Determinants of dementia attitudes in young people

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Abstract

Background: The increasing prevalence of dementia affects individuals, their families, and society. The stigmatisation of dementia leads to poor well-being, social isolation, and delayed support. Improving public awareness and attitudes is crucial to mitigate these effects. Effective anti-stigma interventions require an understanding of the determinants of dementia-related attitudes, and identifying ideal targets. Young people (10-18 years old) are particularly susceptible to attitude change but remain an under-researched demographic for shaping societal perceptions. This thesis aims to identify the determinants of dementia-related attitudes among young British people.

Method: This thesis employs review methodology and quantitative cross-sectional methods. First, a scoping review identified measures capturing dementia-related attitudes in young people. Second, using textual narrative synthesis, a systematic review identified factors associated with dementia-related attitudes in young people (10-18 years old). Third, a cross-sectional secondary data analysis (n=470) explored dementia-related attitudes in 12-15-year-olds, employing validated questionnaires, multiple regressions, and structural equation modelling. Fourth, a cross-sectional survey recruited 11-18-year-olds (n=1,600) across six regions of England. Structural equation models identified whether modifiable factors (e.g., contact, empathy, knowledge) or demographic factors (e.g., age, ethnicity, sex) are more important determinants of dementia-related attitudes. Descriptive statistics were obtained on the various experiences and knowledge of dementia. Lastly, using questionnaires and an implicit attitudes test, a sub-study examined the association between implicit and explicit dementia-related attitudes in 13-18-year-olds (n=130).

Results: The scoping review identified 13 unique measures (n=14 studies), revealing gaps in psychometric properties and theoretical frameworks. The systematic review identified seven factors (n=8 studies), with contact and knowledge, consistently associated with attitudes. The secondary data analysis indicated empathy as a key mediator between contact and attitudes. The cross-sectional survey found that modifiable factors (empathy, level of contact, and dementia knowledge) were the strongest mediators in the SEM. Young people also held common misconceptions about dementia, with contact mainly through media. Adolescents generally had

positive direct experiences of dementia. The exploratory sub-study found no association between explicit and implicit attitudes.

Conclusion: This thesis contributes to the understanding of how factors such as level of contact and empathy potentially play a crucial role in forming dementia-related attitudes in young people. This thesis is the first to explore these factors in young people beyond associations, by presenting the interactions of these determinants. This thesis addresses a population gap by recruiting more diverse socio-demographic groups.

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Abbreviations

A-ADS – Adolescent Attitudes towards Dementia Scale

AANN – Anderson's Associative Network Notation model

ABC model – Affective, behavioural, and cognitive model

ACT-R – Activation Theory of Memory

AD – Alzheimer's disease

ADI – Alzheimer's Disease International

ADQ – Approaches to Dementia Questionnaire

AGFI – Adjusted Goodness-of-Fit Index

ALOCD – Adolescent Level of Contact with Dementia

AQ-8-C – Attribution Questionnaire Children's Version (eight items)

AQ-9 – Attribution Questionnaire (nine items)

AQ-27 – Attribution Questionnaire (27 items)

ATOP – Attitudes Towards Older People Scale

Brief A-ADS – Brief Adolescent Attitudes Towards Dementia Scale

BsCI – Bias-corrected Confidence Interval

BSDS — Brief Social Desirability Children's Scale

CB-SEM – Covariance-based structural equation modelling

CFA – Confirmatory Factor Analysis

CFI – Comparative Fit Index

CI – Confidence Interval

CVI – Content Validity Index

DAS – Dementia Attitudes Scale

DBS – Disclosure and Barring Service

Df – Degrees of Freedom

DRA – dementia-related attitudes

EAM – Environmental Association Model

EFA – Exploratory Factor Analysis

EH – Esra Hassan (researcher/reviewer)

EmQue-CA – Empathy Questionnaire for Children and Adolescents

GFI – Goodness-of-Fit Index

IAT – Implicit Association Test

IER – Insufficient Error Responding

IMD – Index of Multiple Deprivation

IRAP – Implicit Relational Assessment Procedure

KIDS – Kids Insight into Dementia Scale

LEAP – Lived Experience Advisory Panel

LSOA – Lower Super Output Areas

MI – Multiple Imputation

ML – Maximum Likelihood

MMAT – Mixed Methods Appraisal Tool

MODE model – Motivation and Opportunity as Determinants model

NF – Nicolas Farina (supervisor/reviewer)

NILTS – Northern Ireland Life and Times Survey

NR – Not Reported

OR – Odds Ratio

PHE – Public Health England

PLS – Partial Least Squares

PPI – Patient Public Involvement

PRISMA – Preferred Reporting Items for Systematic Reviews and Meta-Analyses

RAS – Relational Ageism Scale

RMSEA – Root Mean Square Error of Approximation

S.E – Standard Error

SEM – Structural Equation Model

SPIDER strategy – Sample, Phenomenon of Interest, Design, Evaluation, and Research Type

TLI – Tucker Lewis Index

TPB – Theory of Planned Behaviour

VR – Virtual Reality

WHO – World Health Organization

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Authors declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed: Esra Hassan

Dated: 31/01/2025

Overview of the thesis

As the number of people living with dementia increases, so will the reach of its impact; affecting those with the condition, their families, and society at large. The presence of stigma that surrounds dementia can lead to negative consequences such as social exclusion, reduced quality of life, and barriers to care (Rewerska-Juśko & Rejdak, 2020). Understanding the determinants of dementia-related attitudes (DRA) is a crucial step in addressing these consequences. Young people represent a significant demographic in society who may already have experience with dementia. Yet, their experiences and DRA are rarely explored, despite young people's potential to shape societal perceptions and behaviours. This thesis presents the case for why young people are an important demographic for tackling negative DRA, and also identifying the potential determinants of DRA in young people. The findings of this thesis delve beyond mere bivariate associations by presenting the interactions of these factors with each other (both socio-demographic and modifiable factors), highlighting the weight of their influence on DRA. This thesis provides an understanding of what (and who) to target when developing strategies to improve DRA in young people. The knowledge gained from this thesis provides a foundation for the design of anti-stigma interventions bespoke to young people that are more effective, through leveraging factors that are most important in the formation of DRA in young people. Understanding how attitudes form in the first place better equips stakeholders, researchers, and policymakers to create lasting improvements to DRA within the general public, fostering a more inclusive society.

In this thesis, the term 'determinants' is used rather than 'association'. The use of determinants is to emphasise that this thesis focuses on identifying the factors that actively shape and influence DRA. While causation is not established, the intended study design for this thesis such as qusai-longitudinal design, exploring multiple mediatory mechanisms that may influence DRA using structural equation models, and repeat testing of the mediatory pathways between the variables across two chapters goes beyond the nature of bivariate relationships and correlations. Thus, the term 'association' does not adequately capture the complex interplay of the factors underlying DRA that is explored in this thesis.

Moreover, the terms ‘young people’ and ‘adolescents’ are used. ‘Young people’ refers to a societal group, while ‘adolescents’ is used when discussing a specific demographic, recognising their developmental milestones. Although the World Health Organization (WHO) defines adolescents as ages 10-19 years old (early adolescence: 10-14 years old, mid-adolescence: 15-16 years old, and late adolescence: ending at age 19) (Sawyer, Azzopardi, Wickremarathne & Patton, 2018; World Health Organization [WHO], 2024)), participants aged 11-18 years were selected for this thesis to reflect the secondary education school system in England (UK Government, 2014). This was also to distinguish between adolescents at school and those aged above 18. Those above the age of 18 have already been widely studied in the literature in the context of the general public and university setting (see Herrmann et al., 2018). While some literature exists on primary school-aged children (those under the age of 10), key developmental differences may make younger children less optimal for anti-stigma initiatives (Jaworska & MacQueen, 2015).

This thesis emphasises ‘dementia’ and ‘Alzheimer’s disease’ due to their prevalence and recognition in public discourse. Alzheimer’s disease, as the leading cause of dementia globally (Alzheimer's Association, 2024), further justifies this focus. While other forms of dementia exist, concentrating on these terms addresses a substantial portion of public attitudes, and enhances the relevance of the research.

Structure of thesis

Chapter 1 sets the context for this research, defining the scope of the thesis and setting out the thesis aims and objectives.

Chapter 2 presents a scoping review to explore what outcome measures are currently used when exploring DRA in adolescents.

Chapter 3 presents a systematic review of the factors associated with DRA in adolescents.

Chapter 4 presents a cohort secondary data analysis on the factors associated with DRA in British adolescents.

Chapter 5 presents a cross-sectional study exploring the determinants of DRA in British adolescents, and presenting descriptive data on their experience and knowledge of dementia.

Chapter 6 presents a sub-study exploring the association between DRA in explicit and implicit attitude measures.

Chapter 7 summarises the key findings. The implications of the findings, contributions to the field, and potential avenues for future research are discussed as well as the strengths and limitations of this thesis.

Chapter 1 Introduction

1.1 Background

Dementia

Dementia has become an emerging global public health priority (Kafadar, Barrett & Cheung, 2021; Livingston et al., 2024). It is estimated that 55.2 million people worldwide were living with dementia in 2019. With a globally ageing population, these numbers are forecasted to rise to 78 million by 2030 (Nichols & Vos, 2021; WHO, 2021b). Within the context of the United Kingdom (UK), there are approximately 850,000 people currently living with dementia (Kafadar et al., 2021; Public Health England [PHE], 2022). Societal costs of dementia are £34.8 billion a year in the UK which is primarily attributable to the cost of dementia care (PHE England, 2022). Dementia care costs are projected to increase by 172% in the UK by 2040 (Wittenberg et al., 2019). There is currently no cure for dementia. Thus, policy directives have sought to support people to 'live well' with the condition (Morris, Tomkow, & Blakeman, 2023). Dementia is an umbrella term encompassing various medical conditions that interfere with an individual's ability to perform everyday tasks and is typically progressive or chronic (Orgeta, Mukadam, Sommerlad, & Livingston, 2019). The umbrella term includes different types of dementia, each with distinct causes and symptoms such as memory deterioration, issues with communication and language, and reasoning and perception (Lanctôt et al., 2017). Alzheimer's Disease, the most prevalent form, accounts for approximately 60% to 80% of dementia cases (Alzheimer's Association, 2024; Ferreira et al., 2014). Other types include vascular dementia, which results from problems with blood supply to the brain (Pathan et al., 2024), and frontotemporal dementia, characterised by progressive damage to the frontal and temporal lobes (Olney, Spina, & Miller, 2017). Each type of dementia presents unique challenges and requires tailored approaches for understanding and management (PHE, 2022). While the most significant risk factor for dementia is age, it is not the cause (Dening & Sandilyan, 2015).

Dementia stigma

There is a lack of understanding of dementia which has led to continued stigmatisation of the condition and those living with dementia (Herrmann et al., 2018). Although there are varying definitions, stigma conceptualised by Goffman (Theory of stigma - 1963), has been commonly adopted (Goffman, 1963 cited in Aranda, Helms, Patterson, Roulet, & Hudson, 2023). Goffman defined stigma as a discriminatory discreditation held by society towards a person or a group due to their characteristics. Being 'marked' with such characteristics could lead to adverse outcomes such as social isolation within the social context (Alzheimer's Disease International [ADI], 2019; Goffman, 1997; Herrmann et al., 2018; Nguyen & Li, 2020). The stigmatisation of dementia by members of the general public falls under the term 'public stigma' (Nguyen & Li, 2020). In the context of dementia, public stigma can be defined as a collection of negative attitudes and beliefs that lead to discriminatory behaviour towards people living with dementia (Cheng et al., 2011; Rüsch, Angermeyer, & Corrigan, 2005; Werner, 2014). This stigma is shaped by misconceptions about dementia, including the erroneous belief that it is an inevitable part of ageing (Lowe et al., 2015). Addressing these misconceptions through increased awareness is crucial for challenging ageist stereotypes and improving public understanding of dementia (WHO, 2017). Public stigma encapsulates interrelated terms such as 'attitudes', 'stereotypes', 'perceptions', 'beliefs', and 'discrimination' (Corrigan & Kleinlein, 2005).

Classifying dementia as a disease impacts societal views since the biomedical approach shapes our understanding of its progression (O'Sullivan, Hocking, & Spence, 2014). The biomedical approach refers to a model of health that emphasises biological and physiological underpinning of a disease rather than social or psychological factors. For example, the model highlights diagnosis, treatment and prevention of a disease (Innes & Manthorpe, 2013). From this perspective, dementia is framed as not curable. This can lead to fear and stigma, which harms individuals with dementia and their families by reducing quality of life and creating barriers to diagnosis and care. These barriers have economic, psychological, physical, and social repercussions (Herrmann et al., 2018; Rewerska-Juśko & Rejdak, 2020). Internalising stigma can lead to self-stigma, diminishing self-worth and increasing psychological

distress (ADI, 2019; Corrigan & Watson, 2002; Milne, 2010; Werner, 2014). Self-stigma can also worsen feelings of disability and hinder meaningful activities (Mukadam & Livingston, 2012; Nguyen & Li, 2020). To address these issues, current policies aim to improve dementia education and alter societal attitudes through targeted awareness initiatives (WHO, 2012).

Policy

Key policy directives have sought to address the detrimental impacts of societal and self-stigma by seeking to improve dementia attitudes (Innes & Manthorpe, 2013; Quinn et al., 2022) and increase knowledge of dementia through awareness-raising in the general public (Department of Health and Social Care, 2016; WHO, 2021b). In 2013, the UK launched a 'Global Action Against Dementia' agenda, which was a significant step in this direction. The agenda included a key priority in increasing public awareness of dementia and a broader priority to tackle stigma by creating dementia-friendly societies (WHO, 2015). The World Health Organization (2017) emphasised that a dementia-friendly society would mean people are educated on dementia and provide inclusive, accessible, and stigma-free communities for those living with the condition and their carers (Parkinson, Sullivan, & Graham, 2022; WHO, 2017; Wu et al., 2019). These initiatives are important given that a global survey conducted in 2019 of almost 70,000 people across 155 countries found poor dementia awareness levels, with two-thirds of the general public still believing that dementia is a normal part of ageing. Over 62% of healthcare professionals also share this view (ADI, 2019).

People with personal experience of dementia have identified key strategies for increasing community awareness and understanding of dementia (Parkinson et al., 2022; Hung et al., 2021; Shannon, Bail, & Neville, 2019). This includes public education about dementia (Buckner et al., 2019; Hebert & Scales, 2019) and anti-stigma initiatives, which are widely accepted strategies to achieve greater dementia awareness (Baker et al., 2019; Mukadam & Livingston, 2012; WHO, 2012). However, such initiatives have only recently started to show modest effectiveness (Farina et al., 2020b; Mukadam & Livingston, 2012). There are some initiatives, such as the 'Dementia Awareness Program', that provide school students with the opportunity to

volunteer at a dementia care home weekly for example. Such initiatives aim to raise awareness and tackle negative DRA (Chow et al., 2018). However, these are currently not based on rigorous empirical evidence with ambiguity as to the theoretical foundations used to inform such initiatives (Hebert & Scales, 2019). The efficacy of initiatives is further doubted due to the questionable psychometric properties of DRA outcomes (Herrmann et al., 2018). The modest effectiveness of initiatives may be driven by their lack of evidence rooted within them to understand what factors determine DRA in the first place. There is a need to develop evidence-based anti-stigma and dementia awareness initiatives that tackle the underlying causes of stigma, ensuring that they are tailored and culturally appropriate for different communities (WHO, 2017). It is not only important to identify which demographic groups and members of the public are most susceptible to developing stigmatising attitudes, but also those who may be most receptive to anti-stigma and dementia awareness interventions that lead to attitude change.

1.2 Attitude theory and stigma frameworks

This section summarises key components that underpin attitude development and stigma theory, central to the conceptual foundations and methodology of this thesis. The frameworks discussed, while adapted for dementia, originate from mental health stigma research due to the lack of specific frameworks for DRA. While the key frameworks relevant to this thesis are highlighted, it is important to note that other frameworks, such as the Modified Labelling Theory (Link et al., 1989; Link & Phelan, 2001), have also influenced the stigma concept. The Modified Labelling Theory refers to stigma that arises due to social labelling of people (e.g., people with mental illness) which can lead to individuals internalising the negative perceptions that reinforce the stigma (Link et al., 1989). This framework is less relevant to this thesis as it focuses on the effect of stigma rather than the mechanisms that shape stigma.

Understanding attitude development is crucial as it shapes perceptions and behaviours (Haddock & Maio, 2017). Attitudes influence societal citizenship, can emerge from early socialisation (Gniewosz & Noack, 2015), and impact well-being (Shakespeare, Zeilig, & Mittler, 2019). Accurate measurement of attitudes is vital for informed public health decisions and effective interventions (Santesso et al., 2020).

Definitions of attitudes have evolved, initially encompassing 23 distinct definitions (Nelson, 1939). Contemporary definitions focus on attitudes as evaluations of objects, expressed through a psychological inclination of liking or disliking (Albarracin et al., 2014; Eagly, 1993; Eagly & Chaiken, 2007). A popular definition of attitudes includes that attitudes consist of cognitive, affective, and behavioural components (Eagly & Chaiken, 2007). This tripartite model views attitudes as multi-dimensional, with changes in one component influencing the others (Petty & Krosnick, 2014; Rosenberg et al., 1960). In contrast, the bipolar model focuses solely on cognitive and affective aspects. 'Attitude structure' involves determining whether attitudes are uni-dimensional, organised under a single belief (Samra, 2014), or multi-dimensional (bipolar or tripartite). It also examines whether attitudes are stable entities or constructs based on current information (Bohner & Dickel, 2011; Schwarz, 2007).

Using the tripartite model, latent attitudes are derived from evaluative statements on questionnaires (Gawronski & Bodenhausen, 2007). Ostrom (1969) supported the multi-dimensional model, showing stronger correlations within each tripartite component than between the different components of the tripartite model. Bagozzi (1978) also found unique variance for each component, albeit some evidence also suggests that there are intercomponent correlations, likely due to similar learning experiences (Greenwald, 1968). Unidimensional scales, such as Likert's, which use total sum scores to capture attitudes along a positive-to-negative scale (Likert, 1932), often fail to capture individual attitude nuances, as similar scores may not reflect identical cognitions and emotions (Donat, Brandtweiner, & Kerschbaum, 2007).

While attitudes can influence behaviour, attitudes can be inferred from our behaviour (Ajzen, 1991). The Theory of Planned Behaviour (TPB) suggests that behavioural intentions are influenced by attitudes (negative or positive), subjective norms (perceived judgements from parents and friends for example), and perceived control (an individual's perceived ability to achieve a given behaviour) (Conner et al., 2015; McEachen et al., 2016). Although TPB does not specify where beliefs originate from (Ajzen, 2011), it does point to background factors (e.g., direct experience and level of knowledge) (Fazio, Powell, & Herr, 1983; Kane, 1999). A strength of the TPB is that it can be empirically tested through regressions or structural equation modelling (Ajzen, 2020). In the context of the DRA literature, the primary outcome measured is

usually ‘attitude’ instead of treating behavioural intention as a separate main outcome (Hebditch et al., 2022).

Similarly, stigma models also typically focus on cognitive, affective, and behavioural responses (Pryor & Reeder, 2011). Stigma involves negative attitudes that lead the general public to fear, avoid, and discriminate against individuals with mental illnesses (Corrigan, Druss, & Perlick, 2014). The World Alzheimer’s Report (ADI, 2019) notes the lack of a unified theoretical approach to DRA in contemporary stigma models. Werner (2014) found that 73% of research between 1990 and 2012 did not use established theoretical models (Werner, 2014), with the remaining 27% primarily applying Corrigan’s (2000) Attribution Theory (Blay & Peluso, 2010; Herrmann et al., 2018; Young, Lind, Orange, & Sayundranayagam, 2019).

The Attribution Theory (Corrigan, 2000; Werner et al., 2019) explains how people attribute causes to behaviour, shaping attitudes towards conditions like dementia. In the context of DRA, this theory suggests that individuals may attribute dementia to internal causes, such as personal character flaws, or external causes, like biological factors. If dementia is seen as an internal issue, it may lead to social exclusion and negative DRA. Conversely, attributing dementia to external factors can foster empathy and support (Bernstein, Chen, Poon, Benfield, & Ng, 2018). While Attribution Theory helps us to understand the cognitive processes, it may oversimplify the complexities of stigma by overlooking culture, media influences, and individual differences (Banerjee, Gidwani, & Rao, 2020).

Corrigan and Watson's (2002) framework, part of Attribution Theory, categorises stigma into public and self-stigma, addressing cognitive (stereotypes), affective (prejudice), and behavioural (discrimination) aspects. The model's ability to isolate these concepts makes it valuable for empirical research, assessing public attitudes, and designing anti-stigma interventions for dementia (Kim, Richardson, Werner, & Anstey, 2021; Rüsch et al., 2005). Given its applicability to dementia, Corrigan’s model is useful for exploring DRA.

A more recent stigma framework by Pryor and Reeder (2011) integrates cognitive, affective, and behavioural responses, distinguishing between implicit (automatic) and

explicit (controlled) reactions (see section 1.3 for an overview on implicit and explicit attitudes). Their model highlights the importance of understanding both response types to improve stigma measurement and intervention effectiveness. The model suggests that stigma arises from cognitive representations that perceivers hold of stigmatised individuals, leading to negative emotional and behavioural responses. Research indicates that perceivers often have automatic aversions, followed by controlled reactions, reinforcing negative responses. Incorporating both implicit and explicit measures is essential for enhancing the validity and reliability of stigma research (Cvencek, Meltzoff, & Baron, 2012; Pryor & Reeder, 2011).

1.3 Overview of attitude measurement

Explicit measures are thought to be confined by consciously endorsed attitudes (Brauer, Wasel, & Niedenthal, 2000; Devine, 1989), while implicit measures are thought to capture unconscious attitudes that is independent of motivations (Gawronski et al., 2007). Since prejudice is thought of as a multidimensional construct (Samra, 2014), it is likely to consist of automatic activation, biased attributions, as well as conscious actions and attitudes towards the target group. Implicit attitude measures are typically experimental paradigms such as response interference tasks. An example of such implicit attitude measures is the implicit association test (IAT) (Greenwald, McGhee, & Schwartz, 1998), affective priming (Olson & Fazio, 2003), and semantic priming (Gawronski, 2007).

Studies often find low or non-significant correlations between explicit and implicit measures of attitudes (Hofmann, Gawronski, Gschwendner, Le, & Schmitt, 2005; Phipps, Hagger, & Hamilton, 2019). This supports the notion that explicit and implicit measures tap into different aspects of attitudes. Alternatively, it may reflect that the two are influenced by different underlying processes (Rudman, Phelan, & Heppen, 2007). Developmental events are thought to distinctively predict implicit attitudes, while more recent events are distinctively predicted by explicit attitudes. Three notable studies' findings highlight that early experiences may need to be emotional to influence implicit attitudes (Greenwald & Banaji, 1995; Rudman, 2004; Wilson, Lindsey, & Schooler, 2000). Implicit attitudes are thought to derive from early experiences in socialisation. That is, implicit attitudes are thought to stem from an associative learning system compared to explicit attitudes which stems from a more reflective

learning system. Associative learning systems are influenced mostly by emotion (DeCoster, Banner, Smith, & Semin, 2006). To effect, implicit attitudes are influenced via affective mechanisms. Therefore, it is likely that different events contribute to implicit and explicit attitudes. This may explain why implicit and explicit attitudes do not correlate with each other often or have a low correlative relationship (Rudman et al., 2007). There are likely conceptual distinctions between automatic and controlled evaluations (Rudman et al., 2007). In contrast, some studies have found a moderate correlation between the two (Hofmann et al., 2005).

The use of implicit measures has been used widely in developmental research generally, particularly in younger children, and can be used alongside explicit measures (Greenwald, Nosek & Banaji, 2003). In a meta-analysis looking at the relationship between implicit and explicit attitudes in children, the authors confirmed that methodologically, IAT has superior reliability in children compared to other types of implicit tests (Degner & Wentura, 2010).

