people living with dementia, family carers and stakeholders such as other researchers and health professionals to make is as usable for those who might benefit from this programme.

The original programme consists of a booklet that people living with dementia and carers work through in three group sessions with a person facilitating the session. The booklet contains information and exercises accompanied with quotes from people living with dementia to support people with making decision around sharing the diagnosis that feels comfortable to them.



who might benefit from this programme.

The original programme consists of a booklet that people living with dementia and carers work through in three group sessions with a person facilitating the session. The booklet contains information and exercises accompanied with quotes from people living with dementia to support people with making decision around sharing the diagnosis that feels comfortable to them.

Development of the website

During the COVID-19 pandemic, it became apparent that there is widespread lack of support for many people affected by dementia living in the UK, especially in more rural areas. In addition, some people might not feel comfortable discussing their diagnosis with people they do not know in a group setting. For this reason, we developed a digital version of 'Who to tell, how and when'. This website has been developed in consultation with people living with dementia, family carers of people living with dementia and web designers working for the Alzheimer's Society UK.

You can learn more about the development of the programme by clicking on this link.

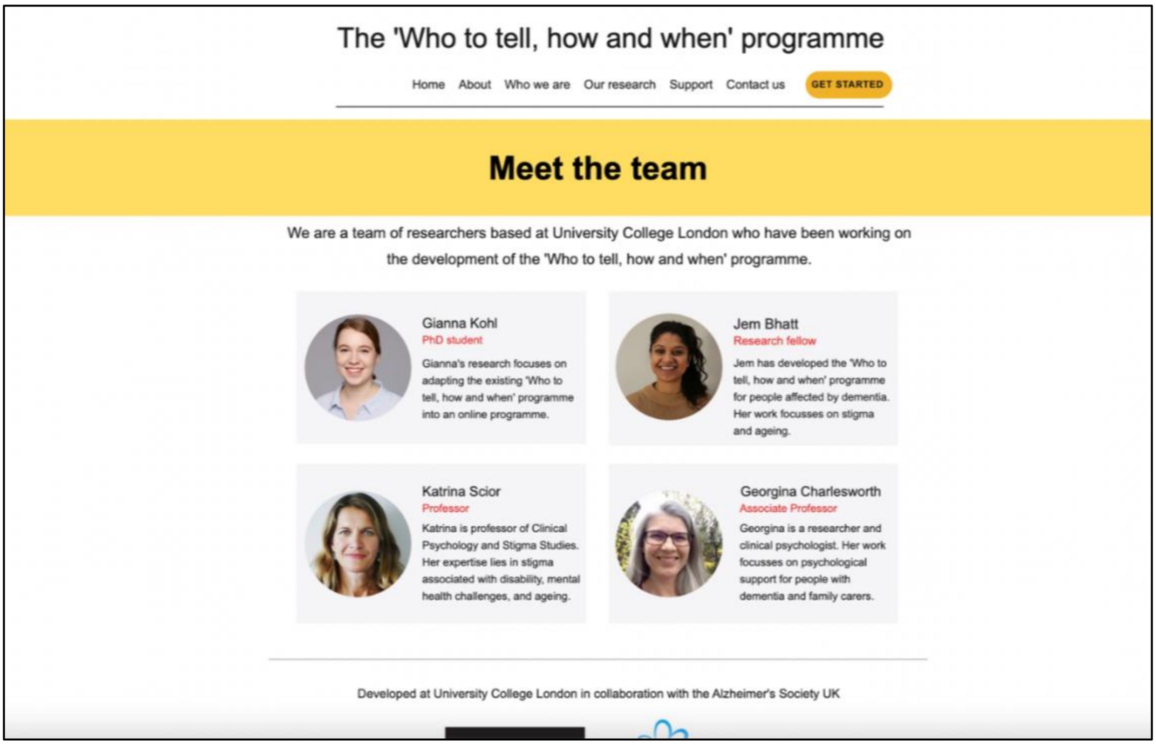
Developed at University College London in collaboration with the Alzheimer's Society UK

TalkingAboutDementia@ucl.ac.uk

© 2022

University College London - The 'Who to tell, how and when' programme

This 'Who we are' page contains information on the people involved:



Meet the team

We are a team of researchers based at University College London who have been working on the development of the 'Who to tell, how and when' programme.

Gianna Kohl
PhD student
Gianna's research focuses on adapting the existing 'Who to tell, how and when' programme into an online programme.