There is generally a limited number of studies in the DRA literature that have explored the relationship between implicit DRA and explicit DRA. An implicit measure that explores attitudes towards various social groups including older adults, is the implicit relational assessment procedure (IRAP) (Cullen, Barnes-Holmes, Barnes-Holmes, & Stewart, 2009). However, comparisons between the IRAP and self-report measures demonstrate that implicit bias is not revealed in self-report questionnaires (Nicholson & Barnes-Holmes, 2012). In the context of DRA, IRAP alongside a self-report DRA measure (DAS) demonstrated that young adult participants from the UK (aged 18 to 25) ($n = 56$) displayed significant negative DRA. However, there was little to no correlation between IRAP and DAS trial types (Kane et al., 2020). This reflects similar associations within the broader implicit-explicit attitudes literature (Schimmack, 2021). While the authors identify that the small sample size was a limitation of the study, the topic of DRA has not been previously explored in IRAP research (Kane et al., 2020).

This highlights that implicit measures may be capturing a unique aspect of attitudes that cannot be captured by explicit measures alone. Incorporating implicit measures alongside traditional questionnaires could provide novel insight into previously

unexplored dementia biases (Kane, Murphy, & Kelly, 2020). It may be possible that various factors influence the relationship between explicit and implicit measures. This includes social desirability, context, and individual differences (Hofmann et al., 2005).

Social desirability refers to the tendency of responding to questionnaires in a way that will be viewed as favourable by others (e.g., over-reporting socially acceptable attitudes) that lead to under-reporting true attitudes (e.g., less socially acceptable attitudes) (Ried, Eckerd, & Kaufmann, 2022). Controlling for demographic variables can help ensure that the relationship between explicit and implicit attitudes are more likely due to the construct rather than demographic characteristics (Charlesworth & Banaji, 2022). Age, for example, can shape implicit attitudes. Implicit biases against outgroups are detectable from an early age (Degner & Wentura, 2010). Other studies have demonstrated that younger and older participants differed in their implicit anti-old/pro-young attitudes across several countries with younger people exhibiting stronger implicit pro-young/anti-old biases than older people (Charlesworth & Banaji, 2022).

It is important to assess the association between explicit and implicit attitudes with social desirability to not only limit the likelihood of its occurrence, as it undermines the validity of findings, but also to understand what groups are susceptible to responding in a socially desirable way. For example, a study which examined social desirability (via the Children's Social Desirability Short Scale) in 843 10-year-olds, found that the tendency to give socially desirable answers is higher in girls than boys (Camerini & Schulz, 2018).

1.4 Attitudes across the life span

This thesis considers the ABC (affective, behavioural, and cognitive) model as the primary framework for examining attitude formation. The ABC model is a broad attitude model that describes how attitudes are shaped by affective, behavioural, and cognitive components (Breckler, 1984). While this framework has similarities with Corrigan and Watson's model, in respect to viewing attitudes as multi-dimensional and consisting of these three components, Corrigan and Watson's framework

specifically focuses on stigma from the lens of the social impact of stereotypes, prejudice, and discrimination (Corrigan & Watson, 2002).

Attitude formation involves continuously evaluating information and developing beliefs or feelings toward an attitudinal target (e.g., dementia) (Albarracin & Shavitt, 2018; Crano & Prislin, 2011). Attitudes are both memory-based and constructed in the moment, integrating new information with existing knowledge stored in long-term memory (Calanchini & Sherman, 2013). Negative information tends to have a greater impact on shaping attitudes than positive information (Bakanauskas, Kondrotienė, & Puksas, 2020). Anderson's Associative Network Notation (AANN) model supports this, suggesting that attitudes are formed by integrating new information with existing categories stored in memory (Anderson, 1983). In the context of adolescents, AANN would imply that limited experiences with dementia may lead them to rely on related categories in their memory to form attitudes about it.

Research on adolescent attitude formation often utilises the eco-contextual model (Petani, 2011). The term eco-contextual refers to how ecological (environmental) and contextual (social and cultural) factors shape individuals' attitude (Petani, 2011). The term captures the different systems that influence development. This aligns with Bronfenbrenner's (1977) Ecological Systems Theory, which initially defined these systems that influence development. The Ecological Systems Theory outlines how children and adolescents' attitudes are shaped by three main systems. First is the microsystem. This involves direct communication and parental upbringing. Second is the exosystem. This includes schools and immediate surroundings that impact the adolescent indirectly. Third is the macrosystem. This encompasses cultural influences and traditions (Bronfenbrenner, 1977; Perron, 2017; Petani, 2011).

Each component of this model contributes uniquely to attitude formation. The microsystem shapes attitudes through direct interactions with family and peers, while the exosystem, particularly schools, provides structured environments where attitudes can be influenced by curriculum and peer interactions. Schools offer consistent settings for interventions that can promote positive attitudes on a broad scale, integrating lessons on social justice and inclusion. The macrosystem guides how

adolescents perceive social groups through societal norms and values (Lam, Shum, Chan, & Tsoi, 2021).

Adolescence, particularly between the ages of 11 to 18, is a crucial period for attitude development due to significant cognitive, emotional, and physical changes. Adolescents develop advanced cognitive abilities, such as abstract thinking, enabling them to form nuanced attitudes. This developmental stage also involves identity formation, making adolescents more receptive to interventions that consider multiple perspectives. In contrast, younger children's attitudes are more influenced by immediate surroundings (e.g., parental and authoritative figures), while older individuals have more stable attitudes, although life experiences can still lead to attitude changes (Bassili, 2008; Krosnick & Alwin, 1989).

Integrating the ABC model with the eco-contextual model provides a comprehensive approach to understanding attitude formation during adolescence, considering the interplay of memory, social factors, and developmental changes.

1.5 Thesis position on attitude and stigma-related frameworks

This thesis adopts a definition that views attitudes from the lens of the tripartite model, consisting of cognitive, affective and behavioural components. These components are thought to capture the multifaceted nature of attitudes. Both stable and constructionist entities are likely to be relevant (Albarracin & Shavitt, 2018) to adolescents. This is since younger adolescents are less likely to have experienced dementia compared to adults (i.e., due to less life experience on difficult life problems – Pasupathi, Staudinger, & Baltes, 2001), and therefore have less schema to form associations.

There is limited research that integrates a theoretical framework when understanding stigmatic beliefs towards dementia in young people (Werner, 2014). One notable study by Werner examined public stigma amongst Israeli and Greek college students by assessing the cognitive, emotional and behavioural aspects of public stigma (stereotypes, prejudice, and discrimination). The evidence favoured Corrigan's (2000) Attribution Model for explaining public stigma towards AD (Werner et al., 2019). This thesis therefore adopts a flexible and unified framework that accepts the

interconnectedness of tripartite constructs, while acknowledging their distinctive phenomena. The main frameworks include the Attribution Model (Corrigan, Markowitz, Watson, Rowan, & Kubiak, 2003; Weiner & Weiner, 1985) due to the prominent use of the model in the DRA literature, and Pryor and Reeder's (2011) position where explicit and implicit measures are both used. The term 'DRA' is used to encompass the related terms used in the literature under the discourse of public stigma in dementia (i.e., beliefs, emotions, and behavioural tendencies that range from positive to negative) since literature using the terminology 'attitudes' also encapsulates these elements (Eagly, 1993; Link & Phelan, 2001). This aligns with attitude theory and global policy objectives.

1.6 Young people in the context of dementia

Apart from a few exceptions, young people are often neglected in dementia strategies and policy, although they are not immune from the impact of dementia. Previous research has shown that 45.8% of adolescents have spent time with someone with dementia (Farina, Hughes, Griffiths, & Parveen, 2020a). There is also a growing number of grandchildren of people living with dementia (Celdrán, Triadó, & Villar, 2011), which is not surprising given the estimated 1.8 million multigenerational households in the UK (CBRE, 2021). However, establishing the extent to which young people care for people with dementia is difficult since there are no national surveillance figures (Algar & Windle, 2023; Masterson-Algar et al., 2023; National Children's Bureau, 2016; Santini et al., 2020; Venters & Jones, 2021). A prior study highlighted that nearly a quarter of adolescents have provided some form of care (i.e., "looked after") for someone with dementia in the past (23.2%, n=901; 13-18-year olds) (Farina et al., 2020a). The study did not claim to be representative, however, applying this figure to national statistics could mean that 1.6 million young people have provided care for someone with dementia. This frequency of direct contact could be captured in a more diverse cohort of British adolescents so that there is a more representational understanding of these experiences.

It is also unclear whether these personal experiences of dementia inform dementia attitude formation. Typically, how adolescents acquire their dementia-related information is thought to come from a range of sources such as parents, grandparents

and TV (Cahill, Pierce, Werner, Darley, & Bobersky, 2015; Farina et al., 2020a; Felc & Felc, 2021; Olsen et al., 2020; Parveen, Griffiths, & Farina, 2020b). However, the accuracy and quality of this information are not well understood. Generating a more accurate picture of young people's experiences, how DRA can form, and whether they are susceptible to change over time, will better inform policymakers about what support and guidance young people may require.

Fostering awareness of dementia also makes theoretical sense in adolescents as posited by developmental models (Farina, Griffiths, Hughes, & Parveen, 2022). Adolescents are particularly thought of as ideal targets for anti-stigma initiatives due to the 'impressionable years hypothesis' (Krosnick & Alwin, 1989). This theory outlines that adolescence is a key developmental stage that plays a major role in shaping attitudes, where relationships and social networks established during this developmental period contribute to their perceptions and worldviews. The impressionable years hypothesis is a prominent hypothesis relating to age and attitude change susceptibility. Krosnick and Alwin argue that adolescents are highly susceptible to attitude change. Once people pass early adulthood, this susceptibility to attitudinal change is low (Krosnick & Alwin, 1989). It is theorised that socialising experiences at a young age significantly impact people's thoughts throughout their lives (Birch & Birch, 1997). Once early socialisation passes, flexibility decreases and change in attitudes is less likely (Krosnick & Alwin, 1989). Understanding the role played by other's views on adolescents (i.e., friends, family, or social media inputs), remains an important focus in attitude research. Nevertheless, the exploration of these influences and their impact on dementia experience in adolescents is still in its infancy (Farina et al., 2020a).

While the impressionable years hypothesis is a useful framework for understanding adolescent attitudes, it is limited by its over-generalisation, given the likelihood that there is not a 'one size fits all' approach to attitude change. The model fails to provide sufficient perspective on potential individual differences. For example, particular groups of people may display one pattern of attitude change over the lifespan that differs from others. Thus, the model lacks an account for complex factors influencing attitudes across the lifespan (Peterson, 2017). Moreover, it may not fully account for attitudes beyond the critical developmental window (i.e., adolescents approaching adulthood). At ages 17 and 18, adolescents may display openness to new perspectives,

while forming persistent beliefs. Thus, the model should be considered as one part of the explanation of adolescent attitudes, rather than the whole piece of the puzzle. This is particularly relevant if applying the model to attitude change interventions, which may not be as useful in explaining attitude patterns for those transitioning between adolescence and adulthood. Other theories may help explain attitude formation and change during this transitional period. Other attitude flexibility explanations that also have empirical support include the lifelong openness model, for example, which is where individuals are thought to have adaptable attitudes throughout their life span (Tyler & Schuller, 1991). Meanwhile, the increasing persistence hypothesis explains that individuals persist in holding certain attitudes which strengthen over time (Dinas, 2013; Krosnick & Alwin, 1989).

1.7 Dementia stigma reduction initiatives

Only five out of 37 countries have tailored dementia awareness initiatives for specific audiences (WHO, 2021b). However, the report (WHO, 2021b) does not explicitly state whether any of these initiatives target young people. A scoping review identified key components of such initiatives to reduce the stigma of dementia including education (dispel myths with facts), contact (direct and indirect interaction with people with dementia), mixed approaches (education and contact), and protest (challenge negative attitudes) across 21 studies (Bacsu et al., 2022). Education and contact are the most commonly used. However, the findings highlighted the need for more dementia awareness, tailoring to preferred modalities of education (e.g., videos and social media) for young people. A key component of this study was the importance of targeted interventions tailored towards specific age groups. Few studies addressed the importance of culture or geographic context (e.g., urban, rural, or remote) in developing interventions to reduce the stigma of dementia (Kontos et al., 2018; Zheng, Chung, & Woo, 2016). However, local culture and context play an important role in addressing stigmatising beliefs surrounding dementia. Accordingly, more research is needed to develop culturally and geographically informed interventions to address negative DRA. In addition, future studies need to clearly define DRA and articulate the specific measures used to assess it, to enhance the replicability and utility of the study findings (Bacsu et al., 2022).

Where interventions are successful, the effects tend to be modest, with significant heterogeneity of short-term and long-term effects reported in the population health literature more broadly (Michie, Johnston, Francis, Hardeman, & Eccles, 2008; Michie & West, 2021). For example, small to moderate positive impacts are observed from both mass media campaigns and interventions for target groups in terms of knowledge, attitudes, and intended behaviour. However, the limited evidence from follow-up data suggests it is not clear whether short-term contact interventions have a lasting impact (Gronholm, Henderson, Deb, & Thornicroft, 2017). In anti-stigma initiatives towards specific target populations, those that are contact based, appear to demonstrate short-term improved attitudes, but this is less evidenced in demonstrating significant changes in the level of knowledge (e.g., Heger et al., 2020).

In 2015, the Prime Minister of the United Kingdom updated the national dementia challenge policy to include the aim for the younger generation, including all primary and secondary schools to increase awareness and understanding of dementia (Policy paper: Department of Health and Social Care, 2015). This policy is likely to be welcomed by young people who have shown a desire in learning about dementia (Parveen, Farina, Shafiq, Hughes, & Griffiths, 2020a). Schools are a modality to the community whereby an intervention can reach a large cross-section of society (Cheney, Schlösser, Nash, & Glover, 2014; Dimond & Freudenberg, 2016). In addition, this reach is further amplified by the potential transfer of knowledge from children to parents (Istead & Shapiro, 2013; Stephan, 2020), thus providing opportunities to spread messages to communities that are often considered ‘difficult to access’ (Dimond & Freudenberg, 2016). Schools can therefore be effective in delivering national and widespread interventions, particularly in the knowledge that all members of society should strive for positive attitudes (Lloyd, 2006), not just a select subgroup. This is supported by Baker and colleagues who argue that there is a need to tackle attitudes at a generational level given that stereotypes are more susceptible to change in early adolescence and that adolescents display more responsiveness to anti-stigma education (Baker et al., 2018a; Baker et al., 2019; Werner, Jabel, Reuveni, & Prilutzki, 2017).

In the context of higher education, the ‘Time for Dementia’ educational programme based in England aims to increase positive dementia attitudes and knowledge, and

interactions with dementia in healthcare professionals (Banerjee et al., 2017). Understanding DRA in those who are in healthcare education is of value, as they represent a group more likely to work with people with dementia. The programme pairs healthcare students with families affected by dementia which allow students to gain first-hand experience of living with dementia over time (Daley et al., 2023). Although this programme is not specifically adolescent-focused, the premise of the programme highlights that early and meaningful interactions can increase dementia knowledge and foster positive attitudes among future healthcare professionals. This provides a rationale for engaging adolescents and schools in stigma reduction efforts at an earlier developmental stage, when attitudes are still forming.

Adolescents can also be considered future health practitioners and carers and choose subjects at school that align with their developing interests in their future careers. It may be useful to capture how factors that influence attitudes may relate to future willingness to work with people with dementia through behavioural intention measurement. Exploring this can provide insight into whether there is a lack of interest in working with people with dementia in the next generation. This allows policy makers to make decisions on how to address this challenge. However, it is not clear what factors are associated with willingness to work with dementia in adolescents. Attitude theory and empirical evidence suggest that attitudes are likely to predict and be associated with behavioural intention (i.e., TPB) (Ajzen, 2011; Ajzen et al., 2018). For example, positive attitudes are associated with a greater willingness to engage in geriatrics, while negative attitudes may be a barrier (Guo et al., 2021). Thus, DRA may be associated with willingness to work with people with dementia.

Despite the potential theoretical benefits of anti-stigma and dementia awareness initiatives in schools, the evidence base within this area is still weak. Moreover, the limited success of current dementia awareness initiatives may be due to their failure to target the correct mechanisms to change DRA. For instance, the widespread roll-out of dementia awareness sessions like Dementia Friends in adolescents is often seen as inherently beneficial, despite evidence of low efficacy (Farina et al., 2020b). The Dementia Friends initiative in England, developed by the Alzheimer's Society (2015), aims to increase understanding of dementia by providing one-off information sessions for both adolescents and adults. These sessions are designed to tackle the stigma and

discrimination that people with dementia face (Alzheimer's Society, 2023; Farina et al., 2020b). However, studies evaluating the effectiveness of Dementia Friends in British adolescents found little to no improvements in DRA. Scores between those in the dementia awareness group and the control group did not significantly differ (Farina et al., 2020b). These findings may be due to the brevity of the one-off session or the ineffectual mechanisms applied by the initiative. Research demonstrates that contact rather than awareness raising could be more effective in reducing DRA since there is less evidence supporting achieving attitude change in short-term knowledge-based approaches (Gronholm et al., 2017). However, positive contact exchanges and education together are relatively effective for young people (Corrigan Morris, Michaels, Rafacz, & Rüsch, 2012).

Intergenerational initiatives involve people from different generations doing activities together (Gerritzen, Hull, Verbeek, Smith, & de Boer, 2020). This can be people living with dementia and children engaging in music, games, and education together, which can provide mutual understanding, reduce dementia stigma, and improve the well-being of both generations. However, generalisability is limited due to small effect sizes, small sample sizes (Galbraith, Larkin, Moorhouse, & Oomen, 2015), or lack of validated outcome measures (Di Bona, Kennedy, & Mountain, 2019; Skropeta, Colvin, & Sladen, 2014). The practical challenges around implementing all these types of initiatives include the concern about the potential negative impact of participation (i.e., worsening attitudes) and difficulty in selecting appropriate activities (Jarrott & Bruno, 2007). To address these concerns, further research is needed to better understand the mechanisms behind DRA (e.g., the role of knowledge and contact), which this thesis aims to contribute to. By focusing on these mechanisms, this research will help to inform and improve the design of future initiatives for young people, ensuring they are grounded in a stronger evidence base (Galbraith et al., 2015). This will enable stakeholders to better deploy evidence-based initiatives that are cost- and time-effective. These are more likely to be adopted within schools and wider communities.

Anecdotally, there is a tendency for anti-stigma initiatives to be developed from the ground up by well-meaning advocates, with theory and evidence often taking a back seat. Understanding the factors that drive DRA, how knowledge, contact, and attitudes

interact, and within the target population (i.e., young people), may improve the effectiveness of these initiatives. While the literature does highlight some evidence on the effectiveness of anti-stigma initiatives in the school setting, caution is needed in inferring this from similar studies in adults to adolescents in absence of clear evidence. For example, one program called 'In Our Own Voice' demonstrated positive outcomes in adults but disappointing results in young people (Mellor, 2014; Pinto-Foltz, Logsdon, & Myers, 2011). This demonstrated that transferring interventions from adults to young people may not be effective because they likely use different mechanisms. In a meta-analysis by Corrigan and colleagues, it was shown that contact-based anti-stigma initiatives were superior to pure education initiatives in adults. However, this was not demonstrated in adolescents, with a mixed intervention approach for adolescents thought to be more effective (Chen, Koller, Krupa, & Stuart, 2016; Corrigan et al., 2012; Mellor, 2014).

1.8 Factors associated with dementia attitudes

There is generally a limited understanding of what factors determine DRA in the first place. A comprehensive systematic literature review on the topic found that in the general public, stigmatising attitudes were more evident in individuals who had limited contact with people with dementia, those with limited dementia knowledge, men, and younger individuals (Herrmann et al., 2018). These factors have also been identified in other reviews (Blay & Peluso, 201; Nguyen & Li, 2020) and studies (Cheston et al., 2019; Werner, Goldberg, Mandel, & Korczyn, 2013).

Importantly, there is a need to distinguish whether the determinants of DRA are predominantly modifiable ones in the context of anti-stigma initiatives that make them ideal targets (e.g., level of contact and level of knowledge) or whether they are mostly non-modifiable where we can identify groups most at risk of stigmatising attitudes (e.g., age and sex). Identifying groups most at risk of stigmatising attitudes are important so that we can develop interventions for these groups. While it is not possible to change people's sex, we can develop sex-specific interventions that address underlying factors contributing to DRA. This knowledge will be generated by this thesis and is essential to curating an intervention that is rooted in evidence and tailored specifically for the targeted population.

This section also highlights how different factors and mechanisms likely interact with each other. This is likely linked to differences in socialisation, personal experiences (e.g., contact with dementia), and societal expectations (e.g., gender roles and caregiving differences amongst different ethnic and religious groups) (Naz, de Visser, & Mushtaq, 2022). Currently, there is no analysis in the DRA adolescent literature that explores all these factors together. Exploring mediatory interactions between the factors may help begin to explain how DRA forms in the first place in adolescents.

This section touches on some of the potentially relevant factors in this thesis. See Table 1 for an overview of the factors.

Table 1 - Overview of factors

Non-modifiable Factors	Summary	Key references
Cultural	Dementia often linked to broader social meanings such as ageing. Caring expectations and level of dementia knowledge vary across cultures, influencing DRA. DRA may differ cross-culturally across generations (age differences). White British over-represented in DRA research, limiting our understanding of cultural factors on DRA. Potential interaction effects with ethnicity or religion: ageism (ageing), age, knowledge, and DRA.	Botsford et al., 2011; Johl et al., 2016; Kafadar et al., 2021; Mukadam et al., 2011; Young et al., 2019.
Sex	Females display better DRA than males. Potential explanation: empathy differences (empathy peaks at difference points for male and females in adolescence); empathy underpins prejudice. Gender roles: females engage in more caregiving and family socialising, increasing empathy and contact with dementia. Males have less dementia contact, leading to lower knowledge and more negative DRA. Potential interaction effects with sex: empathy, contact, knowledge, age, and DRA.	Blay & Peluso, 2010; Carvalho, 2015; Cheng et al., 2011; Cheston et al., 2016; Cheston et al., 2019; Farina et al., 2020a; Miklikowska, 2018; Van der Graaff et al., 2018.
Age	DRA differences between those over age 18 and under 18. Key developmental milestones in maturity, empathy, and experience. There is a research gap in exploring different adolescents ages in DRA research despite developmental differences. Potential interaction effects with age: empathy, knowledge of dementia, contact, and DRA.	Allport, 1954; Batson et al., 1997; Wu et al., 2022.

Note. DRA = Dementia-related attitude

Continued. Table 1 - Overview of factors

Modifiable Factors	Summary	Key references
Awareness	Little change in public awareness of dementia. Adolescents exposed to information (and misconceptions) through media. Adult literature: dementia knowledge influences contact, DRA, and dementia career intentions. Adolescents gain knowledge from direct (e.g., parents) and indirect (e.g., media) sources. Dementia knowledge and contact are expected to influence DRA and behavioural intention outcomes.	Cahill et al., 2015; Curran et al., 2015; Farina et al., 2020a; Felc & Felc, 2021; Olson et al., 2020; Scott et al., 2019.
Media	Film and media contribute to dementia awareness. Media can reinforce misconceptions of dementia through ageist portrayals. Adolescents engage with dementia indirectly via media, but its impact on DRA is unclear. Potential interaction effects: level of dementia knowledge and contact (information gained from the media is also a source of indirect contact); and ageism (ageist media portrayals) which may lead to negative DRA.	Farina et al., 2020a; Harper et al., 2019; Hillman & Latimer, 2017; Low & Purwaningrum, 2020; Milne, 2010; Mukadam & Livingston, 2012.
Dementia Education	Greater dementia knowledge associated with more positive DRA. Existing dementia awareness programmes lack robust evaluation. Theatre, film, and storytelling improve dementia awareness and DRA in young people. Effectiveness of stand-alone vs. contact-based education is unclear. Integrating education with contact strategies might be more effective. Possible interaction effects: dementia contact, dementia knowledge, and DRA.	Atkinson & Bray, 2013; Bacsu et al., 2022; Chow et al., 2018; Di Bona et al., 2019; Farina et al., 2020b; Gronholm et al., 2017; Lokon & Parajuli, 2017; Mukadam & Livingston, 2012; Parveen et al., 2015.
Contact	Direct contact with dementia associated with positive DRA in the adult literature. Direct contact can reduce prejudice by increasing empathy. Quantity and quality of contact shapes attitudes. Contact alone may not change stereotypes-positive, frequent contact is key. Sources of contact include grandparents, TV, but quality of contact is not yet quantitatively explored or whether direct or indirect contact is more influential on DRA. Potential interaction effects: all listed factors.	Allport, 1954; Batson et al., 1997; Cahill et al., 2015; Cheston et al., 2016; Cheston et al., 2019; Farina et al., 2020a; Felc & Felc, 2021; Kim et al., 2021; Mukadam & Livingston, 2012; Pettigrew & Tropp, 2008; Tajfel & Turner, 1986.

Note. DRA = Dementia-related attitude

1.8.1 Modifiable determinants

Awareness

Media

It is argued that there has been little change in public awareness of dementia over the years (Olsen et al., 2020), with evidence suggesting that dementia knowledge in the UK remains poor (Cahill et al., 2015). Media is one way of creating awareness of dementia. Film and media are thought to influence DRA (Hillman & Latimer, 2017). However, the media can be a common source of misconception and stereotyping of dementia through the negative and ageist portrayals of dementia. This could worsen stigma and discrimination towards people living with dementia (Low & Purwaningrum, 2020) as the depiction of dementia is usually negative and fear-inducing (Evans, 2018; Hillman & Latimer, 2017; Zeilig, 2015). Ageism (defined as discrimination towards age) is distinct from DRA (dementia specific discrimination), but do overlap in underlying constructs of stigma (i.e., Attribution Model mechanisms) (WHO, 2021a), sharing features such as stereotyping towards a particular group. In contrast, some argue that public messaging campaigns and more recent portrayals of dementia are increasingly positive (Harper et al., 2019; Mukadam & Livingston, 2012), especially with the awareness of dementia raised by high-profile celebrities (Milne, 2010; Olsen et al., 2020; Zeilig, 2015).

Given that young people have the highest media usage (Goodyear, Armour, & Wood, 2018; Livingstone & Third, 2017), media may play a role in shaping DRA, especially since 66.4% of adolescents in England have never been taught about dementia in school (Farina, 2020). Empirically, adolescents primarily have indirect contact with dementia through media (n = 901, 77.3%) (Farina et al., 2020a), but the extent of media's influence on adolescents' perceptions of dementia currently remains limited. It is also not known whether ageism and media (indirect contact) interact in their potential influence on DRA in adolescents, given the overlap in DRA and ageism. Media can significantly shape public attitudes towards various conditions, often perpetuating stigma towards mental illness and disabilities. For example, the media frequently reports negative news about individuals with Schizophrenia (Maletta & Vass, 2023) and typically portrays disabilities as a significant life obstruction

(Vertoont et al., 2022). However, there are positive counter-frames, such as balanced media coverage of the Paralympic games, which enhances disability visibility and reduces stigma (Kolotouchkina, Llorente-Barroso, García-Guardia, & Pavón, 2021).

Dementia education

Increasing public dementia knowledge and awareness is a key priority in global dementia action plans (Cahill, 2020; WHO, 2021b). Dementia awareness initiatives and education programmes aim to increase dementia knowledge, improve DRA, and improve early dementia symptom recognition (ADI, 2019; WHO, 2012). Greater dementia knowledge is generally associated with more positive DRA (ADI, 2019; Casado, Hong, & Lee, 2018; Mukadam & Livingston, 2012).

Various educational interventions have been evaluated for their effectiveness in raising dementia awareness. For instance, the 'Understanding Dementia Massive Open Online Course' has improved global dementia knowledge, with positive results regardless of participants' educational background or prior experience (Eccleston et al., 2019). Similarly, the 'Un Café por Alzheimer' initiative improved general knowledge of Alzheimer's Disease through in-person and online sessions (Friedman et al., 2016). However, public health campaigns in the Netherlands aimed at raising dementia awareness did not significantly increase overall awareness (Heger et al., 2020).

Dementia awareness initiatives specifically developed for adolescents do exist (Atkinson & Bray, 2013; Chow et al., 2018; Parveen, Robins, Griffiths, & Oyebode, 2015). However, these have not been robustly evaluated (Farina et al., 2020b). Some evidence suggests that in adolescents, theatre and film is used to convey dementia education with research-informed plays, art (Lokon & Parajuli, 2017), and films improving knowledge and DRA (Zheng et al., 2016). Contact interventions such as intergenerational storytelling have positively improved dementia awareness and DRA. One such intervention is the 'Adopt a Care Home' initiative in England, which demonstrated an effective increase in children's (aged 10) knowledge of dementia through direct interaction with people with dementia (Di Bona et al., 2019). These diverse dementia education initiatives highlight the importance of tailored, evidence-

based approaches to effectively improve dementia knowledge and reduce negative DRA across different populations within the general public (Bacsu et al., 2022).

The mixed findings on the effectiveness of dementia education highlight two main issues. First, there is a need for more robust evaluations of dementia education interventions due to the lack of rigorous evaluation (Farina et al., 2020b; Matsumoto, Maeda, Igarashi, Weller, & Yamamoto-Mitani, 2021). Secondly, it is unclear which type of dementia education (stand-alone or combined with contact strategies) is most effective. Evidence suggests that combined approaches may be effective for young people (Gronholm et al., 2017). Single-session interventions like the 'Dementia Friends' initiative (see section 1.7) have shown insufficient impact on attitudes or knowledge. While brief interventions can be beneficial in raising awareness and improving stigma-related knowledge, the evidence that they create lasting change in attitudes is weak (Thornicroft et al., 2016).

Contact

Understanding the role of contact in attitudes is important because social categorisation, as proposed by the intergroup theory (Allport, 1954; Tajfel, Billig, Bundy, & Flament, 1971), leads to discrimination (Bigler, Jones, & Lobliner, 1997). Intergroup Contact Theory suggests that interaction between members of different social groups can reduce prejudice and improve intergroup relations under the right conditions. Intergroup processes are considered important components of stereotyping and prejudice in young people (Sherif & Sherif, 1953 cited in Kessler & Mummendey, 2008, p. 295). One study found that negative intergroup attitudes in children can influence a range of behaviours, including helping behaviour (Katz & Cohen, 1976 cited in Sierksma, 2022). Social identity theory supports this by stating that categorisation involves grouping ourselves and others into distinctive categories, with inferences based on stereotypes (Abrams & Hogg, 2010). Social identity refers to how individuals perceive stereotypical ingroup attributes (Verkuyten, 2021). For example, outgroup stereotypes about older adults can be neutral, positive (older adults are knowledgeable), or negative (older adults no longer contribute to society). These evaluative elements shape the overall image of social categories and groups (Global Report on Ageism, WHO, 2021a).

There is an association between level of contact and DRA found in the adult DRA literature (Aihara, Kato, Sugiyama, Ishi, & Goto, 2020; Cheston, Hancock, & White, 2019; Kim et al., 2021; Mukadam & Livingston, 2012), healthcare professionals (Lokon, Li, & Parajuli, 2017; Zhao, Jones, Wu, & Moyle, 2022), and the broader student population including college and university students (Liu, Yan, Wang, & Jiang, 2022). This is also evident in adolescent mental illness stigma literature (Addison & Thorpe, 2004; Greenblatt, Pinto, Higgins, & Berg, 2016). Direct contact with dementia (i.e., first-hand experience) is thought to mediate more positive DRA compared to those with no experience with dementia (Cheston, Hancock, & White, 2016). Contact with dementia is a popular approach in anti-stigma initiatives due to its support (Mukadam & Livingston, 2012). A meta-analysis of over 500 studies showed that direct contact can reduce prejudice through increased empathy and perspective-taking (Pettigrew & Tropp, 2008). Empathy is the ability to recognise and comprehend the feelings of others and so relate to other people (Vossen & Valkenburg, 2016). Empathising with a member of a stigmatised group can reduce prejudice towards the entire outgroup and foster positive attitudes (Batson et al., 1997). This is known as the empathy altruism hypothesis (Batson et al., 1991; Batson, Chang, Orr, & Rowland, 2002). A recent study by Matera and colleagues demonstrated this. The authors found that direct interactions with people with disabilities in students aged 11-17 (n = 437) significantly enhanced empathy and reduced prejudice more effectively than hypothetical scenarios. Direct contact fostered deeper understanding through perspective-taking, increasing positive attitudes (Matera et al., 2021). Thus, from a theoretical perspective (empathy altruism hypothesis and intergroup contact theory), empathy and contact may interact with each other to influence DRA. Though, it is not currently understood which influences the other, or whether this relationship is reciprocal.

Social identity theory (Tajfel & Turner, 1986 cited in Harwood, 2020), which describes how individuals categorise themselves and others into social groups (i.e., ingroup versus outgroup), can help us understand adolescents' contact with dementia (outgroup). Once establishing whether the level of contact is a strong factor associated with DRA in this demographic, this information can inform the most suitable type of contact for anti-stigma initiatives in this age group (face-to-face or indirect contact) (Parveen et al., 2020b). Cost-effective, indirect contact-based stigma reduction

initiatives may fail to significantly change attitudes, while direct contact can be more resource-intensive. Allport (1954) suggested that the factors influencing attitudes include the quantity (frequency) and quality (relationship context and social atmosphere) of contact (Allport, 1954; Hewstone, 2015). Qualitative evidence suggests that the relationship between contact level and DRA may be more nuanced than 'more direct contact is better', as it can also provoke feelings of fear (Baker et al., 2018a). Allport also argued that contact alone cannot change stereotypes; frequency and positive quality contact are both necessary (Allport, 1954; Pescosolido, Martin, Lang, & Olafsdottir, 2008). Adolescents' contact with dementia is thought to come from various sources, such as parents, grandparents, and television (Cahill et al., 2015; Felc & Felc, 2021; Olsen et al., 2020), but these experiences have not been formally contextualised. For example, while we have some understanding of the frequency of adolescent contact with dementia (Farina et al., 2020a), the quality of this experience is yet to be explored quantitatively.

Descriptively, it would be useful to know whether adolescents perceive the information presented by the media as generally positive or negative, to begin unpicking this. The importance of contextualising this in the future is to better advocate for dementia messaging to consider that young people are also absorbing material about dementia, despite young people not being the usual target audience. This is important since how individuals perceive dementia can derive from social representations that establish a social reality which influence an individual's perception, beliefs, and behaviour according to the Cultivation theory (Romer, Jamieson, Bleakley, & Jamieson, 2014).

1.8.2 Non-modifiable determinants

Cultural factors

Cultural beliefs and religion significantly influence the conceptualisation of dementia within the general public (Algahtani et al., 2020). Current evidence suggests that dementia is viewed differently cross-culturally. Some perceptions of dementia across different cultures includes the belief that dementia is caused by an act of God (ADI 2019; Cations, Radisic, Crotty, & Laver, 2018) and the misconception that dementia is a normal part of ageing. This is thought to derive from other culturally rooted social

representations of ageing (Hulko, 2009; Kafadar et al., 2021; Young et al., 2019) which can drive negative DRA (Nwakasi, de Medeiros, & Bosun-Arije, 2021). Differences between various religions and ethnic groups also exist in level of dementia knowledge (Kafadar et al., 2021) as well the expectations for caring for someone with dementia within the family (Botsford, Clarke, & Gibb, 2011; Mukadam, Cooper, Basit, & Livingston, 2011). Given these distinctions, it is important to consider how different cultural and religious contexts may lead to differing DRA. As a result, capturing DRA in diverse demographics is important (Berwald, Roche, Adelman, Mukadam, & Livingston, 2016). In many of the studies exploring ethnicity and DRA, sample sizes are small (less than 200), which makes it difficult to generalise to the population. There is also a limited age range of participants (predominantly adults) (e.g., Nielsen & Waldemar, 2016) despite evidence of generational differences cross-culturally (Johl, Patterson, & Pearson, 2016). Moreover, a limited number of ethnic groups are included in such research, where the White British are over-represented compared to other groups (Kafadar et al., 2021). Therefore, our current understanding of the influence of cultural factors on DRA in adolescents is limited. This warrants further investigation.

Sex

Prior research suggests that females tend to display better attitudes than males towards people with dementia in the general public (Cheston et al., 2016).However, other studies have not always found sex differences in DRA (Shulman & Adams, 2002). Investigating the association between sex and DRA will help build its consensus as a socio-demographic factor. Although there is limited discussion for why sex differences in DRA may exist, one potential explanation is empathy differences between males and females (Trentini, Tambelli, Maiorani, & Lauriola, 2022). Developmental theories suggest that the development of prejudice towards stigmatised conditions is underpinned by empathy (Miklikowska, 2018). The development of empathy peaks and plateaus at different points for males and females during adolescence. Females mature quicker than males developmentally and empathetically (Van der Graaff, Carlo, Crocetti, Koot, & Branje, 2018). One longitudinal study found greater empathetic response in female than male adolescents at the same age (Mestre, Samper, Frías, & Tur, 2009). Sex differences are also found to have a larger effect size

as participants got older in the developmental stages (Colom & Lynn, 2004). Thus, sex as a variable could be dichotomised to gain a clearer understanding if males are at greater risk of developing negative DRA. Separately, there is evidence that empathy is influenced by contextual factors and can be biased through stereotyping and gender roles (Löffler & Greitemeyer, 2023). Gender norms is one potential explain for gender differences (Chung & Rimal, 2016). For example, females tend to have more direct contact with people with dementia than males (Rosato, Leavey, Cooper, De Cock, & Devine, 2019) and carry out more care work than males (Revenson et al., 2016), or are more involved in caregiving (Xiong et al., 2020) and family socialising (Carvalho, 2015). Female adolescents also tend to have more contact with dementia than males (Farina et al., 2020a). This in turn may influence attitudes (see section 1.8.1 on contact). There remains little understanding behind the drivers of sex differences in DRA in adolescents. Given the potential interplay between empathy, contact, age, and sex, it will be useful to explore whether sex influences DRA directly or interact with these potential mediatory factors.

This research considers both (biological) sex and (psychosocial) gender. Biological sex is relevant due to the differences in empathy, maturation, and developmental differences between males and females (Van der Graaff et al., 2018) which are rooted in biology (see Appendix B). This is particularly since these differences occur during puberty. Gender, on the other hand, is pertinent to the societal expectations and norms associated with being male and female, which can also inform attitudes and empathy (Löffler & Greitemeyer, 2023). Socialisation processes may also play a role in shaping attitudes (e.g., care roles) (Rosato et al., 2019). Theoretically, Social role theory highlights the role of gender-typed behaviours (gender norms) and attributes in shaping attitudes. It posits that behaviours are influenced by social norms that shape attitudes differently for males and females (Chung & Rimal, 2016). Thus, there is a complex interplay between sex, gender, and socialisation in influencing attitudes. Therefore, it is important to acknowledge this potential dynamic. See Appendix B for further rationale on the use of ‘sex’ and ‘gender’ terminology in the thesis chapters.

Age

Age is likely to influence attitudes (Ajzen, Fishbein, Lohmann, & Albarracín, 2018, p. 61). Research has shown that older people are more likely to hold stigmatising attitudes than younger people (McParland, Devine, Innes, & Gayle, 2012). Similarly, DRA differences have been demonstrated between those over the age of 18 and those under 18 years old (Wu, Leong, Che, Van, & Chuang, 2022). Older people may have a more balanced outlook on the reality of what it may be like to live with dementia due to greater cognitive maturity (Birch & Birch, 1997). However, the age range of participants in these studies has a considerable age gap. For example, in one study, the group 'under 65-year olds' included participants as young as 16 years old alongside those aged 60 (Cheston et al., 2016). This makes it difficult to ascertain whether there is a linear association with DRA. Moreover, age may interact with other factors such as cultural factors in influencing DRA. There is evidence that third-generation ethnic minorities held different dementia care attitudes than older generations from the same ethnic background (Lawrence, Murray, Samsi, & Banerjee, 2008). This suggests that older and younger generations may not share similar attitudes despite the same cultural background.

There are also key developmental milestones in cognitive maturity, understanding of the world with more life experience, and gaining social perspective over time on others behaviours and beliefs (see cognitive theories – Hess, 2006). This may lead to older adolescents exhibiting greater levels of dementia knowledge compared to younger adolescents, but also can lead to positive or negative DRA (Allport, 1954; Colom & Lynn, 2004). It would therefore be expected that age differences may be observable between different ages within adolescence in DRA and level of dementia knowledge. This is empirically supported in the ageism literature (John, 2013). However, current studies tend to recruit those either at the start of adolescence, mid-adolescence, or at the end of adolescence, making it more difficult to explore and compare DRA across the stages of adolescence. Further research is therefore warranted to address this gap.

Other developmental milestones include empathy differences at the start of adolescence before peaking during the middle and then can remain stable until after this mid-adolescent period. In particular, prosocial behaviours towards others increase over childhood and during mid-adolescence and shortly decline thereafter (Van der Graaff et al., 2018). There is evidence that suggests prosocial responding and empathy

are associated with less prejudice (Dovidio et al., 2010), with prosocial responding development at its peak between the ages of 13 and 18 years old (Eisenberg, VanSchyndel, & Spinrad, 2016; Silke, Brady, Boylan, & Dolan, 2018; Van der Graaff, et al., 2018). On the contrary, developmental changes during adolescence, such as brain maturation, may negatively influence adolescent's prosocial development by impacting emotion regulation during mid-adolescence (Crone & Dahl, 2012). These changes make it difficult for adolescents to direct their attention to others' emotional needs which diminishes prosocial inclinations (Padilla-Walker & Christensen, 2011; Van der Graaff et al., 2018).

While empathy is a potential explanation for the association between age and DRA, there is a dearth of studies exploring whether there is actually an association between empathy and DRA. It would be useful to not only explore the extent to which empathy is explored in the DRA adolescent literature, but also to identify if empathy is a mediator of DRA through interacting with socio-demographic variables like age.

1.9 Rationale for the thesis

The scope of this thesis is the focus on dementia with a specific emphasis on understanding what DRA look like in adolescents, alongside outcomes relating to behavioural intention towards dementia.

There is a need for more robust research outlining the determinants of DRA in young people to inform the development and successful delivery of more evidence-based anti-stigma interventions. Currently, adolescents under 18 years old are an overlooked age group within DRA and stigma research and policy. In the World Alzheimer Report (Attitudes to dementia), which was the largest study of its kind (sample size of 70,000 respondents), the report only captured DRA in those aged 18 and above (ADI, 2019). This means we only understand the drivers of DRA in a homogenous sociodemographic cohort, which does not necessarily reflect society as a whole. With these associations primarily drawn from the adult population, it leads us to infer associations in younger cohorts under age 18. However, associations found in the adult population may not necessarily be generalisable to younger cohorts. Specificity in

which factors associated with DRA are related to specific populations is instrumental for effective anti-stigma interventions for populations who may hold negative DRA.

Moreover, studies with student cohorts have mainly consisted of university students, including those in healthcare education. This is despite evidence highlighting that young people under the age of 18 do hold some negative DRA, and may develop negative attitudes at a young age (Farina et al., 2022). Therefore, there is a need to better understand adolescents' attitudes, particularly as this may be a prime period, where they are most susceptible to attitude change, and more responsive to anti-stigma initiatives (Corrigan et al., 2012; Baker et al., 2019; Krosnick & Alwin, 1989; Werner et al., 2017; Werner et al., 2019). Furthermore, prior studies in this field have been limited to a single geographical region of England (Farina et al., 2020a; Isaac et al., 2017). While it is not necessarily expected that a single geographic region would have a different outcome from other regions, including more regions would increase the representation of young people and the generalisability of the findings. In addition, previous research has often been limited to associations with individual variables (e.g., gender), rather than acknowledging the interplay of multiple socio-demographic characteristics. Understanding these varying socio-demographic factors associated with DRA in adolescents allows us to better identify at-risk groups, such as those most likely to hold stigmatising attitudes. It also allows stakeholders to deploy evidence-based interventions in the community that are cost and time-effective, by targeting factors that are likely to improve DRA.

The focus on public stigma, rather than self-stigma or stigma by association, is due to the broader societal impact and relevance to the majority of adolescents who have indirect contact with dementia. Addressing other forms of stigma would require a more targeted approach, relevant to a smaller subset of adolescents with substantial personal experience of dementia through affected family members (Masterson-Algar et al., 2023). This approach captures a wide range of societal attitudes and offers actionable insights to combat stigma at the societal level, contributing to the quality of life for those living with dementia.

Focusing on England allows for a practical and culturally nuanced understanding of dementia, while the deliberate exclusion of 18-year-old university students ensures

that the research remains focused on a less-studied demographic. This thesis sets the foundation for future evidence-based interventions by providing a comprehensive understanding of the factors influencing DRA in adolescents, rather than implementing an intervention without sufficient empirical grounding. The findings will provide timely insights for policymakers and stakeholders, contributing to ongoing efforts to address dementia stigma.

1.10 Limitations and gaps in the literature

The central gap in the DRA literature is that studies examining factors associated with public DRA (Kim, Anstey, & Mortby, 2022) have primarily focused on those above 18. Several limitations have been identified across the literature this thesis aims to address. First, it is unclear which factors contributing to DRA in adults are most relevant to adolescents. Second, there is limited knowledge about the interactions between different factors, such as how dementia knowledge impacts DRA alongside factors like empathy. Third, there are several factors that have only been explored in a limited number of studies. Fourth, there is limited understanding of how attitudes change over time in the context of dementia. Few studies assess changes in beliefs, emotional reactions, and behaviours at different time points (Albarracin & Shavitt, 2018). Due to the lack of studies on attitudinal change in adolescents, it remains unclear for how long it is necessary to detect such changes. Lastly, associations between factors and DRA are often measured using unvalidated outcome measures (e.g., Felc & Felc, 2020; Isaac, Isaac, Farina, & Tabet, 2017). Standardised measures are necessary for comparability and synthesis across studies. More knowledge is needed on which outcome measures are used in adolescents and whether these are validated. Thus, there is a need to establish validated measures in DRA research to work towards a gold standard measure in the future. Additionally, DRA assessment has relied heavily on explicit self-report measures (O'Connor & McFadden, 2010; Scerri & Scerri, 2013), with minimal exploration of implicit measures in the context of DRA and young people. Employing both self-report and implicit measures could provide a more nuanced assessment of DRA in young people, even in an exploratory capacity.

1.11 Aims and Objectives of the thesis

The main aim of this thesis is to determine what factors contribute towards negative DRA and to provide an understanding of how DRA change over time in young people. Table 2 outlines the aims, research questions, and objectives of the thesis for each Chapter.

Table 2 - Aims, Research questions and Objectives of the thesis

Chapter	Aim	Research Question	Objectives
2	Identify what DRA outcome measures are used for the adolescent population.	What methods are used to measure DRA in adolescents?	Conduct a scoping review to identify methodologies used to measure DRA in adolescents. Identify which measures could be adopted or adapted in the subsequent empirical chapters of this thesis to measure DRA in adolescents. Describe the psychometric properties of validated measures. Identify the limitations of the measures currently used in DRA research in adolescents.
3	Explore what evidence exists on factors associated with DRA in adolescents.	What factors are associated with DRA?	Conduct a systematic literature review to identify factors associated with DRA in adolescents. Investigate the strength of the association between identified factors with DRA in adolescents. Identify the gaps in the current literature.
4	Identify demographic groups more susceptible to negative DRA and associated modifiable factors.	What factors are associated with DRA in an adolescent cohort (<18 years) and how does modifiable factors (e.g., contact) or non-modifiable factors (e.g., age, sex, and ethnicity) influence these attitudes?	Conduct a secondary analysis of existing cross-sectional data to explore factors associated with adolescent DRA. Analyse the association between modifiable factors, non-modifiable factors and DRA using multiple regression. Explore direct effects of non-modifiable and modifiable factors, and DRA using exploratory structural equation models to determine which factors are more influential on DRA. Explore mediatory effects of non-modifiable and modifiable factors, and DRA using exploratory structural equation models to determine which factors are more influential on DRA.

Continued. Table 2 - Aims, Research questions and Objectives of the thesis

5	A) Understand how DRA forms and changes over time.	How does DRA change over time in young people?	Conduct a quasi-longitudinal survey to capture and examine changes in DRA and its determinants over time. Measure baseline mean DRA in a cohort of adolescents to establish initial DRA. Measure changes in DRA overtime through a follow-up survey one year later and paired samples t-test to assess change. Identify key determinants that influence change in DRA over time (1-year period) using multivariable regression models. Analyse temporal patterns in DRA change using multilevel modelling to explore how modifiable and non-modifiable factors influence change in DRA.
	B) Explore determinants of DRA in British adolescents.	What are the drivers and facilitators of DRA in British adolescents?	Identify demographic groups more susceptible to stigmatising DRA and modifiable factors through a novel cross-sectional study. Analyse the association between modifiable factors, non-modifiable factors, and DRA using multiple regression. Explore direct effects of non-modifiable and modifiable factors, and DRA using structural equation models to determine which factors are more influential on DRA. Explore mediatory effects of non-modifiable and modifiable factors, and DRA using structural equation models to determine which factors are more influential on DRA.