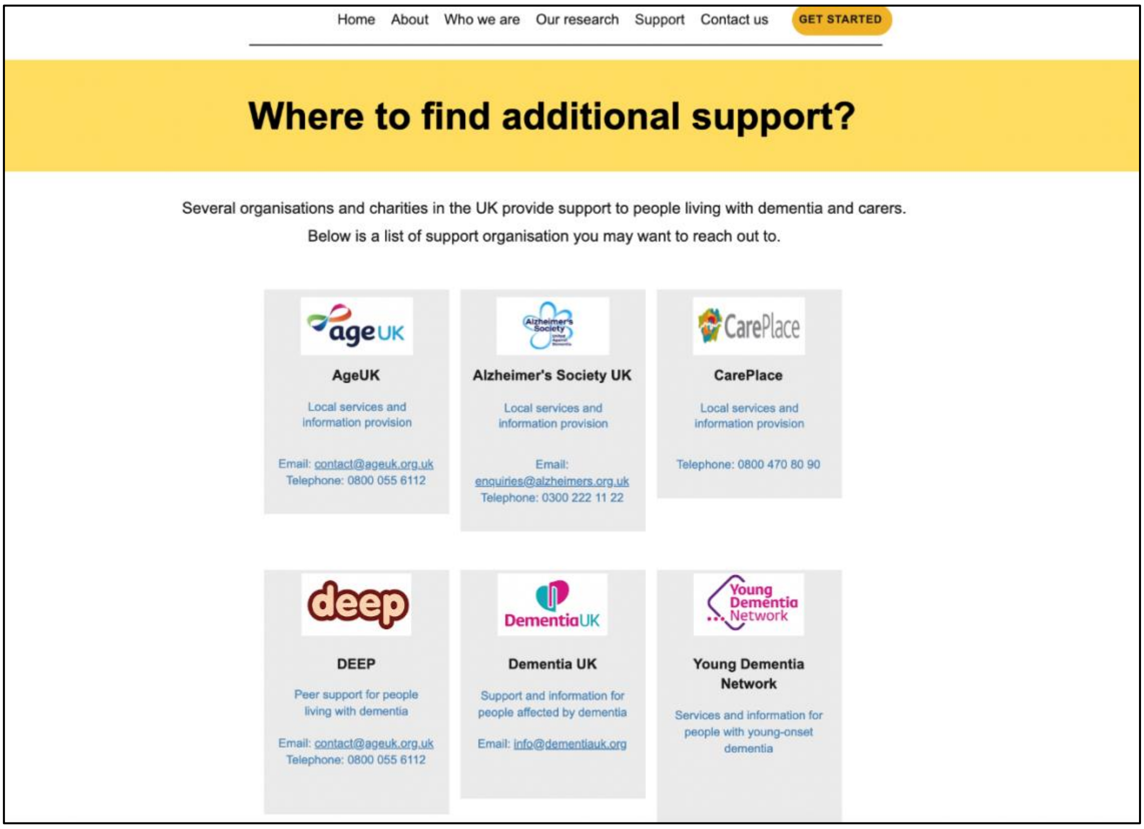
Jem Bhatt
Research fellow
Jem has developed the 'Who to tell, how and when' programme for people affected by dementia. Her work focusses on stigma and ageing.

Katrina Scior
Professor
Katrina is professor of Clinical Psychology and Stigma Studies. Her expertise lies in stigma associated with disability, mental health challenges, and ageing.

Georgina Charlesworth
Associate Professor
Georgina is a researcher and clinical psychologist. Her work focusses on psychological support for people with dementia and family carers.

Developed at University College London in collaboration with the Alzheimer's Society UK

The ‘Support’ page contains information on dementia organisations:



Where to find additional support?

Several organisations and charities in the UK provide support to people living with dementia and carers.
Below is a list of support organisation you may want to reach out to.

AgeUK

Local services and information provision

Email: contact@ageuk.org.uk
Telephone: 0800 055 6112

Alzheimer's Society UK

Local services and information provision

Email: enquiries@alzheimers.org.uk
Telephone: 0300 222 11 22

CarePlace

Local services and information provision

Telephone: 0800 470 80 90

DEEP

Peer support for people living with dementia

Email: contact@ageuk.org.uk
Telephone: 0800 055 6112

Dementia UK

Support and information for people affected by dementia

Email: info@dementiauk.org

Young Dementia Network

Services and information for people with young-onset dementia

Appendix V: Topic guide for step 2 of Chapter 5

Thank you for agreeing to take part in this focus group discussion. My name is Gianna and as you know I am a researcher from UCL, and I will carry out this focus group.