Continued. Table 2 - Aims, Research questions and Objectives of the thesis

5	C) Determine the level of dementia knowledge in British adolescents.	What is the level of dementia knowledge among British adolescents?	Obtain mean dementia knowledge in British adolescents by calculating the percentage of correct knowledge items. Assess which items were answered most correctly using descriptive statistics and a one-sample binomial test. Assess which knowledge items were answered correctly the least using descriptive statistics and a one-sample binomial test.
	D) Identify the various experiences of dementia in British adolescents.	Are different experiences of dementia generally positive or negative?	Identify whether the quality of contact with dementia is generally positive or negative through a cross-sectional study. Explore whether dementia experiences differ by contact type (direct or indirect) using cross-tabulations. Obtain the percentage of participants who reported positive and negative experiences within each contact type.
	E) Identify the frequency of dementia contact in British adolescents.	Do British adolescents have more direct or indirect contact with dementia?	Obtain the percentage of adolescents across different levels of direct (e.g., family member) and indirect contact (media) with dementia. Obtain the most frequent and least frequent type of contact using a one-sample binomial test.
6	Explore the relationship between implicit and explicit DRA.	What is the relationship between implicit and explicit DRA in adolescents?	Conduct an exploratory cross-sectional, correlational study to examine the relationship between implicit and explicit DRA measures in adolescents. Examine implicit DRA in adolescents using an implicit attitudes test. Explore whether implicit attitudes vary across demographic variables using independent samples t-test to assess group differences in implicit d-scores. Compare the mean difference between adolescents' low and high social desirability against implicit and explicit measures.

1.12 Methodology overview

This section presents the overall methodological approach adopted in this thesis. Each chapter details the methodology commentary of the research design, including participant characteristics, recruitment, and data analyses.

The quantitative design was most applicable to this thesis due to the nature of using surveys as the source of data collection and statistical techniques to analyse the data (Pluye & Hong, 2014). Statistical techniques such as regressions and structural equation modelling were chosen due to the need to identify patterns and relationships to address the thesis aims of exploring the factors associated with DRA in young people. A scoping and systematic review was selected because there was a need to provide a comprehensive summary of existing evidence on what measures exist and their psychometric properties, and what factors are associated with DRA in young people. This was to help inform evidence-based decision-making in the relationships, theoretical frameworks, what tools were most appropriate, assess the strength of evidence, and identify gaps in the literature (Moons, Goossens, & Thompson, 2021; Pham et al., 2014) to apply to the empirical chapters.

Quantitative methods were chosen over qualitative or mixed methods design due to the need for a structured, standardised approach to obtaining objectivity in data collection and analysis (Mehrad & Zangeneh, 2019). This thesis aims to address generalisability issues in the literature. Therefore, a larger sample size and replicable patterns were needed to provide generalisability. This was to apply the findings to a larger population to enhance external validity (Murad, Katabi, Benkhadra, & Montori, 2018). Statistical analyses were necessary to make inferences about the adolescent population. Survey research (large scale with close-ended questions and scaled responses) was therefore deemed most appropriate. The strength of the quantitative approach is that it provides measurable results that can be quantified, and the standardised approach allows for the replication of findings (Choy, 2014). However, this limits the contextual understanding of DRA in young people, which is likely to be context-dependent given the variety of experiences. This includes more complex phenomena such as cultural factors in the role of DRA, knowledge, and contact, given historical contexts and social class differences (Cipriani & Borin, 2015). This also

limits the depth of human experiences we can understand from this data (Choy, 2014). While the measures and scales used in the empirical component of this thesis introduce some bias, mainly if they did not capture the complexity of the studied construct (i.e., attitudes and empathy) (Podsakoff, MacKenzie, Lee, & Podsakoff, 2003), a social desirability scale was adopted to help identify the level of bias in the findings (Van de Mortel, 2008).

Attitude measures (such as DRA measures) are generally susceptible to social desirability that threaten internal validity (Ross & Bibler Zaidi, 2019) due to the societal stigma around dementia that may lead to participants providing a response that align with perceived social norms (Farina et al., 2020a). Adolescents, which are the focus of this thesis, are also particularly susceptible to social desirability due to peer relationships and social acceptance being important at this stage of development (Güroğlu, 2021). Thus, social desirability measures being used alongside explicit measures can help determine the level of social desirability responding in a sample.

Reflexivity

While reflexivity is emphasised in qualitative research, it is also relevant to quantitative research, where subjective decisions, researcher background, and motivation can shape the study design (Jamieson, Govaart, & Pownall, 2023). As a researcher working with schools and young people, my own experiences have influenced various aspects of this thesis, including participant recruitment, consent process, and variable inclusion.

Having worked in schools for over 10 years as a mentor, a STEM ambassador, and school governor focusing on inclusion and behaviour in adolescents, EH brought insights such as familiarity with the school system and connections with prior school colleagues into the ethical and logistical considerations.

The focus on school recruitment was initially in Brighton and Sussex due to the proximity to the university. However, the decisions in which schools to target were also influenced by EH's prior connections to certain schools. These connections facilitated access to schools that might otherwise have been difficult to recruit. EH

was able to target the Bedfordshire region as a result. The motivation on focusing on this region stemmed on EH's upbringing in a socio-economically deprived and culturally diverse town in Bedfordshire. Thus, EH felt it was important to design a study that attempted to be as inclusive as possible. This then led EH to recruiting schools in other regions that are also considered deprived or culturally diverse. As an ethnic minority, EH felt this also influenced the decision to wanting to include schools with a higher ethnic minority intake.

Working with schools in Bedfordshire before EH undertook a PhD also meant there were existing connections with ex colleagues from those schools. EH utilised those relationships and friendships to gain access to those schools. On reflection, it was likely these teachers were more willing to help EH by taking part in the study and greater effort into facilitating the study compared to schools with no prior connections. This may have biased the sample to include schools with greater willingness to help EH rather than a genuine interest in dementia research. Members of staff could have let participants know EH was a prior member of staff at the school or used to be a student at this school which could have influenced participants. However, to the best of EH's knowledge, this was not revealed to the participants and EH emphasised to participants that they were anonymous, at their own free will to not take part, and there were no consequences to deciding not to take part.

With connections to school governors, a local councillor, educational needs leads and senior school leaders, EH was familiar with the school day, how many students would be feasible, what resources schools may or may not have, and schools safeguarding procedures. This allowed EH to design the studies by consulting the expertise of all these professionals regarding obtaining appropriate consent for ethics, and understanding what barriers there are for parental consent, and in general. School leaders were able to ensure the material was in line with other topics taught at school (citizenship and mental health).

Regarding consent procedures for ethics, EH was influenced by growing up with a parent with little spoken English. Knowing that 'dementia' is a word that does not exist in many languages, EH considered that participants with parents with little English comprehension may be less likely to engage in the parent information sheet.

Thus, consent opt-out procedures were adopted along opt-in consent to minimise excluding participants that may have been disadvantaged by this.

Lastly, EH felt that social media was an important variable to consider in some way based on prior experience working with young people despite no studies exploring the media and DRA association in adolescents. This influenced EH to consider creating a few items on how dementia is represented in the media following a discussion with patient public involvement (PPI) who also agreed that the quality of contact via the media was likely relevant to young people.

Chapter Five - Aim A

It was originally intended to fulfil thesis aim A (see Table 2: Chapter 5, aim A) by carrying out a quasi-longitudinal study with a time point one that would address how attitudes may form in the first place, with time point two aiming to assess whether DRA changes over time. However, following time point one, it was evident that the schools were not interested enough to participate in point two. An ethics application for time point two was sought as a contingency, but ultimately, the schools did not engage well in time point two. One reason gatekeepers gave for lack of interest in taking part in time point two included schools having the 16-year olds that took part in time point one leaving the setting for further education, with the younger cohorts now focusing on exams themselves. As a result, the thesis treats time-point one as a stand-alone cross-sectional study. It focuses on addressing how attitudes may form in the first place, with future work from this thesis including the potential to create a longitudinal study to assess whether DRA changes over time in adolescents. The discussion Chapter (Chapter 7) explains the limitations and barriers faced regarding why time point two did not work, why there may have been a lack of engagement from the schools, and potential solutions that could overcome these limitations in future work.

Philosophical assumptions

The underlying philosophical assumptions of this thesis are positivism and post-positivism (Ryan, 2006). *Positivism* is the approach that emphasises the importance of

empirical observation via scientific method to gain generalisable knowledge. Positivism is associated with deductive reasoning, where a hypothesis is tested through systematic observation and measurement. This philosophical assumption aims for the reliability and replicability of the research (Park, Konge, & Artino, 2020). Post-positivism acknowledges the limitation of strict positivism and recognises the role of interpretation and context in the research process. This approach involves a more flexible research design incorporating inductive and deductive reasoning. This thesis adopted these approaches since multiple sources of knowledge were used to help understand the determinants of DRA in young people. Due to the limited knowledge of the determinants of DRA in young people, this thesis aimed to amalgamate prior research and existing data and generate new data, both in an exploratory capacity and for hypothesis testing. The philosophical assumption for both scoping and systematic reviews is often associated with a positivist philosophical assumption. This thesis adopts deductive and inductive reasoning due to its exploratory nature in identifying patterns and relationships without a predefined hypothesis, and utilising theorised relationships to form a hypothesis in the novel cross-sectional study.

Patient Public Involvement

Three young people (12-15 years old) were recruited to discuss the design of the study, the questionnaire items and wording to ensure the survey is acceptable and optimised to limit desirability bias. They also determined whether it was difficult to interpret the questions, and maximise response rates by reducing participant fatigue. The young people panel were consulted twice (one before the start of the cross-sectional data collection (Chapter 5) and one at the end of this data collection. They were also consulted to discuss age-appropriate dissemination strategies. For their time, they were compensated with a £20 Amazon voucher at each consultation. Two of the young people had experience with a grandparent with dementia, which was also crucial in terms of whether the content was distressing and if the debrief had appropriate signposted resources. Since stigmatising attitudes negatively impact people living with dementia and carers, people living with dementia needed to be involved during the project to obtain outcomes that are ultimately important to them. Throughout the PhD, people living with dementia and carers have been incorporated through a partnership with the Sussex Partnership NHS Trust Lived Experience Advisory Panel (LEAP).

The LEAP (comprising six members) were consulted through two meetings and compensated for their time in monetary value (£). The LEAP and the young people panel were also brought together to serve as an intergenerational LEAP to foster voices across the generation.

Ethical Approval

The Brighton and Sussex Medical School Research Governance and Ethics Committee approved the research carried out for chapters 5 and 6 of this thesis (ER/BSMS9PCH/1) (see Appendix C). An ethical amendment was submitted in 2023 to reflect the changes in thesis aim A and the IAT timeline, which was approved (ER/BSMS9PCH/2) (Appendix D). Along with ethical considerations, further details are found in chapters 5 and 6.

Methodology conclusion

This thesis adopts a multifaceted methodology that is mainly quantitative in design. Each component of this thesis is driven by evidence. The combination of scoping, systematic reviews, and quantitative methods strengthens the validity and overall generalisability of the study. The integration of those with lived experience, young people panel, thoughtful discussions with school leaders, and governors on important ethical considerations, and study design strengthen the validity of the thesis.

1.13 Conclusion

Young people will have an important role in dementia policy and care. This thesis aims to expand the current knowledge on the limited literature on the factors driving DRA in young people (under 18 years). The knowledge gained from this thesis can help researchers, advocates, and educators to better understand how and why stigmatising attitudes towards dementia form. Additionally, the contributions of this thesis to the field includes providing recommendations on the DRA measures that could be used to measure DRA in adolescents so that we work towards creating a gold standard measure. The systematic review synthesises what evidence already exists in the literature and identifies theoretical frameworks that may be useful to apply in future work. The structural equation modelling provides greater nuance to

understanding the associations between factors and DRA by exploring the mediatory mechanisms beyond direct relationships that may have already been identified in the literature. The thesis also attempted to address a limitation of the literature by integrating an implicit measure alongside explicit measures. Lastly, by addressing a population gap by including more diverse demographics of adolescents across several regions of England, there is more representational data on DRA, knowledge, and experiences of British adolescents. Together, all these new contributions can aid the development of evidence-based interventions.

Chapter 2 The Outcome measures used to determine DRA in adolescents: A Scoping review

This Chapter presents a scoping review of the outcome measures used to determine DRA in young people. The scoping review protocol is detailed in Appendix E. The associated publication is the first in DRA literature to map out measures used in young people under 18 years old. It highlights the strengths and limitations of current measures, offering insights for future research on DRA in this demographic;

Hassan, E., Hicks, B., Tabet, N., & Farina, N. (2023b). Measures determining dementia-related attitudes in adolescents: A scoping review. *Journal of intergenerational relationships*, *22*(3), 461-481.

2.1 Attitude measurement

Before it is possible to empirically evaluate DRA in adolescents, there is a need to be able to accurately measure it. See section 1.3 for an overview on explicit and implicit attitude measures.

2.1.1 Measuring DRA in the general adult population

There is a growing body of literature on developing, validating, and applying instruments to assess DRA (Diaz et al., 2022; see also Herrmann et al., 2018). This is in response to explicit questionnaires measuring DRA producing conflicting findings on whether the general public holds negative or positive DRA. This could be explained by how researchers interpret the results, with no definitive cut-off being applied to the measures and the variability in measures. For example, some research indicates that stigma towards people with dementia in the general public is still prevalent (Aboseif & Woo, 2020; McParland et al., 2012), while others suggest that the general public may hold positive DRA (Olsen et al., 2020). Research on DRA measures have seen the development of validated instruments to assess public stigma within the general adult population in the form of explicit measures such as questionnaires that capture 'belief', 'emotional', and 'behavioural' constructs (Blay & Peluso, 2010; Cheng et al., 2011; Johnson-Kwochka et al., 2024; Nguyen & Li, 2020; Piver et al., 2013; Wadley & Haley, 2001). Examples of such measures include the Dementia Attitudes Scale

(DAS) (O'Connor & McFadden, 2010), which assesses DRA across constructs such as empathy and social comfort (Ebert, Kulibert, & McFadden, 2020; Scerri & Scerri, 2013). Another widely used measure is the Approaches to Dementia Questionnaire (ADQ), which assesses positive and negative DRA (Cheston et al., 2016).

Validated tools provide validity and reliability to the outcome of DRA. These have been useful in quantifying and understanding DRA that the general adult population hold. Having validated tools in this population has better positioned public health researchers to facilitate targeted interventions aiming to reduce dementia stigma in this population (Diaz et al., 2022; O'Connor & McFadden, 2010). Despite this, such measures have limitations. Contextual variability means that DRA may vary depending on cultural, ethnic, and educational attainment contexts (Cipriani & Borin, 2015). Due to the variability of DRA in these contexts, it is challenging to validate these tools cross-culturally and ensure they are suitable for a wide range of different populations. Thus, establishing a gold-standard measure of DRA in the adult population is difficult (Herrmann et al., 2018). Nguyen and colleagues (2020) noted the lack of a gold-standard DRA measure was a methodological weakness in DRA studies generally. Another limitation in DRA measures in the adult population is the need to operationalise definitions of DRA. The lack of DRA definitions makes it challenging to know what outcome researchers intended to capture (O'Connor & McFadden, 2010).

DRA measures rooted in a theoretical framework may help understand the factors underpinning stigma (Kim et al., 2021), albeit a review by Werner identified that an underwhelming number of studies adopt a theoretical framework (Werner, 2014). Although there are widely used tools in the DRA literature (e.g., DAS), these need to be more extensively studied and validated in different populations and need robust evaluation of their psychometric properties. Due to the limitations of current DRA measures (e.g., issues with item transparency, limited generalisability, social desirability bias, and whether they tap into each component of the tripartite model) (O'Connor & McFadden, 2010), it is not surprising that there may be conflicting findings on DRA. Moreover, Herrmann and colleagues conducted a review spanning a decade (2004 to 2015) and identified that the studies assessing DRA mostly modified measures initially developed for other conditions such as HIV and mental health

(Herrmann et al., 2018). In support, another review explains that many quantitative studies investigating public stigma adopt different measures, with most studies combining different scales in their measurement (Nguyen & Li, 2020). Alongside not having a consistent or standard DRA assessment tool, the review also identified that there are no validated DRA tools to assess change in stigma over time (i.e., pre/post-intervention research) (Herrmann et al., 2018). Consequently, DRA studies should be interpreted cautiously, due to the heterogeneity of measures used (Kim et al., 2021).

2.1.2 Importance of standardised outcome measures and validation

In a systematic review examining public stigma towards people with dementia, 17 quantitative studies were identified (Nguyen & Li, 2020). These studies mostly used vignettes and survey questionnaires (e,g., Blay & Peluso, 2010; Cheng et al., 2011; Piver et al., 2013). However, the use of these self-report measures has not always led to consistent findings, even when using the same tools (e.g., Werner & Davidson, 2004). Thus, it is necessary to identify higher quality DRA measures (Herrmann et al., 2018) and the consideration for more rigorous study designs.

Measures not rigorously developed may not accurately capture the underlying construct or lead to measurement error (Bound, Brown, & Mathiowetz, 2001; Kimberlin & Winterstein, 2008). DRA measurement should be validated against external evidence. However, this is challenging to achieve. Bennett and colleagues highlighted several issues in measuring attitudes. There is 1) a lack of precision over key definitions of terms, 2) poor design of instruments, 3) reliability and validity are not addressed adequately, 4) there is a lack of standardisation of instruments, and 5) there is a lack of psychological theory rooted in the measures (Bennet et al., 2001 cited in Reid, 2006; Wu & Leung, 2017).

The term ‘validated’ refers to measures that have undergone assessment to determine whether it accurately captures the construct it intends to measure (Dowrick, Wootten, Murphy, & Costello, 2015). This includes various forms of validity. Validity refers to the extent to which a measure accurately captures a construct it is intended to assess (Ahmed & Ishtiaq, 2021). Validity includes construct validity (whether a measure aligns with existing theoretical expectations and knowledge of the construct), content

validity (the extent a measure represents all aspects of the construct being measured), criterion validity (whether the measure correlates with other valid measures of the same construct), predictive validity (the extent to which a measure accurately predict or correlate with related outcomes measured at a future time (Ahmed & Ishtiaq, 2021), convergent validity (measures that have the same or similar constructs should correlate well with each other) (Chin & Yao, 2021), and concurrent validity (whether a measure correlates with another measure of the same construct that is administered at the same time) (Lin & Yao, 2024). Reliability which relates to the consistency of a measure in measuring something (i.e., consistency and stability of a measure) is distinct from validity (i.e., accuracy of a measure capturing the intended construct). Reliability consists of internal consistency (whether items in a measure correlate together, reflecting the same construct), inter-rater reliability (consistency of a measure across raters), and test-retest reliability (consistency of a measure over time) (Ahmed & Ishtiaq, 2021).

Within the DRA literature, research adopts different measurement scales depending on the targeted stigma. This has important implications, such as measures capturing different outcomes from the one intended. Corrigan and Watson's (2002) stigma framework is typically adopted in assessing public DRA and behaviour towards dementia (Rüsch et al., 2005). Moreover, the dual process model (Pryor, Reeder, Yeadon, & Hesson-McInnis, 2004) suggests that people have implicit and explicit negative responses to stigmatised conditions. It is therefore important to understand whether current measures integrate both implicit and explicit measures when assessing DRA, as this may help increase the validity and reliability of the DRA phenomenon, and may help limit the impact of social desirability bias typically found in explicit attitude measures (Pryor & Reeder, 2011; Silke, Swords, & Heary, 2017).

There is a need for ongoing questionnaire development and standardised measures to evaluate the impact of new anti-stigma initiatives (Griffiths, Parveen, Shafiq, & Oyebode, 2018; Silverstein & Sherman, 2010). Presently, the evaluation of DRA change in the general DRA literature tends to use qualitative methods or single-item questions (e.g., Baker et al., 2019). While this allows for a rich understanding of the experience of these interventions, using standardised measures alongside these would allow for objective cross-comparison with other initiatives (Farina et al., 2022).

2.1.3 Importance of adolescent-specific outcome measures

Despite the lack of a 'gold standard' measure for DRA in general (Harper et al., 2019), even measures that are rigorously developed for the general public, may not be reliably used in a younger cohort (Isaac et al., 2017). Many of the reviews mentioned in section 2.1.1 and 2.1.2 attempting to understand DRA measurement did not include under 18-year olds. Young people may need help with questionnaires' readability, complexity, and applicability compared to adults (Bell, 2007). Thus, measures that are not developed from the ground up risk influencing the responses of younger participants (under the age of 18). This is particularly true if unvalidated measures have not been previously piloted in young people for suitability and readability (Isaac et al., 2017). As such, when DRA or changes in DRA following an intervention are being captured, it is unclear whether the measures used accurately capture attitudes in a standardised manner in this demographic.

Providing transparent insight into measures' psychometric properties may help identify current validated measures that could be suitable to use with adolescents. As highlighted in section 2.1.1, there is a lack of theoretical frameworks used in DRA research (Werner, 2014). It is currently unknown how many measures of DRA designed for young people exist where a public stigma framework underpins the measure (Rüsch et al., 2005). Identifying validated measures that have theoretical underpinnings for capturing DRA in adolescents may lead to more consistent use of validated measures by DRA researchers. Consistently using validated measures with a theoretical underpinning would also make it clearer what specific constructs of attitude/stigma are being captured.

2.2 Rationale

There is a need to identify high-quality DRA measures (Herrmann et al., 2018). This includes validated measures to increase the accuracy of attitudes measured within the adolescent population for the integrity of studies and effective anti-stigma initiatives. There are currently no reviews focusing on the measures used to assess DRA in young people.

The findings will help identify measures that are most appropriate for capturing the determinants of DRA in the novel cross-sectional study (Chapter 5) for this thesis, what measures currently exist, and which are validated need to be established. This is to determine which is most appropriate for British adolescent samples and consider the limitations of these measures. In addition, the review has the potential to inform and shape future research on adolescent DRA measures. By mapping the existing landscape, researchers can make more informed decisions about what measures to use and what requires further validation when measuring DRA in adolescents more widely.

2.3 Objectives and Aims

The main aim of this review was to identify the types of measures used to measure DRA in young people. This entailed:

1. Identifying which measures could be adopted or adapted in the subsequent empirical chapters of this thesis (chapters 4, 5, and 6) to measure DRA in adolescents.
2. Describe the psychometric properties of validated measures.
3. Identifying the limitations of the measures currently used in DRA research in adolescents.
4. Highlighting theoretical frameworks underpinning DRA measures.

2.4 Methods

2.4.1 Scoping Review protocol

A scoping review protocol was formulated following Arksey and O'Malley's (2005) scoping review framework. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses scoping review guidelines (PRISMA-ScR) (Tricco et al., 2018) was adopted to help formulate the scoping review protocol and methods. The PRISMA study flow diagram was used for transparency in the reporting, selection, and analysis (Moher et al., 2010; Page & Moher, 2017).

Arksey and O'Malley's (2005) scoping review framework was selected for this scoping review. The framework consists of the following steps: 1. Identifying the research question, 2. Identifying relevant studies, 3. Study selection, 4. Charting the data, 5. Data synthesis, and 6. Consultation. The framework was chosen for its transparency (Munn et al., 2018). It was used alongside additional scoping review recommendations by Levac and colleagues to further strengthen the methodology of defining concepts and target populations, and provide a more precise scope on the eligibility criteria (Levac, Colquhoun, & O'Brien, 2010).

Levac and colleagues extended Arksey and O'Malley's (2005) framework by providing additional criteria that address the limitations of the six-stage framework. For example, Levac's recommendations improve the original framework by providing more specific and detailed criteria for each stage of the framework. This enhances the research process allows researchers to follow a more structured approach (Levac et al., 2010).

Levac (2010) emphasises transparent and comprehensive reporting on the review process, such as rationales and methods employed at each review stage, which increases transparency and reproducibility of the review. The recommendations acknowledge that scoping reviews often need flexibility and adaptability in the reporting. This allows for adjustments based on the research context's unique characteristics. Despite these recommendations, Arksey and O'Malley's (2005) framework is still widely used and recommended (Colquhoun et al., 2014; Levac et al., 2010) due to its transparency, rigorousness and the ability to replicate the search strategy which further increases the reliability of the review (Munn et al., 2018). Therefore, Levac's recommendations were adopted wherever pragmatically possible. The scoping review implemented all the recommendations, except for the optional consultation stage (stage six) (Pham et al., 2014). There is no consensus on approaching the consultation in scoping reviews. One review on scoping review methodology reported that scoping reviews only sometimes report consultation exercises in meaningful detail (Buus et al., 2022). One reason cited for this is that there are power imbalances between researchers and stakeholder consultants and ethical implications regarding whether stakeholder consulting is participatory research (Buus et al., 2022). See Figure 1 for the framework overview.

A risk of bias was not conducted as it falls outside the scope of the review (Arskey & O'Malley, 2005), particularly with limited literature expected.

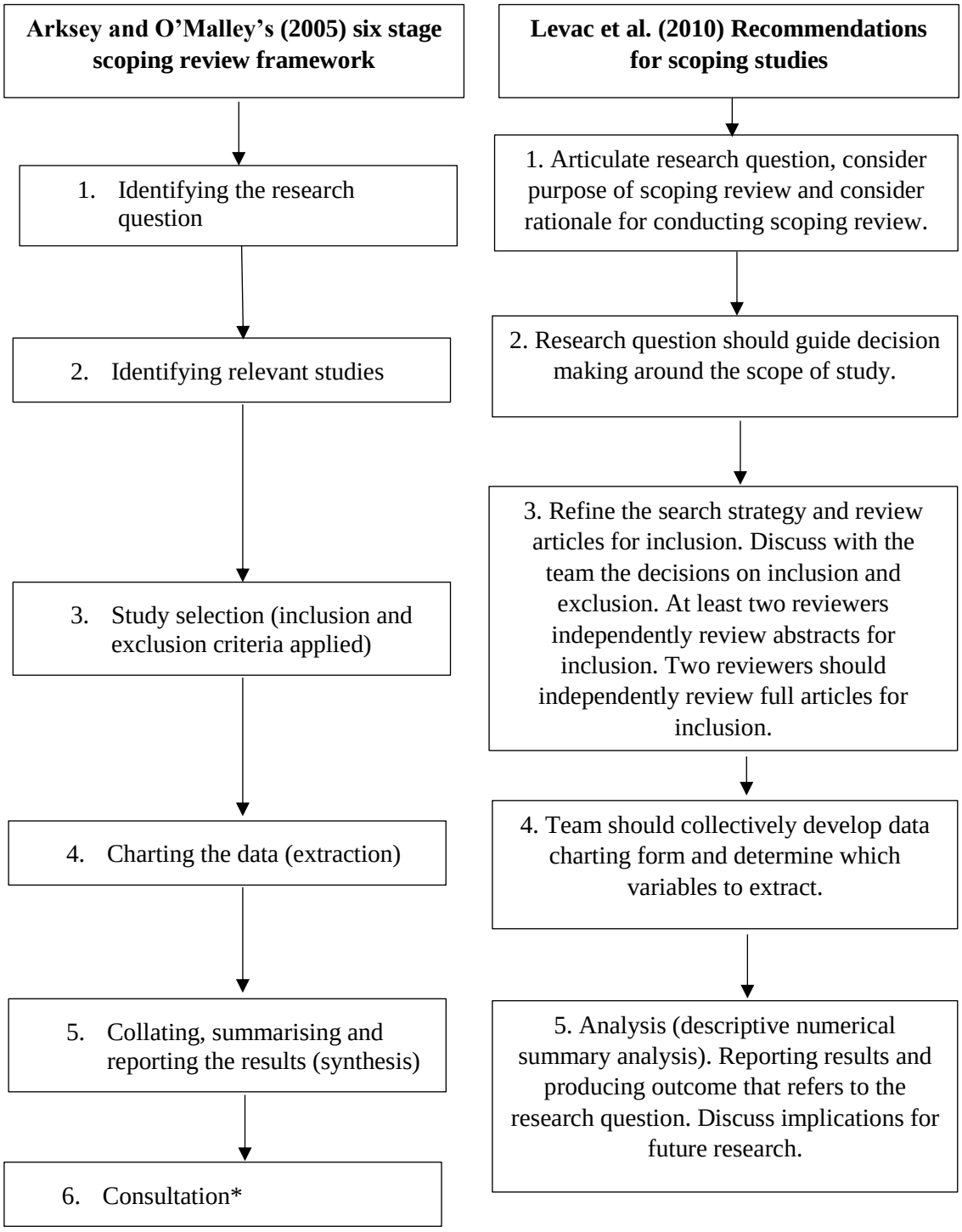

Figure 1 - Arksey and O'Malley's (2005) scoping review framework with a summary of Levac's (2010) scoping review recommendations. *Stage six is considered optional and was not adopted in this scoping review.

Levac's recommendations (2010) stages one to five were adopted, with the arrows demonstrating the order of the stages followed. Levac's framework expands on Arksey and O'Malley's framework for each stage.

2.4.2 Identifying the research question

The following research question was formulated: 'What measures are used to determine DRA in adolescents?'.

This research question was formulated using Arksey and O'Malley's (2005) scoping review framework. The research question serves as a guide to clarify what inclusion and exclusion criteria are used to determine the eligibility of studies to ensure that they fulfil the objectives and aims of the scoping review. A research question should be within a broad topic, yet narrow enough to provide knowledge within an area in the existing topic (Arksey & O'Malley, 2005).

2.4.3 Identifying relevant studies

Information sources

The initial search was conducted on the following electronic databases: PubMed, Web of Science and PsycInfo (ProQuest). To ensure the inclusivity of all relevant literature, these databases were searched with no period limit for the article's publication. There were no filters applied to the database searches. Only peer-reviewed studies were eligible for this scoping review. The 'snowballing' method (Pham et al., 2014) was crucial in checking reference lists of eligible primary studies. The 'cited by' citation function was adopted to identify further relevant measures studies, thereby ensuring a comprehensive search.

Search strategy

Initial search strategies were drafted for each database to ensure the search was wide-ranging and relevant. Initially, Boolean operators 'AND', 'OR', and 'NOT' were used to search for the relevant articles in PubMed, Web of Science and PsycInfo. In the first instance, the Boolean operator 'NOT' was used for exclusionary terms such as 'nursing

students' and 'self-stigma'. However, exclusionary terms were removed from the search strategy. This was to ensure that the literature was included where mixed populations such as students and nurses, and measures that also captured different stigmas, including public stigma, were not discriminated against in the search. The draft searches informed the final search strategy for each database. This is located in the scoping review protocol, with the date of the search and exact Boolean strings used (see Appendix E). A combination of MeSH terms, synonyms, and spelling variations for search words and text words were used to the search string. The key search terms included those associated with 'dementia', 'stigma', and 'adolescents'. Table 3 outlines an example of the search component and search terms. All searches were performed using the terms in the English language.

The rationale for the selection of which databases and the number of databases to use was based on evidence on the top databases used in reviews and within subject-specific areas. Web of Science and PubMed were the top databases most frequently used in a sample of 153 review papers (Chapman, 2021). It was also found that Web of Science and PubMed provided broad coverage across many subject disciplines. PsycInfo was found to be selected mostly for social science disciplines. PubMed was the most frequently used, followed by APA PsycInfo and Web of Science within the social science area (Chapman, 2021).

Table 3 - Example search strategy terms

	Search component	Search strategy	Boolean Operator Used
1	Dementia	Dement* OR Alzheimer*	OR
2	Adolescents	adolescent* OR teen* OR "young people" OR child* OR student* OR "college students"	OR
3	Stigma	Stigma OR perception OR attitude* OR discrimination OR "social distance" OR prejudice	OR
	Combined Search Query	1 AND 2 AND 3 ((Dement* OR Alzheimer*) AND (adolescent* OR teen* OR "young people" OR child* OR student* OR "college students") AND (Stigma OR perception OR attitude* OR discrimination OR "social distance" OR prejudice)	AND

2.4.4 Study records

All articles were exported from each database and imported onto the reference manager Zotero to remove duplications through automated de-duplicate entries and manually searching for duplicates. Articles were included in the review if they were in English. Only English-language papers were included for practical reasons. Additionally, there was no concern for which language the measures had been developed or used in, though, the language the measures were developed and used in was noted at the extraction and synthesis stage.

2.4.5 Study selection

After removing duplicates, the articles underwent a screening process. Article titles and abstracts were screened against exclusion and inclusion criteria by two reviewers independently (EH and NF) on the online Rayyan platform (Ouzzani, Hammady, Fedorowicz, & Elmagarmid, 2016). The blind procedure was applied with inclusion and exclusion labels assigned by each reviewer to each article, and a reason for exclusion was noted. Conflicts were discussed between EH and Nicolas Farina (NF), with any unresolved conflicts included in the full-text screening stage for further deliberation. At the full-text screening stage, a similar process of independent review

occurred. Cohen's kappa coefficient (κ) as an agreement measure was calculated to determine interrater reliability between EH and NF. This is used to measure the extent to which raters assign the same score to each study (in this case, exclude or include) and measured as a percent agreement. A kappa result of 0.61-0.80 indicates substantial agreement, with 0.81-1.00 being almost perfect agreement (McHugh, 2012). Full eligible texts underwent citation screening through snowballing to identify any further eligible articles not identified in the initial database search.

2.4.6 Eligibility criteria

The following inclusion criteria were applied: A) English language paper; B) Adolescents (10-18 years old); C) Outcome measures for DRA or associated domains; D) Quantitative outcome; and E) Peer-reviewed articles.

The exclusion criteria were as follows: A) Population target was above 18 years old; B) Population was exclusively composed of university students; C) Only qualitative research methods and outcomes were used; D) Studies reporting on specialist professions views exclusively (medical or healthcare professionals); E) Measures exclusively measuring self-stigma or stigma by association; F) Only measures knowledge as an outcome and G) Grey literature (i.e., information not produced by commercial publishers such as conference abstracts and blogs) (Adams et al., 2016).

The PRISMA study flow chart (Figure 2; adapted from Page et al., 2021) was adopted to exhibit the transparency of the scoping review process in the identification, screening and eligibility of studies.

2.4.7 Population

The age range of 10-18 was selected based on the WHO definition of adolescents (ages 10-19). While the WHO's definition of adolescents includes 19-year-olds (WHO, 2024), the decision was made to limit the inclusion to individuals up to age 18. This was done to reflect the standard education models in England (GOV.UK, 2014). Excluding those aged 19 years old, minimises the potential heterogeneity introduced by including university students, who may have specialist training and are likely to represent a biased cross-section of society (e.g., education level). Studies were

excluded if the average age of participants did not fall within the required age range (10-18 years old).

2.4.8 Data charting and extraction

Full texts that were identified as appropriate to include following the exclusion and inclusion criteria underwent complete extraction. Data charting was performed by EH using Excel to create tables of:

1. Study characteristics, including descriptive data such as study design and demographics;

2. Psychometric properties where reported (validity and reliability); and

3. Measure characteristics, such as a Likert scale and theoretical framework.

Only directly reported and available data from the eligible studies were extracted.

The key features of the data charting included; A) Study characteristics. This includes descriptive information such as population sample, study design and outcome, demographic information, and the measure name. Where possible, data related to participants who completed the DRA measure were extracted; B) Psychometric properties of outcomes were extracted where reported. The validity and reliability of the measures were noted, including confirmatory factor analysis, exploratory factor analysis, Pearson's correlation, and Cronbach's alpha; C) Theoretical frameworks underpinning the measures and scale characteristics of the measure such as the Likert scale and the number of response items.

2.4.9 Data synthesis

Data was synthesised narratively, and the narrative was split into themes based on the key characteristics of the outcome measures. The study characteristics and key data are presented in a table with a descriptive narrative of the main features, such as demographics and sample size.

The descriptive narrative for scoping reviews was chosen due to its ability to include formal analytical processes, transparency, and ability to allow for the compilation of descriptive data, as well as integrate interpretation and drawing on what literature exists (Tricco et al., 2016). The data was categorised into themes based on the characteristics of the outcome measures. This included validated measures used in the target population, validated measures used but not in the target population, and unvalidated measures. The theme categorisation process was carried out by researchers EH and NF and was guided by the inclusion criteria (i.e., whether participants were below age 18 or not, and whether psychometric properties were reported. The inclusion characteristics were predetermined in the scoping review protocol (see Appendix E). Theme extraction was completed independently by EH and NF by checking each full text for participants age and psychometric properties. Extraction was cross-checked for discrepancies to ensure consistency in the thematic characteristics. There were no conflicts to resolve. Validity and reliability outcomes were reported by quantitative data such as p values, alpha (α), and correlation coefficient (r). An overview of theoretical frameworks underpinning outcome measures, outcome measure limitations, and cross-measure comparison were synthesised to draw conclusions narratively. The preferred reporting items of the systematic review and meta-analysis (PRISMA) study flow diagram were adopted for transparency of the literature's selection, analysis, and reporting (Moher et al., 2010; Page & Moher, 2017).

2.4.10 Risk of bias and critical appraisal

A risk of bias assessment and critical appraisal falls outside the scope of this review. This is in line with the scoping review framework proposed by Arksey and O'Malley (2005).

2.5 Results

2.5.1 Study selection

The search was conducted on 03/11/2021. At the time of this search, there was no existing review on DRA outcome measures used in young people. Searches were saved using the exact search strategy, date, and number of results from each database.

The date of publication of the studies from all the databases combined that were retrieved, ranged from 1979 to 2022. After duplicates were removed, EH and NF screened 630 titles and abstracts. Thirty-six records were eligible and moved to the full-text screening stage, in which full texts were obtained. Where EH was unable to obtain full-text records, and received no response after contacting the corresponders, these studies were not included.

The full-text review had a 94.6% agreement rate ($\kappa = 0.88$) between the reviewers. Two conflicts arose at the full-text review stage, which was resolved between EH and NF. Twelve full-text articles were initially included in the review. Two additional studies (Felc & Felc, 2020; Werner et al., 2017) were identified through snowballing (i.e., checking reference lists for eligible studies). As a result, 14 studies in total were extracted and synthesised. The PRISMA flow study outlines the identification and screening and includes studies extracted for this scoping review. See Figure 2.

An additional search was conducted in June 2024. This was a supplementary search to identify any new literature that may influence conclusions drawn from the 2021 search. See Appendix F for the 2024 supplementary search.

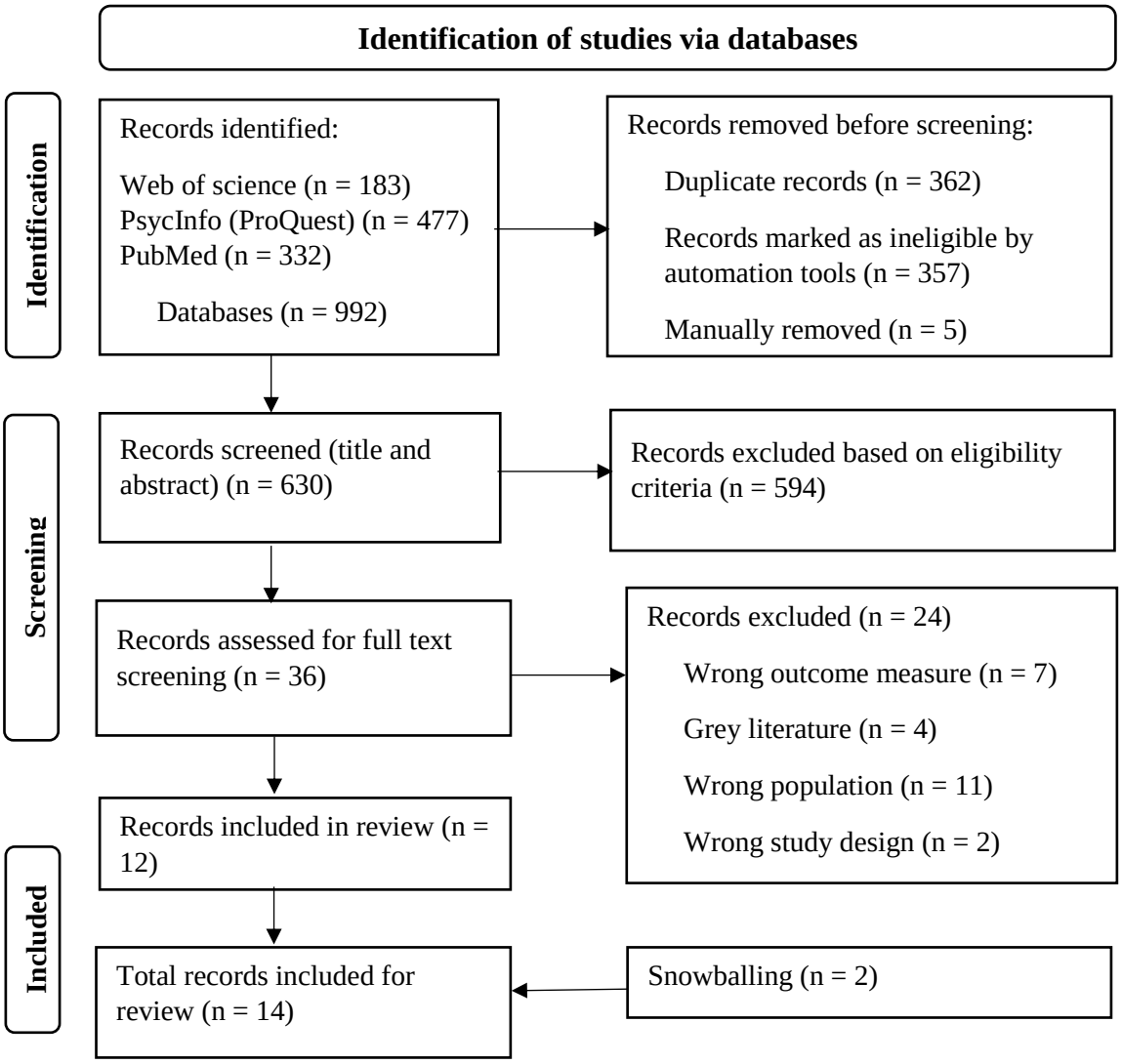

Figure 2 - PRISMA study flow chart. Study flow chart adapted from Page et al. (2021)

2.5.2 Study characteristics

The main characteristics extracted encompass the study design, sample characteristics, origin of the study, and recruitment setting. Tables 4 and 5 provide an overview of the study's characteristics.

Study design

Of the 14 studies included in the review, nine had a quantitative study design consisting of survey-based design studies, two had a mixed methods design, and three had an intervention study design.

Sample size

Sample sizes varied from four (Chow et al., 2018) to 5,515 (Fuh, Wang, & Juang, 2005) with a median of 330 participants.

Age

In line with the inclusion criteria, all samples had a range between 10-18 years old, or an average that fell between this range. The youngest age was six years old (Fox, 2020) and the oldest was 20 years old (Lo, Zeng, Lei, Lam, & Lou, 2020).

Sex

Overall, more females (58%) than males (42%) were included in the studies. One study did not report any number or percentage for sex (Chow et al., 2018).

Ethnicity and nationality

Most of the studies (10 studies) did not report on ethnicity. Where ethnicity was reported, samples were mostly homogenous (i.e., white British) (Farina et al., 2020a; Farina et al., 2020b; Griffiths et al., 2018). Three studies reported on nationality (Baker et al., 2018b; Baker et al., 2019; Felc & Felc, 2020), with two studies recruiting Australians (>85%) and one study recruiting Slovenian participants.

Geographic location of study

Most of the studies using DRA outcome measures were conducted in England (k=6, 37.5%), followed by Australia (k=2, 25%) and Taiwan (k=2, 25%). There was also one study each from Canada, Israel, Macao, and Slovenia.

Recruitment Setting

The most common recruitment setting was schools. Specifically, three studies were recruited from primary schools, while 11 studies were recruited from secondary schools. Three of the studies did not report how many schools were recruited for the

study (Chow et al., 2018; Farina et al., 2022; Felc & Felc, 2020). The largest number of schools recruited by a study was ten (Lo et al., 2020), albeit one study targeted 50 schools but did not report how many of those 50 schools consented to participate (Felc & Felc, 2020).

Table 4 - Study characteristics of studies measuring DRA in adolescents

Author and year of publication	Study design	Country	Recruitment setting	Name of measure used	Outcomes
Baker et al. (2019)	Mixed methods design	Australia	Three schools	Kids Insight into Dementia Survey (KIDS)	Improved attitudes towards people with dementia for students who participated in KIDS4Dementia.
Baker et al. (2018b)	Quantitative – scale development	Australia	Three schools	KIDS; Dementia Attitudes Scale (DAS)	KIDS 52 items were reduced to 14 items and three three-factor solution was identified.
Chow et al. (2018)	Intervention	Canada	NR	The survey was developed for the program to evaluate attitudes. Assessment of students' perception	Students expressed significantly more positive attitudes following the intervention.
Farina et al. (2020a)	Quantitative - questionnaire	England	Four schools	Adolescent attitudes toward Dementia scale (A-ADS); Allophilia scale	More adolescents had positive or neutral attitudes towards dementia while a proportion of adolescents had misconceptions or negative attitudes.
Farina et al. (2022)	Quantitative – scale development	England	NR	Brief Adolescent attitudes toward Dementia scale (Brief A-ADS); Allophilia scale; A-ADS	Brief A-ADS demonstrated good internal consistency and good predictive and concurrent validity.

Continued. Table 4 - Study characteristics of studies measuring DRA in adolescents

Farina et al. (2020b)	Intervention	England	Three schools	Brief A-ADS; KIDS	Dementia Friends is successful in reach and impact but may fall short of improving attitudes towards dementia.
Felc & Felc (2020)	Quantitative - questionnaire	Slovenia	Targeted 50 schools	Questionnaire (name not stated)	Adolescent students had positive attitudes towards activities for reducing dementia risk. Some responses to items reflected more negative attitudes.
Fox (2020)	Mixed methods design	England	Two schools	Card selection task - name not stated	Depression, anorexia nervosa, and dementia elicit differing responses in children.
Fuh et al. (2005)	Quantitative - questionnaire	Taiwan	Seven schools	Attitude Toward Dementia Questionnaire	Most children and adolescents had overly optimistic attitudes towards dementia.
Griffiths et al. (2018)	Quantitative - scale development	England	Four schools	A-ADS; DAS; Young adult attitudes about Alzheimer's disease measure	A-ADS captures three factors: perceptions of dementia, personal sacrifice, and empathy with people with dementia.
Isaac et al. (2017)	Quantitative - questionnaire	England	Two schools	No name given	Adolescent students had both positive and negative attitudes toward dementia.

Continued. Table 4 - Study characteristics of studies measuring DRA in adolescents

Liao et al. (2022)	Intervention	Taiwan	Nine schools	DAS	Exergaming improved the attitudes of adolescents towards dementia and older adults.
Lo et al. (2020)	Quantitative - questionnaire	Macao	Ten schools	Knowledge, attitude and preventive practice on dementia care	A positive relationship between preventive practice and attitude and knowledge.
Werner et al. (2017)	Quantitative - questionnaire	Israel	Two schools	Adapted version of the Attribution Questionnaire 9 (AQ-9)	Higher levels of stigma toward a person with Alzheimer's disease in Israeli Arab students compared to Jewish students.