Before we start, I want to briefly repeat some of the things stated in the consent form that you have all read and signed:

- Reminder there are no right or wrong answers, just interested in people's opinions
- Participation is voluntary, free to withdraw during the discussion; you can let us know if you do not want anything you have said used in any write-ups
- Everything you say will be anonymised for the write-up, it won't be possible to identity you
- Because this is a group discussion, we want to remind you to please respect everyone's privacy and not repeat what is discussed to people outside of the group.

Is everyone still giving consent to take part?
Are there any questions before we start?

I would like to start the focus group with brief introductions from everyone. After the introductions, I will tell you a bit about the research we are doing and then I will show you pictures of the website I have been developing to get your feedback and comments on the design or 'look and feel' of the website.

Introductions:
You might know each other already because of your work in the Research Network, but it would be nice if you could introduce yourselves. If you want, you can also tell us a bit more about yourself, for example, where you are based.

Description of the research

We are in the process of developing a website for the “Who to tell, how and when” face-to-face programme. This programme has been developed at UCL for people with dementia and their family members who are worried about sharing the diagnosis with other people. We did a round of three focus groups in July with people with a dementia diagnosis and people who provided support to a person with a dementia diagnosis to see how they feel about an online version of this programme and how that could look.

We hope this online programme will be a useful alternative to face-to-face for people affected by dementia who feel uncomfortable participating in a group-based intervention or who would like to take part in the comfort of their own home.

Before we finalise this website, we would like to hear your thoughts and opinions about what we developed so we can make improvements or changes based on your comments. We are asking you as we know you have responded to the Alzheimer’s Society invitation because this is something you are interested in and most likely have experience of. We want to make use of your knowledge.

The online “Who to tell, how and when” programme is a resource for people affected by dementia who are worried about or feel uncomfortable sharing the diagnosis with wider family members/friends.

This program consists of three sessions which are each about different aspects of sharing the dementia diagnosis with wider family members/friends and includes exercises and discussions of issues that people with dementia may encounter.

Session one includes information on talking about dementia including how dementia is spoken about, the effect of receiving the diagnosis and the advantages or disadvantages of telling or not telling others.

Session two includes information about who, how and when to tell others about the diagnosis and how other people may react when being told.

Session three includes information about what happens when others do the telling and where you can find additional support.

There is also a dementia forum where you can discuss the topics of each session with other people with dementia and informal carers.

Give the participants a few minutes to look through the website.

Explain this is not the final draft and will be improved upon based on their comments.

Questions

System design characteristics, perceived usefulness, perceived ease of use and credibility questions are based on the technology acceptance model (Davis, 1986).

Prompts are to be used ***only*** *if not already covered.*

Mock-ups and discussion

Open Google Jamboard and share the screen: Show the participants the first slide of mock-ups and present a summary of what they are seeing

For each page in Google Jamboard:

- General thoughts (if they like/dislike the design & how these designs could be improved)

System design characteristics

1. What do you think of the website?
2. What are your thoughts on the design of the website e.g., tabs, images?
3. What device would you use to access this website?

   Prompt: Should there be more/less pictures? Should the pictures be different?

   Prompt: Do you have any other feedback about the layout, design etc. of the website?

Perceived usefulness

1. What do you think about the information provided on the pages? – do you think the information is helpful/not helpful?
2. Do you think it would be useful to have more pages?
3. How interested would you be to use this website based on how it looks?
4. Do you think this would be beneficial for a range of people?
   - E.g., different ethnicities

- Ages
- level of knowledge about dementia
- Family members/friends etc.

Perceived ease of use

1. Is the website easy to read and follow e.g., not too much text on each page/fonts/font size/colours/distracting images?
2. What do you think could make it difficult for people affected by dementia to use this website?

   Prompt: How could these difficulties be improved?

Credibility

1. Do you think it is important to state who developed this programme and website, both in terms of researchers but also organisations?
   - (i.e., would a collaboration with a dementia organisation make you more likely to trust/use the website?)
     - What about the NHS website?
     - What about the UCL website?

Overall satisfaction

1. What do you like about having the programme delivered via a website?
2. What do you dislike about having the programme delivered via a website?