Note. NR = Not Reported

Table 5 - Studies characteristics measuring DRA in adolescents by demographic data and sample size

Author and year of publication	Sample age range (m)	Sample gender (%)	Sample ethnicity (%)	Sample size
Baker et al. (2019)	9-12-years-old (m=10.5)	63.7% female	NR	195
Baker et al. (2018b)	9-12-years-old (m=10.49)	60% female	NR	203
Chow et al. (2018)	15-17-years-old (m – NR)	NR	NR	4
Farina et al. (2020a)	13-18-years-old (m=14.9)	53.3% female	80% White British	901
Farina et al. (2020b)	12-16-years-old (m=12.6 years)	57% female	78.1% White British	301
Farina et al. (2022)	13-18-years-old (m=14.9)	57.4% female	NR	630
Felc & Felc (2020)	14-19-years-old (m – NR)	68.3% female	NR	1128
Fox (2020)	10-11-year-olds (m= 10.35)	51.7% female	NR	120
Fuh et al. (2005)	10-15-years-old (m=13.4)	50.48% female	NR	5515
Griffiths et al. (2018)	13-18-years-old (m=15.5)	59% female	89% White British	262

Continued. Table 5 - Studies characteristics measuring DRA in adolescents by demographic data and sample size

Isaac et al. (2017)	15-18-years-old (m=15)	64.3% female	NR	359
Liao et al. (2022)	12-18 years-old (m=14.65)	76.1% female	NR	200
Lo et al. (2020)	14-20-years-old (m=16.5)	41.1% female	NR	586
Werner et al. (2017)	14-15-years-old (m – NR)	55.1% female	Jewish 64.6%, Israeli Arab 35.4%	460

NR = Not Reported; m = mean

2.5.3 What measures are used to determine DRA in adolescents?

To answer the research question, 'What measures are used to determine DRA in adolescents?', the broad factors identified during the extraction of the data are presented. Summaries of synthesised factors are presented in tables that report on measure characteristics, psychometric properties, theoretical frameworks, and scale properties. A descriptive narrative is provided to give the quantitative data context and draw on evaluative points.

Thirteen unique measures were identified, which were grouped into three categories:

1. Validated measures in the target population

2. Validated measures not in the target population

3. Not validated

The term 'target population' refers to a measure created, adapted, or adopted for the age range of 10-18. All measures identified from the data extraction and their categorisation into three categories are presented in Table 6 as an overview. In summary, five measures were validated in adolescents, three measures were validated but not in the target population, and five measures were not validated.

Table 6 - All measures identified from the eligible studies categorised

All Measures of DRA	Category
Kids Insight into Dementia Survey (KIDS) (developed by Baker et al., 2018b)	Validated in the target population
Adolescent attitudes toward Dementia scale (A-ADS) (developed by Griffiths et al., 2018)	Validated in the target population
Brief Adolescent Attitudes Toward Dementia Scale (Brief A-ADS) (developed by Farina et al., 2022)	Validated in the target population
Knowledge, attitude and preventive practice on dementia care (developed by Lo et al., 2020)	Validated in the target population
Adapted version of the Attribution Questionnaire 9 (AQ-9) (developed by Werner et al., 2017)	Validated in the target population
Young adult attitudes about Alzheimer's disease (developed by Lundquist & Ready, 2008)	Validated not in the target population
Dementia Attitudes Scale (DAS) (developed by O'Connor & McFadden, 2010)	Validated not in the target population
The Allophilia scale (developed by Kinney, Yamashita, & Brown, 2017)	Validated not in the target population
Questionnaire (name not stated) (developed by Felc & Felc, 2020)	Not validated
Card selection task - name not stated (developed by Fox, 2020 and adapted from the social distance questionnaire developed by Lester, 1992 – cited in Fox 2020)	Not validated
Attitude Toward Dementia Questionnaire (developed by Fuh et al., 2005)	Not validated
No name given (developed by Isaac et al., 2017) (questionnaire combines questions from the Alzheimer's Disease Knowledge Test (validated measure) (Dieckmann et al., 1988), the Northern Ireland Life and Times Survey (unvalidated measure) (McParland et al., 2012) and questions from the Alzheimer Society fact sheet	Not validated
A survey specifically developed for the program to evaluate attitudes - an assessment of students' perception (developed by Chow et al., 2018)	Not validated

2.5.4 Validated measures in the target population (<18-year olds)

Eight studies used validated measures of DRA (Baker et al., 2018b; Baker et al., 2019; Farina et al., 2020a; Farina et al., 2020b; Farina et al., 2022; Griffiths et al., 2018; Lo et al., 2020; Werner et al., 2017). Across these studies, five unique measures were identified: KIDS (Baker et al., 2018b), the adapted version of the AQ-9 (Werner et al., 2017), A-ADS (Griffiths et al., 2018), the Brief A-ADS (Farina et al., 2022) and questionnaire of knowledge, attitude and preventive practice on dementia care (Lo et al., 2020). Measure characteristics are outlined in Table 7.

The most frequently used validated measures of DRA were the KIDS (k=3) (Baker et al., 2018b; Baker et al., 2019; Farina et al., 2020b) and the A-ADS (k=3) (Farina et al., 2020a; Farina et al., 2022; Griffiths et al., 2018) The Brief A-ADS was used by two studies (Farina et al., 2020b and Farina et al., 2022). The adapted version of the AQ-9 and the Questionnaire on Knowledge, attitude and preventive practice on dementia care were used by one study each (Werner et al., 2017 and Lo et al. 2020, respectively). From these studies, three studies were specifically purposed for validating the measure and scale development (Baker et al., 2018b; Farina et al., 2022; Griffiths et al., 2018).

Outcome of measure

The term ‘attitudes’ is the most common construct being measured from the five measures. Three measures are reported to have the outcome as attitudes towards dementia (KIDS, A-ADS and Brief A-ADS), with one study using the term ‘public stigma’ and measures specifically the stigma towards a person with Alzheimer’s disease instead of dementia (adapted version of the AQ-9). However, this adapted version used by Werner et al. (2017) adopted the term Alzheimer’s disease instead of mental illness as per the original measure (Corrigan et al., 2003). Only two measures (A-ADS and the Brief A-ADS) were designed to measure DRA in adolescents.

Theoretical Frameworks

Three of the measures adopted a theoretical framework. The AQ-9 adopted the Attribution Model of public stigma (Corrigan et al., 2003; Werner et al., 2017).

Meanwhile, the KIDS adopted the tripartite framework of attitudes (Baker et al., 2018b). The tripartite framework of attitudes (cognitive, affective, and behavioural) used by KIDS (Baker et al., 2018b) and the Attribution Model of public stigma adopted in the AQ-9 (Werner et al., 2017) features cognitive, emotional, and behavioural components of stigma and attitudes. The Brief A-ADS (Farina et al., 2022) shares similarities with a public stigma framework (Rüsch. et al., 2005), but it was not developed based on that framework.

Measures adapted from other measures

All measures were reported as adapted from other measures, except for KIDS, which was not found to be reported on in any of the eligible studies. The adapted version of AQ-9 is a shortened version of the AQ-27 (Corrigan et al., 2003), where mental illness is substituted for the term 'Alzheimer's disease'. The A-ADS is devised from items from the dementia attitudes scale (O'Connor & McFadden, 2010), and Young adult attitudes about Alzheimer's disease (Lundquist & Read, 2008). These are validated measures usually used in young adult populations, such as university students. The Brief A-ADS has fewer items based on the A-ADS. The Questionnaire of Knowledge, attitude and preventive practice on dementia care is derived from Chi et al. (2017), Huang et al. (1993) and Yang et al. (2013). However, these were in Chinese. Therefore, it was not possible to obtain further information or the names of the measures for these.

Table 7 - Measure characteristics of validated measures in adolescents and children

Validated Measures	Developed by	Eligible studies using the measure	Outcome of measure	Theoretical framework	Geographic location
Kids Insight into Dementia Survey (KIDS)	Baker et al. (2018b)	3	Knowledge and dementia attitudes	The tripartite framework of attitudes (cognitive, affective, behavioural)	Australia (2) England (1)
Adapted version of the Attribution Questionnaire-27 (AQ-9)	Corrigan et al. (2003)	1	Public stigma toward a person with Alzheimer's Disease	Attribution model of public discrimination (Corrigan et al., 2003) (cognitive, emotional and behavioural aspects of public stigma in mental illness)	Israel (1)
The Adolescent Attitudes Toward Dementia Scale (A-ADS)	Griffiths et al. (2018) based on the DAS (O'Connor & McFadden, 2010) and the Young adult attitudes about Alzheimer's disease measure (Lundquist & Ready, 2008)	3	Adolescent attitudes towards dementia	Not reported	England (3)
The Brief Adolescent Attitudes Toward Dementia Scale (Brief A-ADS)	Farina et al. (2022) based on the 23-item version of A-ADS (Griffiths et al., 2018)	2	Adolescent attitudes towards dementia	Public stigma framework (discrimination and prejudice) (Rüsch et al. 2005)	England (2)
Questionnaire of knowledge, attitude and preventive practice of dementia care	Chi et al. (2017), Huang et al. (1993), and Yang et al (2013)	1	Knowledge and attitudes of dementia care	Not reported	Macao (1)

Psychometric Properties

The validated measures are summarised in terms of validity and reliability. Table 8 provides an overview of their psychometric properties.

Overall, the measures with the most psychometric properties reported (five properties reported out of nine) were the KIDS (construct validity, convergent validity, content validity, concurrent validity and internal consistency) and the Brief A-ADS (construct validity, predictive validity, concurrent validity, test-retest reliability, and internal consistency).

Validity

No study reported on criterion validity. Only one study reported on predictive validity (Farina et al., 2022). The study showed that the Brief A-ADS can significantly distinguish between self-reported positive DRA.

Three studies reported construct validity (Baker et al., 2018b; Farina et al., 2022; Griffiths et al., 2018) and used an exploratory factor analysis (EFA) to demonstrate construct validity. The KIDS (Baker et al., 2018b) and the A-ADS (Farina et al., 2022; Griffiths et al., 2018) both capture three factors, whilst the Brief A-ADS (Farina et al., 2022) demonstrates a single-factor structure. All three of these measures had several items from the scale removed from the original number of scale items. The KIDS and the A-ADS are reported to reflect the construct of 'attitudes' (Baker et al., 2018b; Griffiths et al., 2018). Only one study reported that the factors supported a theoretical framework (Baker et al., 2018b). The tool adopted the tripartite framework of attitudes (cognitive, affective and behavioural) (Baker et al., 2018b). The Brief A-ADS and A-ADS both capture the construct of perceptions of dementia (Farina et al., 2022; Griffiths et al., 2018), with the A-ADS additionally capturing personal sacrifice and empathy (Farina et al. 2020b and Griffiths et al., 2018). The KIDS captures the constructs of personhood, stigma and dementia understanding (Baker et al., 2018b). The AQ-9 (Werner et al., 2017) and the Questionnaire on Knowledge, attitude and preventive practice on dementia care (Lo et al., 2020) did not report on construct validity.

Two studies reported on convergent validity (Baker et al., 2018b; Griffiths et al., 2018). Both the KIDS and A-ADS demonstrated convergent validity. The KIDS measure revealed a positive Pearson's correlation with the DAS measure ($p<0.01$), indicating that they measure similar constructs. Similarly, the A-ADS revealed a strong, positive correlation with attitudes towards older people scale (ATOP) ($p<0.001$) (Griffiths et al., 2018), further suggesting the scales measure similar constructs. There was no reported context of the ATOP scale in the study.

Only two measures with concurrent validity were reported (KIDS and the Brief A-ADS). There was evidence of good concurrent validity for the KIDS and Brief A-ADS, as they significantly correlated with other measures within the dementia literature (Baker et al., 2018b; Farina et al., 2020b; Farina et al., 2022). For example, the KIDS and DAS were significantly correlated with each other ($p<.01$) (Baker et al., 2018b), as did the Brief A-ADS (Farina et al., 2020b) and A-ADS (Farina et al., 2020a) with the Allophilia scale. A moderate, positive correlation between the Brief A-ADS and KIDS was also reported (Farina et al., 2020b). The Allophilia scale and DAS are validated adult measures. However, Farina and colleagues reported that the Allophilia scale is not an adequate measure to assess concurrent validity (Farina et al., 2022).

Three studies reported on content validity (Baker et al., 2018b; Griffiths et al., 2018; Lo et al., 2020). Where content validity was reported, an item pooling procedure from the existing literature and feedback from an advisory committee was observed across the KIDS, A-ADS and Questionnaire of Knowledge, attitude and preventive practice on dementia care. The KIDS underwent an advisory committee of six people (Baker et al., 2018b), while Lo and colleagues reported using five experts to validate their questionnaire (Lo et al., 2020). The A-ADS conducted 15 interviews with those aged 14-17-year-olds to form many items for the measure (Griffiths et al., 2018).

Reliability

All five measures had their internal consistency reported, with six studies reporting internal consistency (Baker et al., 2018b; Farina et al., 2020b; Farina et al., 2022; Griffiths et al., 2018; Lo et al., 2020; Werner et al., 2017;). All measures reported having at least adequate reliability/internal consistency (>0.60), with most measures

demonstrating good internal consistency (>0.70). Only one study explored test-retest reliability (Farina et al., 2020b). The authors demonstrated that the Brief A-ADS had acceptable test-retest reliability (r>0.70), while the KIDS demonstrated 'questionable reliability' (r <0.50) (Farina et al., 2020b). Inter-rater reliability was not reported on for any of the measures (See Table 8).

Table 8 - Psychometric characteristics of the validated measures identified in eligible studies (< 18 years old)

Psychometric properties	**Validated Measures in the Target Population (10-18years old) summary**				
	KIDS (Baker et al., 2018b)	**AQ-9 (Werner et al., 2017)**	**A-ADS (Griffiths et al., 2018)**	**Brief A-ADS (Farina et al., 2022)**	**Questionnaire of knowledge, attitude and preventive practice of dementia care (Lo et al., 2020)**
Construct validity	Good construct validity. Of 33 items, 14 items were retained. EFA showed a three-factor solution (personhood, stigma and dementia understanding) (Baker et al., 2018b).	NR	EFA: scale captures three factors (perceptions of dementia, personal sacrifice, and empathy with people living with dementia) (Farina et al., 2022; Griffiths et al., 2018). Good underlying construct. From 30 items, 23 items were selected to form the A-ADS. Scale designed to yield a single score reflecting one underlying construct of 'attitudes towards dementia' (Griffiths et al., 2018).	EFA demonstrates a single-factor structure (perceptions) for the 13-item. 23 items reduced to 13 items scale (Farina et al., 2022).	NR
Convergent validity	Strong positive Pearson's correlation between KIDS and DAS ($r = 0.76$, $p<.01$) (Baker et al., 2018b)	NR	A-ADS and young adult attitudes about Alzheimer's disease strongly correlated ($r = .94$, $p<.001$). Strong Pearson's correlation also between A-ADS and DAS ($r = .75$, $p<.001$) (Griffiths et al., 2018)	NR	NR

Continued. Table 8 - Psychometric characteristics of the validated measures identified in eligible studies (< 18 years old)

Content validity	Item pool of cognitive, affective and behavioural intention items from two sources. The advisory committee (n = 6) reached a consensus on the master list of 52 items (Baker et al., 2018b).	NR	A-ADS was developed based on items from the DAS and Lundquist and Ready scale. 15 cognitive interviews were conducted with young people aged 14-17 years old. Based on feedback, a draft of 30 items for A-ADS (Griffiths et al., 2018).	NR	The 30-item questionnaire was developed based on questionnaires from Chinese communities, Chi et al. (2017), Huang et al. (1993) and Yang et al. (2013). Validated by 5 experts. The Content Validity Index = 0.973 (Lo et al., 2020).
Criterion validity	NR	NR	NR	NR	NR
Predictive validity	NR	NR	NR	EFA: 13 item A-ADS has good predictive validity ($t = -5.53$, $p<0.001$). CFA demonstrated 13 item A-ADS had good predictive validity ($t = -6.01$, $p<0.001$) (Farina et al., 2022).	NR

Continued. Table 8 - Psychometric characteristics of the validated measures identified in eligible studies (< 18 years old)

Concurrent validity	14-item KIDS and DAS (r = .76, p<.01) Baker et al., 2018). KIDS and children's social desirability scale had a weak positive correlation (r = .20, p<.05) (Baker et al., 2018b).	NR	NR	EFA: A-ADS 13 item good concurrent validity with Allophilia scale (r = 0.77, p <0.001). CFA: good concurrent validity with Allophilia scale (r = 0.73, p <0.001). 23 item A-ADS and 13 item A-ADS very strong positive association (r = 0.95, p<0.001) (Farina et al., 2022; Farina et al., 2020b). Brief A-ADS and KIDS had moderate positive associations with each other (r = 0.47-0.67) (Farina et al., 2020b).	NR
Inter-rater reliability	NR	NR	NR	NR	NR
Test-Retest Reliability	"Questionable reliability" (r = 0.55, p < 0.0001) (Farina et al., 2020b).	NR	NR	Pearson's correlation demonstrated "acceptable reliability" (r = 0.78, p<0.0001) (Farina et al., 2020b).	NR

Continued. Table 8 - Psychometric characteristics of the validated measures identified in eligible studies (< 18 years old)

Internal consistency	Good reliability (Farina et al., 2020b). The McDonald's Omega indicated a good internal consistency (ωt = .83) for 14 item KIDS (Baker et al., 2018b).	Good internal reliability was found (r = .29, .48, and .29 for the cognitive, emotional, and behavioral dimensions, respectively, p<.0001) (Werner et al., 2017).	The three sub-scales showed adequate internal consistency: personal sacrifice subscale (α = .79), empathy with people with dementia (α = .69), and perceptions of dementia (α = .61) (Griffiths et al., 2018). Good reliability (α = 0.85) (Farina et al., 2022).	EFA: Brief A-ADS had good internal consistency (a = 0.88). CFA: 13-item A-ADS had high internal consistency (a = 0.83) (Farina et al., 2022).	Cronbach alpha r = 0.808 (Lo et al., 2020)

NR = Not Reported; CFA = confirmatory factor analysis; EFA = exploratory factor analysis; KIDS (Kids Insight into Dementia Survey); DAS (dementia attitude scale); A-ADS (adolescent attitudes toward dementia scale); Brief A-ADS (Brief adolescent attitudes towards dementia scale)

Scale characteristics

Table 9 summarises the scale characteristics. The characteristics were extracted from the studies that reported on the number of items, scale and response type, and scoring outcome for each measure. The table also summarises the combined findings for each measure collated from the studies that used that measure.

The number of items measures adopted ranged from nine (Werner et al., 2017) to 23 (Farina et al., 2020a; Farina et al., 2022; Griffiths et al., 2018), with one measure having 30 items in total. It was not reported how many of these 30 items were relevant to the attitude domain (Lo et al., 2020). Three studies reported on scale development in which the number of items was reduced before the final number of items on the measure was agreed upon through the validation process. KIDS was reported to have had 33 items before being reduced to the final version of 14 items (Baker et al., 2018b). The A-ADS was reported to have had 30 items before being reduced to 23 items (Griffiths et al., 2018). The Brief A-ADS reported reducing the 23 items from the A-ADS to 13 items to form the brief version of the A-ADS (Farina et al., 2022).

Of the five measures, four measures feature a 5-point Likert scale (KIDS, A-ADS, Brief A-ADS and Questionnaire of Knowledge, attitude and preventive practice of Dementia care), with one measure adopting a 9-point Likert scale (AQ-9). The 'agree' and 'disagree' wording varied. In general, 'strongly agree' and 'strongly disagree' were the most adopted wording (AQ-9, A-ADS and Brief A-ADS), with strongly disagree given a lower numerical value and strongly agree given a higher numerical number. The higher numerical value corresponds with the outcome of the measure where four of the five measures are reported to indicate that higher scores are equated to better/more positive attitudes, with the scoring of one measure not reported (AQ-9). Three measures report scoring DRA specifically (KIDS, A-ADS and Brief A-ADS). Four of the five measures have a neutral response: 'don't know/unsure' (Baker et al., 2018b), 'neither agree nor disagree' (Griffiths et al., 2018; Farina et al., 2022) and 'no comment' (Lo et al., 2020).

Table 9 - Summary of the scale characteristics of the validated measures in the target population

Measure	Number of items	Scale and response type	Outcome
Kids Insight into Dementia Survey (KIDS) (Baker et al. 2018b)	14	5-point Likert scale - (5) agree a lot, (4) agree a little, (3) don't know/unsure, (2) disagree a lot, (1) disagree a lot.	A higher score = more positive attitudes toward people with dementia.
Adapted version of the Attribution Questionnaire 9 (AQ-9) (Werner et al., 2017)	9	9-point Likert-type scale – 'strongly disagree' (1) to 'strongly agree' (9).	NR
The Adolescent Attitudes Toward Dementia Scale (A-ADS) (Griffiths et al., 2018)	23	5-point Likert scale - strongly disagree (1), disagree (2), neither agree or disagree (3), agree (4) to strongly agree (5).	Higher scores = better attitudes towards dementia.
The Brief Adolescent Attitudes toward Dementia Scale (Brief A-ADS) (Farina et al., 2022)	13	5-point Likert scale - (1) strongly disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) strongly agree.	Higher scores = better attitudes towards dementia.
Questionnaire of knowledge, attitude and preventive practice on dementia care (Lo et al., 2020)	NR how many attitude questions out of 30 items	Strong agree, agree, no comment, disagree, Strong disagree for each question in attitude domain	Higher scores = more positive attitudes.

N.b. NR = Not Reported

2.5.5 Validated measures not in the target population (> 18 years old)

This section will explore the purpose of using validated measures not in the target population in studies conducted on under-18-year-olds and their psychometric properties.

Measure characteristics

Five studies adopted measures that were validated in populations over 18 years old. Three measures were identified from these studies: the Allophilia scale (Kinney et al., 2017, used by Farina et al., 2020a and Farina et al., 2022), the Dementia Attitudes Scale (DAS) (O'Connor & McFadden, 2010 used by Baker et al., 2018b; Griffiths et al., 2018, and Liao et al., 2022), and the Young Adult Attitudes about Alzheimer's Disease Measure (Lundquist & Ready, 2008, used by Griffiths et al., 2018). The latter two measures were validated in college (O'Connor & McFadden, 2010) and university students (Lundquist & Ready, 2008).

Context of use in adolescent attitude studies

The DAS assesses "adult" attitudes (Baker et al., 2018b) and has been "used with college students" (Griffiths et al., 2018). Baker and colleagues use the DAS in the context of pilot testing and psychometric evaluation of the KIDS (Baker et al., 2018b). Phrasing and some item wording were adapted to be more child-friendly. For example, “it is rewarding to work with people who have dementia” was changed to “it is rewarding to play with people who have dementia” (Baker et al., 2018b). Griffiths and colleagues also used the DAS for content development of the A-ADS (Griffiths et al., 2018b).

Amendments to the wording of the DAS were made to make wording simpler for the adolescent demographic in the study. An example of this is "difficult behaviours", which was changed to "aggressive behaviours," as the author suggests that young people do not necessarily know what “difficult behaviours” mean (Griffiths et al., 2018). It was not reported which population the Allophilia scale was developed or validated in within the studies that used it (Farina et al., 2020a & Farina et al., 2022). Farina and colleagues used the Allophilia scale within a series of questionnaires about attitudes and experiences of dementia in their adolescent cohort (Farina et al., 2020a). The Allophilia scale was used to establish the validity of the Brief A-ADS (Farina et al., 2022). The Young Adult Attitudes about Alzheimer's disease measure was developed in undergraduates (Griffiths et al., 2018) and was adopted by Griffiths and colleagues for the content development of A-ADS. The scale was challenging for

young people, with some sentences viewed as complex by the participants. Therefore, amendments were made to the items, such as the word ‘caretaker’ being substituted with ‘carer’ (Griffiths et al., 2018). Three studies used these measures to develop or validate measures specifically designed for individuals under 18 (Baker et al., 2018b; Farina et al., 2022; Griffiths et al., 2018). All four of these studies needed to simplify items of the Allophilia scale, DAS, and the Young Adult Attitudes about Alzheimer's disease to make them more accessible to younger participants. In the study by Liao et al. (2022), the DAS was translated into Chinese for participants.

Psychometric properties

Psychometric properties and scale characteristics were extracted from the eligible studies. Table 10 provides a summary of the psychometric properties.

Validity

The reported validity of the Allophilia sale, DAS and the Young Adult Attitudes about Alzheimer's disease measure were extracted. The content, criterion, and predictive validity for all three measures were not reported in any of the studies that used these measures. No measures were reported on its construct validity either, albeit, for the young adult attitudes about Alzheimer's disease measure (Lundquist & Ready, 2008). The scale was reported to have good validity that contained two subscales as constructs (personal sacrifice and sympathy for people living with dementia) (Griffiths et al., 2018). Both the DAS and the Young Adult Attitudes about Alzheimer's disease measure demonstrate convergent validity. Pearson's correlation demonstrated that these measures had the same construct as other validated measures developed in adolescents and children. The DAS, for example, strongly correlated with KIDS (Baker et al., 2018b) and the A-ADS (p<.001) (Griffiths et al., 2018). Concurrent validity was only reported for the Allophilia scale and the DAS. Both exploratory and confirmatory factor analysis (EFA and CFA) suggested that the Brief A-ADS had good concurrent validity with the Allophillia scale (Farina et al., 2022). A strong correlation was also found between KIDS and DAS (Baker et al., 2018b). These reports would indicate a significant agreement between the validated measures for under-18-year-olds and the validated measures used for above-18-year-olds.

Reliability

The studies did not report the inter-rater and test-retest reliability for all three measures. The internal consistency was not reported for the Allophilia scale within the context of these studies on adolescents. The DAS had excellent internal consistency as indicated by Cronbach's Alpha (α = 0.83), which was previously validated (reported by Baker et al., 2018b; Griffiths et al., 2018). This was supported by Baker et al. (2018b) (ωt= .89*)* and Liao et al. (2022) (α = 0.85 – 0.87). Baker et al. (2018b) used McDonald's omega (ωt) instead of Cronbach's alpha due to negative bias estimates occurring in ordinal data or when the tau-equivalence assumption has been violated. The reliability of young adults' attitudes toward Alzheimer's disease was reported as "good" (cited in Griffiths et al., 2018). The DAS was the only of the three measures that had its social desirability correlation reported. The DAS demonstrated no social desirability (Baker et al., 2018b).

Table 10 - Psychometric characteristics of validated measures identified in eligible studies in populations over 18 years old

Psychometric properties	Validated Measures not in the target population (> 18 years old) summary		
	Allophilia scale (Kinney et al., 2017)	**Dementia attitudes scale (DAS) (O'Connor & McFadden, 2010)**	**Young adult attitudes about Alzheimer's disease measure (Lundquist & Ready, 2008)**
Construct validity	NR	NR	Did not report construct validity but did report the scale has good validity and that the scale contains two subscales: personal sacrifice (6 items), and sympathy for people living with dementia (4 items) (Griffiths et al., 2018).
Convergent validity	NR	DAS has "excellent" convergent validity - O'Connor & McFadden, 2010. Convergent validity was observed between KIDS and DAS through the strong positive correlation between the two (Baker et al., 2018b). DAS correlated with A-ADS ($r = .75$, $p<.001$), indicating A-ADS and DAS measured the same construct (attitudes towards dementia) (Griffiths et al., 2018).	Pearson's correlation demonstrated that A-ADS and young adult attitudes about Alzheimer's disease measure strongly correlated ($r = .94$, $p<.001$) indicating the two measure the same construct (Griffiths et al., 2018).
Content validity	NR	NR	NR
Criterion validity	NR	NR	NR
Predictive validity	NR	NR	NR

Continued. Table 10 - Psychometric characteristics of validated measures identified in eligible studies in populations over 18 years old

Concurrent validity	EFA: 13 item A-ADS had good concurrent validity with a total Allophilia scale (r = 0.77, p<0.001). CFA: 13 item A-ADS had good concurrent validity with a total Allophilia scale (r = 0.73, p<0.001). The Allophilia scale which is validated in adults less than optimal to check for concurrent validity (Farina et al., 2022).	A significant strong positive correlation between 14 item KIDS and DAS (r = .76, p<.01). DAS did not correlate with socially desirable responding (r = .12) (Baker et al., 2018b).	NR
Inter-rater reliability	NR	NR	NR
Test-Retest Reliability	NR	NR	NR
Internal consistency	NR	DAS has excellent internal consistency (a = 0.83). In this study, DAS had a reliability statistic of (ωt = .89) (Baker et al., 2018b). DAS demonstrates very good reliability (Griffiths et al., 2018).	"Good reliability" (Griffiths et al., 2018)

NR = Not Reported; CFA = confirmatory factor analysis; EFA; exploratory factor analysis

Scale characteristics

The scale characteristics are summarised in Table 11. The table summarises the combined findings for each measure collated from the studies that used that measure. The Allophilia scale was used by Farina et al. (2020a; 2022). The DAS was used by Baker et al. (2018b) and Griffiths et al. (2018). The Young adult attitudes about Alzheimer's disease measure was used by Griffiths et al. (2018). Initially, the number of items varied from 10 (Young adult attitudes about Alzheimer's disease measure) to 20 (DAS). For the Allophilia scale, Farina et al. (2020a; 2022) reported removing one item from the Allophilia from the analysis; "I would like to be more like someone with dementia", due to conceptually people not aspiring to develop dementia. Therefore, 16 rather than 17 items were included in the total analysis in these studies.

All three measures adopt a Likert scale but vary in the number of responses: 5-point (Young adult attitudes about Alzheimer's disease), 6-point (Allophilia scale) and 7-point (DAS). All measures adopted the wording 'strongly disagree' to 'strongly agree' with the strongly disagree given a lower numerical value than strongly agree. No neutral response was reported in the studies using these measures. The DAS was reported as a 5-point Likert scale instead of a 7-point scale in the study by Baker et al. (2018b). This change was made to keep the scale consistent with other study measures, which were 5-point Likert scales, to avoid confusing participants (Baker et al., 2018b). Likewise, the DAS was also reduced to a 5-point scale to standardise the Likert scaling in the study by Griffiths et al. (2018). The higher numerical value on the Likert's corresponded with the measure's outcome, where all three measures adopting higher scores that equated to more positive attitudes. The Allophilia scale, which measures positive attitudes towards outgroups, was used to measure positive attitudes towards dementia in the study by Farina et al. (2020a; 2022). The DAS measures adult attitudes toward people with Alzheimer's disease and related disorders (Baker et al., 2018b). The outcome of young adult attitudes about Alzheimer's disease measure was not explicitly reported.

Table 11 - Summary of the scale characteristics of the validated measures not in the target population

Measure	Number of items	Scale and response type	Outcome
Allophilia scale (Kinney et al. 2017)	17	6-point Likert scale: strongly disagree to strongly agree.	Higher scores = more positive attitudes towards outgroups (i.e. dementia)
The Dementia Attitudes Scale (DAS) (O'Connor & McFadden, 2010)	20	7-point Likert scale: (1) strongly disagree to (7) strongly agree	A higher score = more positive attitudes
Young adult attitudes about Alzheimer's disease measure (Lundquist & Ready, 2008)	10	5-point Likert scale: (1) strongly disagree to (5) strongly agree.	Higher scores = more positive attitude towards people with dementia.

2.5.6 Unvalidated measures

Five studies used unvalidated measures of DRA in under-18-year-olds (Chow et al., 2018; Felc & Felc, 2020; Fox, 2020; Fuh et al., 2005; Isaac et al., 2017). The measures did not have psychometric properties or a theoretical framework. Two studies used unvalidated measures in England (Fox, 2020; Isaac et al., 2017).

Measures adapted from other measures

Three measures are based on/adapted from other measures (Felc & Felc, 2020; Fox, 2020; Isaac et al. 2017). Felc and Felc (2020) adopted questions from a questionnaire used in their earlier unpublished pilot study. The questionnaire was in Slovenian, and therefore we were unable to report the nature or context of the questionnaire concerning DRA, and whether this had any psychometric properties. Fox (2020) adapted questions about social distance from Lester (1992), however this text or citation was not available. Isaac et al. (2017) also reported that the measure used in their study was based on questions and statements from the Alzheimer's disease knowledge test (Dieckmann et al., 1988), The Northern Ireland Life and Times Survey

(McParland et al., 2012), and the Alzheimer's Society fact sheet. Whether any of these measures were validated within their intended population was not reported.

Scale characteristics

The scale characteristics are summarised in Table 12. The number of items for each measure ranged between four (Chow et al., 2018) and 20 (Felc & Felc, 2020). The measures varied considerably in content with other constructs measured alongside attitude questions/statements, as the questionnaire by Felc and Felc (2020) had 20 items, nine of which were attitudes towards dementia (Felc & Felc, 2020). One study used a vignette (Fox, 2020). Only one measure did not report scale and response type (Felc & Felc, 2020). A five-point Likert scale was the most widely adopted among the studies using unvalidated measures (Chow et al., 2018; Fox, 2020; Isaac et al., 2017). One measure used yes/no questions (Fuh et al., 2005), while one measure used multiple choice questions where participants could select as many choices they wanted (Fox, 2020). Only one study reported on how scores were calculated (Fox, 2020).

Table 12 - Summary of the scale characteristics of unvalidated measures

Measure	Number of items	Scale and response type	Outcome
Questionnaire (name not stated) (Felc & Felc, 2020)	20 (nine questions on attitude towards dementia)	NR	NR
Card selection task - name not stated (Fox, 2020)	Part one: three vignettes. Part two: Social distance (four items), Social functioning (12 items), Emotional response (two items), Trait attribution (18 adjectives for 1 question item)	Likert scales are administered in the form of card selection tasks. Social distance: five-choice cards - 'dislike it a lot', 'dislike it a little', 'don't like it or dislike it', 'like it a little' and 'like it a lot'. Social functioning: four choice cards - 'not at all likely', 'a little bit likely', 'quite likely' and 'very likely'. Emotional response: five-choice cards - for the like/dislike question: 'dislike a lot', 'dislike a little', 'neither like nor dislike', 'like a little' and 'like a lot'; and four for whether they felt sorry for the individual: 'not at all sorry', 'a little bit sorry', 'quite sorry' and 'very sorry'. Trait attributions: 18 different adjectives, and asked to choose the words which applied to the character.	Social distance: higher social distance score = child prefer less social distance between themselves and the principal character. Social functioning: Positive items - the higher the score = the more positive the perception of the social functioning of the character. Negative items - higher score = more negative perception . Emotional response: Higher scores = more positive attitudes. Trait response: higher score = greater number of positive or negative traits attributed.

Continued. Table 12 - Summary of the scale characteristics of unvalidated measures

Attitude Toward Dementia Questionnaire (Fuh et al., 2005)	10	Divided into two categories, six yes/no questions and four responses to questions with a four-point range of strongly agree to strongly disagree (strongly agree, somewhat agree, disagree, strongly disagree)	NR
No name reported (Isaac et al., 2017)	15 on dementia knowledge with 8 questions on attitudes towards dementia.	Attitude questions had a 5-point Likert scale (1) - strongly agree, (2) - agree, (3) - neither, (4) - disagree, (5) - strongly disagree.	NR
Assessment of students' perception (Chow et al., 2018)	4 attitude statements	5-item Likert scale (strongly disagree, disagree, neutral, agree, strongly agree)	NR

NR = Not Reported

2.6 Discussion

This scoping review aimed to identify the types of measures used in studies that explored DRA in adolescents. This scoping review is the first in the DRA literature to map out measures administered in adolescents. In doing so, some of the limitations of the current literature base are available for researchers to consider and help with future work in capturing DRA in adolescents. This scoping review categorised measures by; validation in the target population (defined as under 18 years old), validated not in the target population (over 18 years old), and unvalidated measures. The key findings are evaluated below, drawing on similarities and differences between the measures, common characteristics, and the strengths and limitations of using the measures.

2.6.1 Key findings

The findings of this scoping review reveal that there is limited literature specifically measuring DRA in adolescents. However, from the 13 measures identified, it is encouraging that most measures were validated within the target population. The Brief A-ADS and KIDS were found to be the most used validated measures and had the most comprehensive psychometric properties, although this was in a small number of studies. Both these measures demonstrated psychometric validity and incorporated theoretical frameworks that can be useful in explaining the attitude construct observed. Both measures were developed and used in high economic, English-speaking countries. This limits the future uptake of these measures internationally and cross-cultural validation would be necessary. There are very few studies with cross-cultural comparison in the DRA literature that include young people (e.g., Shulman & Adams, 2002; Werner et al., 2017).

The lack of validating such measures in different cultural groups' geographic locations could mean a lack of capturing DRA diversity from ethnic groups and various exposures to dementia (Diaz et al., 2022). For instance, in both the validated and unvalidated measures, samples were mostly White British or White Australian. However, the reporting of ethnicity was scarce across the studies in this scoping review. Measuring attitudes in a more diverse group is necessary as it ensures the measured attitude is applicable and meaningful across various backgrounds, increasing cultural validity (del Rosario Basterra, Trumbull, & Solano-Flores, 2011).

This is because DRA may significantly differ across different cultural groups due to varying beliefs and norms relating to ageing, mental illness, dementia, and caregiving (Hillman & Latimer, 2017). It would provide researchers with a greater understanding of DRA within a cultural context by capturing nuances, giving a more accurate comparison and generalisation of DRA. Moreover, a lack of diverse samples can introduce bias into the research findings since DRA may differ across different socio-economic statuses and educational attainment (Farina et al., 2024). Lastly, validating measures in diverse cultural groups also allows for the development of culturally sensitive DRA interventions. This could lead to more tailored interventions that better address the population's diverse needs (Gavin et al., 2022).

Attitudes

Collectively, 'attitudes' were found to be the most commonly measured construct in the studies. Dementia attitudes and similar variations of this most commonly occurred with many characteristics of a measure's outcome expressed as ‘better/ more positive’ attitudes towards dementia across identified measures for the studies. However, steps should be taken to reduce the ambiguity of what is being measured by defining the construct of interest. This is because the limitation of 'attitudes' is its variability in definition (Annear et al., 2015). The studies did not typically define attitudes in the context of the measures. Different measures had various constructs such as dementia understanding, dementia knowledge, and dementia attitudes. The outcome was expressed as dementia attitudes, which appeared to be used as an umbrella to also account for ‘understanding’ and ‘knowledge’. This is despite other measures in the literature that specifically measure dementia knowledge, which is a separate construct from attitude (Annear et al., 2015). It is therefore, difficult to distinguish the author's intentions for the measure when constructs are treated as unified rather than individual and specific, mainly since most of the measures were based on existing measures. Drawing on different sources and integrating them into one measure may not accurately capture the author's intended definition of attitude, and may differ from the author of the existing measure being adapted/used (O’Connor & McFadden, 2010). Researchers must therefore be mindful when pooling different items, mainly if measures are unvalidated, given the existence of various definitions of attitudes and not necessarily these definitions being specific to the context of dementia. One

recommendation to address this issue is for researchers to define attitudes in a way that fits within what they are attempting to measure. Adopting a theoretical framework would provide greater clarity regarding what constructs are being measured (Herrmann et al., 2018).

One consideration with measuring attitudes is that other measures in the literature may overlap with similar fields. This includes measures for older adults, ageism, and knowledge that may have included the attitude or stigma construct as a primary outcome (e.g., see Marchetti et al., 2022). However, these fall outside the scope of this review, as it is specifically public stigma towards dementia that is of interest. As ageism is not necessarily the same entity as stigma (i.e., ageism is related specifically to age, while stigma applies to various group of people), it should be treated as a separate construct, despite the overlap (Bacsu et al., 2023). Future studies could investigate where there is an overlap between such constructs to extract attitude items from these measures and assess the psychometric properties between these measures.

What theoretical frameworks underpin dementia attitude measures?

The Attribution Model of stigma framework (Corrigan, 2000; Corrigan et al., 2003), as mentioned in the introduction of Chapter 1 (section 1.2), is the typically adopted framework in assessing public DRA (Pryor & Reeder, 2011; Rüsch et al., 2005). Additionally, it has been noted that there is a general lack of frameworks used in DRA research (Werner, Raviv-Turgeman, & Corrigan, 2020). Researchers have noted that a limited number of studies generally use a framework within the attitude literature. For example, 73% of research that was published between 1990 and 2012 looking at stigma and Alzheimer's disease had not referred to a modern theoretical model of stigma (Werner, 2014). This scoping review recognises this to be the case across the studies. Only a limited number of measures (AQ-9 and KIDS) had a theoretical framework incorporated. In line with the literature, the AQ-9 incorporates the "Attribution Model of public discrimination", which comprises cognitive, emotional and behavioural components (Werner et al., 2019). The Brief A-ADS aligns with the stigma framework by Rüsch and colleagues by including the components of discrimination (adverse behavioural reactions) and prejudice (negative emotional reactions) (Rüsch et al., 2005). Although the KIDS measure (Baker et al., 2018b) uses

the tripartite framework of attitudes, this also parallels with the above frameworks by incorporating the cognitive, affective, and behavioural components that are seen as fundamental aspects of attitude measurement theory (Eagly & Chaiken, 1993). It is therefore not unusual that the KIDS measure and the Brief A-ADS are observed as moderately and positively correlated with each other (Farina et al., 2022) when testing for concurrent validity. It is important to note that the frameworks identified in this scoping review were developed with mental illness stigma in mind (Corrigan et al., 2003; Eagly & Chaiken, 1993; Pryor & Reeder, 2011). No reported theoretical frameworks underpin the measures categorised as 'validated but not in the target population' and the 'unvalidated measures'. It is important to point out that this does not necessarily mean that these measures did not incorporate any framework, they merely have not reported on it in the studies that used such measures. For example, the validation of the Allophilia scale (see Kinney et al., 2017) is underpinned by the social identity theory (Harwood, 2020) and terror management theory (O'Connor & McFadden, 2012; Landau et al., 2004). Terror management theory refers to people having inherent fear of death, with avoidance of out-groups that remind us of mortality (Greenberg & Kosloff, 2008).

Study characteristics

Sample sizes varied considerably amongst the 14 studies. Most of the studies had a sample size of less than 500 respondents. A satisfactory sample size is necessary to offer reliable and reproducible evidence, and to detect the psychometric properties of a measure (Bujang, Omar, & Baharum, 2018). The two largest sample sizes among the studies were unvalidated measures. Almost all of the measures validated in populations over 18 years old required item wording adjustments to make them more accessible to the younger participants (e.g., Baker et al., 2018b). Removal or adaptation of survey items could alter the psychometric outcomes of the original measure. Therefore, measures with these modifications should undergo further psychometric testing to ensure they are fit for purpose within the younger demographic. When items of measure are adjusted to make it suitable for young people, this may compromise aspects of the stigma and attitude construct (Alfieri & Marta, 2011). Only three studies were explicitly designed to validate a measure and were for the purpose of scale development (Baker et al., 2018b; Farina et al., 2022;

Griffiths et al., 2018). A particular strength of the Brief A-ADS is that it was validated using a larger sample size than the original A-ADS, and optimised the original A-ADS.

The knowledge gap from the studies using validated measures was the lack of consensus on the most appropriate measures for assessing DRA (Herrmann et al., 2018). This made it difficult to compare the studies, given the limited adoption of each measure. This is not surprising given that most studies eligible for inclusion in this review were all published between 2017 and 2022. This is likely why no studies in this review reported on criterion validity, since this would demonstrate how scores on a measure correlate with a gold standard or established criterion of DRA (which currently does not exist). Given the varied age range of participants and dimensions adopted by the various validated measures, the interpretation of criterion validity is limited. Another gap in study characteristics includes a lack of information on whether there was input in the outcome measures from those with lived experience of dementia. There is an increasing importance placed on co-production and consulting those with lived experience of dementia (Diaz et al., 2022). None of the studies mentioned whether this was considered or not. Lastly, there was a clear gap in reporting on ethnicity, with just three studies reporting on this (Farina et al., 2020a; Farina et al., 2020b; Griffiths et al., 2018), which limits the generalisability of the measure's findings.

Measure properties

Many of the measures needed to rephrase some item words to make the items more accessible to younger populations. This was due to some sentences viewed as complex or words needing to be simplified as these measures were developed for older populations (e.g., Baker et al., 2018b). This ensures readability was appropriate for the intended user (Oakland & Lane, 2004), given that most of the measures in this scoping review, including the validated measures, derived from existing measures purposed for older adults and college students (e.g., DAS, O'Connor & McFadden, 2010). As such, adapting/removing items may produce different psychometric outcomes than the original measure it is based on (Bramam & Azzam, 2023). Other scholars have empirically found that adaptations on the measure items to change their context can

retain their original psychometric properties, but not the content (Rice, 2024). Therefore, unvalidated measures could do with validating to ensure they are fit for purpose with the modified changes. Only one study reported on measure readability (Farina et al., 2022). This is a limitation common in child measures but is significant to the ease and understanding of text for children (Oakland & Lane, 2004; Patalay, Hayes, & Wolpert, 2018), due to the cognitive effort differences between adults and children (Bell, 2007; Krosnick & Alwin, 1989). These are important pitfalls to consider since these have implications for the accuracy of capturing DRA in intergenerational initiatives. Accurately measuring attitudes in younger and older adults is important to understand the benefits and effectiveness of various intergenerational initiatives that tackle DRA (Silverstein & Sherman, 2010).

There are potential advantages of developing measures that could be used across different age groups. A universally applicable measure could allow comparisons across the whole population for assessing DRA. This could provide insights into DRA across the lifespan, providing insight into how attitudes develop from children to older adults. In England, the majority of adults are in the 11-14-year-old reading age group, albeit 15% of the adult population in England read below this level (NHS Health Education England, 2020). Thus, creating an accessible measure inclusive of adolescents and adults could be possible with simple language and formatting.

Developing such a measure has significant challenges due to the differences in development and cognition across age groups. The accessibility and relevance of items to adolescents are important. For example, the content development of the initial validation for the A-ADS entailed a cognitive walkthrough interview with 15 young people aged 13-17 years old. This content development task involved young people completing existing adult attitude measures and asking them to think out loud about the question's meaning and response. This was to ensure that the wording of the items was suitable, identify any problems with the items, and make the measure culturally and age-appropriate (Griffiths et al., 2018). Additionally, attitudes are shaped by different influences at various stages of life. Children may be influenced by familial, peer, and education contexts (Petani, 2011), while adults may be influenced by lived experience and societal norms (Poortman & Van Tilburg, 2005). Thus, a single measure may fail to capture the nuances of attitudes unique to each age group.

Most measures adopted a 5-point Likert scale in the validated and unvalidated measures, consistent with the literature (Emerson, 2017). On the other hand, only one of the measures validated as not being in the target population had a 5-point Likert scale. While all the validated measures had a Likert scale, there was more variety in the unvalidated measures, where vignettes and multiple-choice selection were also featured. Most studies using existing validated measures adjusted the number of points on the Likert so that it was in line with their measure to avoid confusing participants when validating and assessing psychometric properties (Baker et al., 2018b). Notably, attitude scales such as those that use Likert's usually assume that attitudes are unidimensional, which has been argued as unrealistic given that two individuals who score the same on a given attitude measure would unlikely have the same attitude. An open-ended measure can be viewed as a compromise to account for limitations where specific aspects of attitude can be measured (Samra, 2014).

It was also common that higher scores on the measures equated to more positive/better attitudes, which is also in line with the Likert literature (Emerson, 2017). Other similarities between the measures include typical responses ranging from 'strongly agree' and 'strongly disagree' or some variation of these terms. Whilst most of the measures included a neutral response when using a Likert scale such as 'don't know', some measures did not include this, which could be problematic as this could lead to participants attempting to guess a correct answer. This may not truly reflect participants attitudes (Isaac et al., 2017). Likert scales with odd number responses with an equal amount of positive and negative responses on either side of a central neutral response are considered "well-constructed" (Emerson, 2017). Moreover, one study found no psychometric benefits of having six response options on a scale (Simms, Zelazny, Williams, & Bernstein, 2019). However, this is not universally agreed in all studies. Some researchers argue that seven response categories on a scale work more robustly (Emerson, 2017), with one other study finding that a seven-point rating scale for attitude scales is advisable (Taherdoost, 2019).

There were no more than 30 items for any measure, though the number of items specifically for attitudes within the measure may have been lower. For example, nine out of 20 items were related to DRA (Felc & Felc, 2020). However, it is important to consider the risk of including many items in a measure. Longer questionnaires may

lead to increased non-completion, missing items, and low-quality data, particularly in younger participants due to boredom (Bell, 2007). In support of this, shorter questionnaires result in better survey response rates (Rolstad et al., 2011). It is therefore important to consider whether current measures used in adolescents are appropriate in length to mitigate factors such as boredom effects and burden on the participant, and how this compromises aspects of the DRA construct. Future validation work on measures could focus on optimising questionnaires to mitigate these issues.