Feedback

1. What improvements can be made to the website?
2. Do you think any features could be removed or added to the website?
   - E.g., text-to-speech option for those who are hard of hearing to make sure they can access the website?
   - E.g., colour-blind friendly layout?

Ending the focus group

Before we finish, is there anything else you would like to add that we have already not covered? Thank you for taking part today.

- Send thank you email to everyone who took part
- Send vouchers

Appendix W: Participant feedback from focus groups of step 2 of Chapter 5

Table A3

Feedback on prototype v1 and subsequent changes, resulting in prototype v2

Page	Comments made by participants	Changes made to website
Homepage	- Emphasize more clearly who this website is for - Increase font size - Change the photograph of couple walking into sunset	- More information was added to inform people who this website has been developed for - A video (placeholder) was added which aims to inform people about the intervention - Main photograph was replaced by three separate photographs
'Meet the team'	- Good to see names of researchers - In future development make use of a Patient and Public Involvement group and put their names on the page - Add a photo of someone from the Alzheimer's Society or information that they provided funding to the page to make their involvement clearer	- Added a link to UCLUS website if people would like to learn more about it

‘Our research’	- Too much text, too many details: Just have a short sentence stating what this intervention is intended for - Link to UCLUS website on the manual intervention development	- Removed page; instead a link on the homepage guides people to the UCLUS website to read about the development
‘Support’	- Signpost to memory clinic or dementia cafés - Add additional organisations	- Description what every organisation or charity does was removed to simplify page
Sessions overview	- Have a ‘get started’ button underneath each session to give people freedom to choose which session they want to access - Advise that people best work through all three sessions after another - Use different word for ‘session’ (suggestions were workshop, strand, chapter)	- Added an ‘access module’ button underneath each session - Changed the word ‘session’ to ‘module’ - Changed photographs to ones that went better with new colour palette
‘Session 1 – Talking about the diagnosis’	- Change definition of dementia because it includes more than just memory	- Added more information about what dementia is
‘Exercise 1 – Words being used instead of dementia’	- Suggest range of words people can click on instead of open-ended question - Use this exercise to educate individuals on what dementia is so they can explain it to others	- Range of words one might use to talk about dementia has been added as example of what other people might say - Added information on what dementia is

	- Is it useful to have exercise 1 focus on different (negative) words being used for dementia? Wouldn’t it make more sense to have people think about what words they could use to tell others about their dementia? - Too much information about dementia on this website can be overwhelming. Signpost to other websites instead - Focus more on symptoms of dementia (e.g., sleep, memory, language) and what the person is going through instead of just ‘I have dementia’. This way it might be easier for people to explain their dementia to others - Dementia explanation: Simple terms and not too much detail	- Added link to Alzheimer’s Society factsheet with information on dementia

Appendix X: Think-aloud interview topic guide for Chapter 5

Introduction

Thank you for agreeing to take part in this interview. My name is Gianna and as you know I am a researcher from UCL, and I will carry out and record this interview.

Rechecking consent

Before we start, I would like to remind you that there are no right or wrong answers. I am just interested in your opinions. Your participation is voluntary; you are free to withdraw during the interview and you can let me know if you don’t want your quotes used in any write-ups. All your responses will be anonymised for the write-up and it will not be possible to identify you.

Recording

I will do an audio and screen recording of this interview. Is that okay? *Start recording*

Questions

Do you have any questions before we start?

Description of research

I have used the information I received in July to develop a website for ‘Who to tell, how and when’. I did another round of focus groups two weeks ago where I showed people photos of the website to get their feedback on the design and layout. I have now made changes to the website based on the feedback.

Aim of interview

The aim of the interview today is to have you go through the website and see how that goes. For example, are there any things that don’t work for you? Is the design clear? What do you think of the website overall?

Think-aloud protocol

When you go through the website, I would like to you to tell me what you are doing and what you see. Basically, like you're talking to yourself, but loud enough for other people to hear.

We can do an example. Imagine making a cup of tea. Can you talk out loud what steps you would need to take to make a cup of tea? Imagine you've run out of milk. What would you? Can you speak out loud what you are doing?

While you go through the website, I might ask questions to get some additional feedback from you.

Accessing the website

I will send you a link to the website via the Zoom chat (this will not apply for in-person interviews). The website has not been published yet, so I am sending you a link to a test site. It might therefore look a bit different to usual websites.

Give the participants a few minutes to look through the website and make any general comments.

Explain this is not the final draft and will be improved upon based on their comments.