Psychometric properties

Overall, two measures reported the most psychometric properties, with five properties reported out of the nine psychometric property checklists, KIDS and Brief A-ADS. Only one study reported on predictive validity (Farina et al., 2022) for the Brief A-ADS. However, this predictive outcome should be chosen cautiously, as the outcome 'self-reported attitudes towards dementia' might not be the most appropriate. Some behaviours (e.g., volunteering with people living with dementia) would be a more objective outcome since behavioural action can directly reflect an individual's intention and motivation. This offers external validity (Ajzen et al., 2018). For example, while an individual may self-report positive attitudes towards an attitude subject, an individual may never engage with the attitude subject due to real-world factors such as situational constraints (e.g., economic reasons) (Hjalmarsson, 2023). This confines self-reported attitudes to being less predictive of future behaviour. While predictive validity does not assess all available data, predictive validity is viewed as a robust statistical measure of validity (Taherdoost, 2019). This further increases the strength of the Brief A-ADS over other measures.

The studies that reported on using experts for content validity typically had between five to six experts, which appears to be the norm, with less than five experts in some studies deemed inadequate (DeVon et al., 2007). In one study, Lo et al. (2020) used questionnaires validated by five experts using the content validity index (CVI), common in scale developers. However, other methods are used, such as item-level CVIs and backward inference with purposive samples (Almanasreh, Moles, & Chen, 2019). There was no context or method of CVI for the questionnaires used in the study by Lo et al. (2020) within the study. However, it did reference the original sources of

the existing questionnaire, which needed to be in English. Therefore, further information on the accuracy of the reported CVI in the study by Lo et al. (2020) cannot be accurately reported.

Seven measures had reported internal consistency. All measures indicated suitable internal consistency. The measures indicated suitable internal structures based on reliability coefficient criteria (e.g., Cronbach's alpha). This is important because poor internal consistency may indicate that the measure is not measuring the intended construct accurately, which may lead to invalid results. Higher internal consistency gives greater confidence that the results accurately represent DRA and that the measures can produce consistent results over time and different samples. This provides increased confidence that results are not due to measurement error (Tavakol & Dennick, 2011). Moreover, enhanced replicability increases confidence in the generalisability of findings (Nosek et al., 2022). Cronbach's alpha (α) (also known as coefficient alpha) was the most commonly used to display internal consistency in the measures. The literature supports this, where 'α' is the most widely used statistic to demonstrate scale reliability. A coefficient alpha of .70 or above is the general rule of thumb for good reliability (Taber, 2018). The measures validated in the target population generally indicated good internal consistency. However, it is important to note that a high Cronbach's alpha does not ensure that a scale is accurately measuring a construct. Items on a measure may be highly correlated but fail to measure the intended construct accurately (Tavakol & Dennick, 2011). The McDonald's Omega (ω) was used for the KIDS instead of Cronbach's alpha (Baker et al., 2018b). Some methodologists argue that this is a more optimal measure of reliability for unidimensional constructs (Goodboy & Martin, 2020; Hayes & Coutts, 2020). The rationale given by Baker and colleagues was that the use of ω was based on potential negative bias estimates that can occur in ordinal data or when the tau-equivalence assumption has been violated (Baker et al., 2018b).

Only one study reported on test-retest reliability where an "acceptable reliability" was found (Farina et al., 2020b). When comparing the test-retest reliability of the KIDS and the Brief A-ADS, the KIDS had a correlation coefficient of 0.55, which suggested a moderate positive correlation between the scores at baseline and those obtained at the retest. However, it falls below what is considered acceptable reliability (Farina et

al., 2020b). The Brief A-ADS had a correlation coefficient of 0.78, indicating a strong positive correlation. This suggests that the Brief A-ADS has higher consistency and stability of scores over time. Thus, the KIDS measure displays more reliability concerns in this respect than the Brief A-ADS. However, using test-retest reliability is not necessarily appropriate for constructs that are expected to change over time, such as attitudes (DeVon et al., 2007). This may explain the "questionable" test-retest score reported in the KIDS and the "acceptable" reliability for the Brief A-ADS (Farina et al., 2020b). Low test-retest reliability scores indicate that the measure demonstrates a lower level of stability over time or needs to capture the true stability of the DRA, which reduces the validity of the measure (Kennedy, 2022). The issues with a lower score are usually associated with higher measurement error, where varying scores are not due to actual changes in DRA but rather to random factors. This impacts the accuracy of the measurement, decreases confidence in the findings, and makes it difficult to draw meaningful conclusions about DRA if there are no consistent results over time (Kennedy, 2022). Consequently, lower scores may reduce the sensitivity to detect true changes in DRA, which could make measuring the effectiveness of DRA initiatives accurately more difficult.

Social desirability bias

The studies in this scoping review report susceptibility to social desirability bias. The KIDS, for example, was positively correlated with a children's social desirability scale (Baker et al., 2018b). However, the validated adult measures used in these studies had no significant reporting bias. Although this bias was weak in the KIDS, mitigating bias responding may be possible by incorporating implicit measures (Gawronski, LeBel, & Peters, 2007). There were no reported implicit measures used in the studies of this scoping review despite literature theory, such as the dual process model suggesting that people have implicit and explicit negative responses (Pryor et al., 2004). The incorporation of implicit measures with explicit measures is generally limited in young people, with no implicit DRA tests designed for adolescents currently.

The measures in this scoping review were explicit DRA measures. Explicit measures are more susceptible to social desirability. Young people learn to inhibit socially undesirable attitudes outwardly as they get older and tend to provide socially desirable

answers when in the presence of a researcher (Camerini & Schulz, 2018). A key recommendation for future use of DRA measures is to incorporate implicit or social desirability measures to check for bias in the reported DRA and increase the validity and reliability of the measure (Pryor & Reeder, 2011).

2.6.2 Strengths and limitations of the scoping review

Strengths

First, a key strength of this scoping review is the implementation of features typically used in a systematic review (see section 2.4.1). This includes a systematic search strategy, transparent methodology with clear inclusion and exclusion criteria, and adherence to PRISMA guidelines. The use of the PRISMA flowchart alongside the guidelines, minimise bias and enhance the credibility and transparency of the findings (Moher et al., 2015). Unlike systematic reviews, scoping reviews provide a rapid, big-picture perspective to DRA measures, which was more suitable for this study.

Second, the search strategy was rigorously piloted and optimised to effectively answer the research question. Screening was comprehensive, conducted by two reviewers using Rayyan software, which minimises research bias through blind reviewing procedures. The high agreement between reviewers, supported by a high Cohen's kappa score, further validates the process (McHugh, 2012).

Third, this scoping review is novel in identifying existing measures of DRA in adolescents, allowing researchers to compare measures strengths and limitations and identify gaps in the literature. By summarising psychometric properties, the review facilitates the comparison of measures, which is important given that no consensus exists on a gold standard (Harper et al., 2019). The recommendations provided aim to increase the use of validated measures, improving the assessment of DRA and anti-stigma initiatives (Griffiths et al., 2018).

Lastly, there was careful consideration of the number and type of databases used to enhance the likelihood of including as many relevant studies as possible. This was guided by evidence where Web of Science, PubMed, and APA PsycInfo are deemed

the most popular in the social sciences (Chapman, 2021; Wanyama, McQuaid, & Kittler, 2021). The thorough search process, including forward and backwards citation searching, is believed to have captured the most relevant studies, and search strings were saved for ongoing literature updates.

Limitations

First, the conclusions of this review are dependent on the quality of the reporting in the included studies. If studies did not sufficiently describe their approach or analysis, this may bias the conclusions made. In this review no contact was made to study authors to clarify what was reported or whether other data was available.

Second, the descriptive narrative for scoping reviews was chosen due to its ability to include formal analytical processes, is transparent, and allows for the compilation of descriptive data (Tricco et al., 2016). This makes it a suitable approach for this scoping review synthesis and allowed for contextualising quantitative data. Qualitative studies were excluded from this scoping review. While there may have been room for interpretation for measuring DRA in adolescents as some studies were of mixed design (e.g., Baker et al., 2019), this scoping review's psychometric properties were the focus. Therefore, qualitative data was not appropriate to review. However, future research could consider evaluating how DRA is measured qualitatively and quantitatively, to provide a more comprehensive understanding. This is because the quantitative approach may oversimply complex phenomena like stigma, which consist of multiple dimensions. Quantitative outcomes are also limited because they need to richly capture the contextual nuances and social dynamics (cultural, social, and historical) of attitudes. Yet, quantitative measures do not fully reflect all the experiences of these constructs.

Third, the inclusion of younger children poses a limitation. The inclusion criteria, based on the WHO definition of adolescent, state adolescents are children between the ages of 10 and 18 years old. However, some studies included participants as young as six years old, which may not be entirely relatable to adolescents. However, due the limited number of studies, there was less stringency in disregarding studies that included children under the age of ten. However, measures such as the KIDS (Baker

et al., 2018b), have similar psychometric properties and correlate with other measures designed and validated in adolescents. This justifies including populations younger than ten years old. Nevertheless, only data from participants aged ten and above were extracted for this review.

Fourth, the exclusion of grey literature, while maintaining a higher standard of evidence, may have introduced publication bias and limited the inclusivity of the perspectives within the field. For example, some studies that otherwise would have met the criteria to be included may have been missed. Although this decision aimed to exclude poor-quality measures, it also risked missing relevant insights from non-peer-reviewed sources, potentially undermining the review's comprehensiveness. Additionally, only English-language papers were included, which may have led to the exclusion of relevant non-English papers. For example, a potentially eligible study was in the Chinese language. The properties of these measures were unable to be extracted.

Lastly, this scoping review implemented only some of the Levac recommendations. The optional sixth stage (consulting stakeholders) (Arskey & O'Malley, 2005) was not implemented due to concerns about power imbalances, ethical implications, and its alignment with participatory research (Buus et al., 2022). While this consultation could have added methodological rigour (Levac et al., 2010), it was deemed beyond the scope of this review. However, the other recommendations that were followed enhanced the reviews credibility and transparency given the limited practicality and resources to implement all recommendations. Additionally, a quality assessment was not conducted in this review, as it is not a typical feature of scoping reviews and is not a recommendation of the Arksey and O'Malley (2005) framework.

2.7 Conclusion

Measures that target DRA are mainly purposed to capture the attitudes of people living with dementia, carers, health practitioners, and increasingly, and the general adult population. This may not be generalisable to adolescents. This scoping review is the first in the DRA literature to map out measures specific to adolescents, addressing a knowledge gap in the literature. While just over half of the studies exploring DRA in

adolescents used validated measures, there is still a clear gap between the psychometric properties reported, and the underlying theoretical framework. Measures validated in other populations should take precedence over unvalidated measures since these types of measures have no psychometric support. The Brief A-ADS and the KIDS have the most robust evidence of psychometric validity for measuring DRA in adolescents.

Chapter 3 Factors Associated with dementia-related attitudes in adolescents: A Systematic review

This Chapter systematically reviews the factors associated with DRA in adolescents. See Chapter 1, section 1.8 for an overview of the factors associated with DRA.

3.1 Aims and Objectives

To ensure anti-stigma initiatives carried out in adolescents are evidenced-based and culturally appropriate, there is a need to better understand what factors are associated with DRA in adolescents. The main aim of the systematic review was to identify what factors are associated with DRA in adolescents. This was done by systematically reviewing quantitative, qualitative, and mixed-method literature. There are currently no reviews addressing this area within the adolescent population. Therefore, this Chapter takes the approach to identify what literature exists in this domain and assess the quality of this literature to determine what gaps may need addressing moving forward.

Objectives

1. To identify factors that are and are not associated with DRA in adolescents.

2. To investigate the strength of the association between identified factors with DRA in adolescents.

3. To identify and report the gaps in the current literature.

3.2 Methods

This systematic review follows the traditional methodology in which a systematic and exhaustive search strategy is used to identify relevant studies with explicit criteria and description of the design, synthesis of data, and interpretation of the findings. A systematic review was chosen over a narrative review to provide a structured and defined question to make the search, criteria and reporting of quality assessment

transparent, as well as its ability to integrate qualitative and quantitative summaries (Siddaway, Wood, & Hedges, 2019).

The Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) and PRISMA study flow diagram have been adopted for transparent reporting, study selection and analysis of the literature (Moher et al., 2010; Page & Moher, 2017). A textual narrative synthesis was adopted according to the guidance on narrative synthesis in systematic reviews (Popay et al., 2006) to synthesise quantitative and qualitative data. The textual narrative synthesis for systematic reviews is particularly advantageous for its ability to integrate synthesised evidence that is quantitative, qualitative and of mixed methods design (Barnett-Page & Thomas, 2009).

3.2.1 Protocol and Registration

The protocol for this systematic review can be found in Appendix G. The protocol was written in adherence with the PRISMA-Protocol statement recommendations (Moher et al., 2015). The systematic review protocol has been registered on an open-access depository, protocols.io (dx.doi.org/10.17504/protocols.io.b2hjqb4n) (Hassan, Tabet, & Farina, 2021).

3.2.2 Formulating a research question

The following research question was formulated by EH and NF using the systematic search strategy SPIDER (sample, phenomenon of interest, design, evaluation and research type) to answer the systematic review research question; ‘What factors are associated with DRA in adolescents?’. Research questions can guide search strategy elements and curate inclusion and exclusion criteria (Davies, 2019).

3.2.3 Eligibility

The eligibility of studies and the search strategy were formulated and guided by the systematic search strategy SPIDER. SPIDER was selected due to its allowance for qualitative, quantitative and mixed methods research studies (Davies, 2019; Methley et al., 2014) compared to other strategies such as PICO (patient, intervention,

comparison, outcome) which are better suited for searching intervention studies. Table 13 reflects each aspect of SPIDER that was adopted to guide the eligibility criteria.

Table 13 - SPIDER search strategy guidance

SPIDER	
Sample	Adolescents: 10-18 years old (WHO, 2024)
Phenomenon of interest	Factors associated with dementia-related attitudes
Design	Observational, cross-sectional, interventions (baseline data only)
Evaluation	Themes, validated measures, unvalidated measures, associated factors
Research type	Quantitative, qualitative, and mixed methods

Based on this, the determined inclusion and exclusion criteria were as follows;

Inclusion criteria: A) English language publications; B) participants include adolescents (10-18 years old); C) reports associations between factors associated with DRA within an adolescent population; D) quantitative, qualitative, and mixed methods design; E) peer-reviewed articles and grey literature. Articles with full text available were included in the review.

Exclusion criteria: A) participants following an intervention arm (i.e., data from a second-time point or follow-up period of an intervention); B) populations exclusively recruited from university student populations; C) specialist professions exclusively (medical or healthcare professionals); D) outcome exclusively related to self-stigma.

Studies were excluded if they did not include a sample (or subsample) of participants with an average age within the desired age range (10-18).

The PRISMA study flow chart in Figure 3 reflects decisions on study eligibility. This includes reasons for study exclusions.

3.2.4 Identifying relevant studies

Information sources

The databases selected for this systematic review was based on the evidence of which databases were most appropriate and used for reviews within the broader subject area. Web of Science, PubMed, and PsycInfo were found to be the most widely used for the social sciences discipline. These provide broader coverage across other disciplines (Chapman, 2021). SCOPUS and Open Access Theses and Dissertations (OATD.org) were also employed as information sources for broadening the search for grey literature (dissertations and conference abstracts). Including grey literature can reduce the publication bias of positive results in systematic reviews (Davies, 2019). From the eligible studies, further relevant literature was sought through the snowballing method (i.e., front and backwards citation searches) (Pham et al., 2014) by checking reference lists from the identified sources and using the 'cited by' function.

Empirical studies that were qualitative, quantitative and mixed methods, including theses, were eligible. If the studies were an intervention study such as longitudinal or having a pre and post-comparison, the study was only eligible if it reported an association between the variables at baseline/ pre-intervention. Non-primary data studies (e.g., systematic reviews) were excluded. While conference abstracts were eligible, they were excluded if no full-text study was available. This systematic review adopted a standardised process of identifying potentially relevant full-texts, which included contacting the corresponding author. Only English language papers were included for practical reasons.

No limits were set for the time period the articles were published to ensure all relevant studies were captured. While no time period was applied due to taking an exploratory approach to see what literature exists in general, older articles may be less relevant to adolescents today. The studies needed to report a relationship between factors and DRA (variables associated significantly or non-significantly with DRA).

Search strategy

EH initially drafted the search strategy before consulting with NF on the synonyms of the search terms included. The search strategy was further developed, tested, and adapted for each database to ensure the search was wide-ranging and to optimise the search string to retrieve relevant articles from the databases. EH attended literature searching with the doctoral school librarian to optimise the use of Boolean operators. Boolean operators 'AND' and 'OR' were utilised to search for relevant articles. The operator 'NOT' was not used to ensure articles that consisted of mixed populations that included adolescents and professional healthcare workers were not discriminated against in the search. The final search strategy for each database, the number of results returned and the date of the search have been saved for replicability and are located in Appendix H. All searches were performed using the terms in English.

The search strategy was created using a combination of MeSH terms, variations of the spelling for the search words, and synonyms (Cognetti, Grossi, Lucon, Solimini, 2015). The key search components were 'dementia', 'stigma', and 'adolescents', which are exhibited in an example search strategy in Table 14.

Table 14 - Example search strategy terms and components

	Search component	Search strategy
1	Dementia	Dement* OR Alzheimer*
2	Adolescents	Adolescent* OR teen* OR "young people" OR child* OR student*
3	Stigma	Stigma OR perception OR attitude* OR discrimination OR "social distance" OR prejudice
		1 AND 2 AND 3

3.2.5 Study records

All articles found in the databases were exported onto the reference manager Zotero, where duplicates were removed through automated de-duplication, manually identifying and excluding further duplicates. Microsoft Excel was used to manage the data extraction from the eligible articles and record the screening process decisions.

3.2.6 Study selection

Following the de-duplication process, a single reviewer (EH) independently screened the titles and abstracts using the inclusion and exclusion criteria on ASreview, a systematic review software run through Python software. This replaced a second reviewer since this machine learning software can model the decision-making process and forecast the most relevant articles based on a single reviewer's decision on study eligibility. AS review is particularly advantageous in removing researcher bias at the screening stage, increasing the efficiency of screening titles and abstracts, and making the process transparent and quicker (van de Schoot et al., 2021).

Six previously identified relevant articles and nine irrelevant articles were screened by EH using the eligibility criteria to train the software on the required prior knowledge. The active learning mode selected was as follows: 'Active learning mode: Classifier - Naive Bayes, Query strategy: Maximum, Feature extraction: term frequency-inverse document frequency (TF-IDF)'. In training mode, EH screened 13.03% of articles and stopped once 11 articles were consecutively rejected before allowing the machine learning process to complete the decision modelling. This decision was based on evidence that suggests systematic reviewers that use machine-assisted approaches usually screen five to ten percent of abstracts (Gartlehner et al., 2019). This is further supported by evidence that demonstrated 95% of eligible studies were detected on ASReview after screening between 8% and 33% of studies. The number of eligible abstracts found after reading 10% of abstracts ranged between 70% and 100% (van de Schoot et al., 2021).

The studies that met the inclusion criteria identified through title and abstract screening had full manuscripts sought after and underwent citation screening through snowballing to identify eligible studies further. This method is widely adopted, as

suggested by a recent review that found half of the reviewers declaring that further references were checked for in the reference lists of eligible studies (Chapman, 2021). Where full texts were not available, authors were contacted. If no full text was available or accessible, they were excluded. The eligible studies underwent full-text screening independently and in duplicate by EH and another researcher (NF), where the decisions of both researchers were blinded to each other until the end of the full-text screening process. Any conflicts that arose at this stage were discussed between EH and NF. No conflicts are required to defer to an independent third researcher to resolve a decision. Cohen's kappa coefficient (k) for inter-rater reliability was applied to measure the agreement between EH and NF (kappa result of 0.61-0.80 indicated substantial agreement) (McHugh, 2012). The PRISMA flow study chart was used to record the decisions of each stage of the articles' identification and screening process.

3.2.7 Outcome prioritisation

The associations between the independent variable and DRA are prioritised in the reporting of this systematic review. The dementia outcomes consist of attitudes, perceptions, beliefs, social distance, and discrimination. Further prioritisations include standardised measures, as well as qualitative themes and subthemes to provide contextualisation to the quantitative findings.

3.2.8 Quality assessment

To assess the risk of bias and quality of the eligible studies, the mixed Methods Appraisal Tool (MMAT) was adopted following the guidance of the MMAT version 2018 (Hong et al., 2018). The MMAT was chosen over other appraisal tools due to its specific design, which includes qualitative, quantitative, and mixed-method studies (Souto et al., 2015). The MMAT assesses methodological quality against 25 methodological criteria divided into five study design categories: 1) qualitative studies, 2) randomised control trials, 3) non-randomised studies, 4) quantitative descriptive studies, and 5) mixed methods studies. Reviewers respond to the criteria using a rating scale of three responses for each item; ‘yes’, ‘no’, or ‘cannot tell’. The quality of the studies was assigned based on how many criteria were met. For example, if one criterion was met, the study was categorised as meeting less than 25% of the criteria, which equates to the lowest quality. All five criteria being met, equated to

100% of the criteria being met. This represented the highest quality (Hong et al., 2018). Providing an overall quality score is discouraged as it can be reductionist. Therefore, this systematic review gives a descriptive overview to describe the overall quality, and draw on common limitations and strengths among the studies. All MMAT criteria were treated equally important to ensure consistency and transparency of the quality assessment process. The MMAT was completed by two independent reviewers (EH and NF). Studies judged as low quality were not excluded, as advised by the MMAT guidelines (Hong et al., 2018). This ensured that the quality of the studies in adolescent DRA literature was captured. An independent third reviewer would have been consulted if disagreements were to arise. Both reviewers chartered their evaluations and then compared these evaluations. A master MMAT was created (Appendix I) to merge the reviewer's assessment.

3.2.9 Data synthesis

Following the guidance on stepwise textual narrative synthesis (Barnett-Page & Thomas, 2009; Popay et al., 2006), EH grouped the studies by characteristics, drawing on similarities and providing commentary on the characteristics followed by synthesis according to the factors identified as associated with DRA in adolescents. The stepwise textual narrative synthesis is a method of summarising and interpreting findings from multiple studies in a structured manner. The process involved familiarisation of themes, theme identification (extraction and categorising), integration (cohesive narrative), and interpretation (reflecting on collective result) (Barnett-Page & Thomas, 2009; Popay et al., 2006). To address objective one (identifying factors that are not associated with DRA in adolescents), quantitative data were summarised and tabulated with statistical significance indicating whether it is deemed related or unrelated to DRA. Symbols indicate whether associations are positive or negative (Farina, Llewellyn, Isaac, & Tabet, 2017). Commentary on the qualitative themes is also provided to contextualise the findings in the context of the quantitative associations. The qualitative themes were not self-created, and derived directly from the original studies that reported them. This was to ensure the themes were true to the context and findings of the study that reported them.

Checks of concordance were made by a second reviewer, NF, who independently reviewed the synthesis to ensure consistency and reliability in the interpretation of the data. If there were disagreements between the reviewers, these were resolved through a discussion. If agreement had not been reached, a third reviewer would have been utilised to reach a consensus.

To address objective two (to investigate the strength of association between identified factors with DRA in adolescents), the overall summary of association is reported for all factors derived from variables where DRA was the dependent variable to obtain strength of association (Vancampfort et al., 2014). Decisions were made on whether factors were unrelated (if 0-33% of studies support association), unclear (if 34-59% of studies support association), or related (if 60-100% of studies were associated) to DRA in adolescents. For example, this was done by identifying the factors reported (e.g., age) and then identifying how many studies that report age did or did not find an association with DRA to determine how many studies overall suggest age is related to DRA in adolescents.

The textual narrative synthesis for systematic reviews was selected for its appropriateness due to its strengths in synthesising different types of evidence, providing the ability to describe differences in the eligible studies and integrating commentary on different study designs and the scope of what exists. It also allows for identifying gaps in the literature (Xiao & Watson, 2019), which would address the third objective (to identify and report the gaps in the current literature) of this systematic review.

3.2.10 Meta-analysis bias and confidence in cumulative evidence

Due to the nature of the review and heterogenous nature of the studies included in the review, there were no plans to assess meta-analysis bias or formally assess confidence in cumulative evidence, although it is reported narratively. Meta-analysis combines multiple studies results to identify patterns, while meta-analysis bias refers to biases that can arise from selective reporting and publication bias that can misrepresent evidence synthesis and affect the validity of the research (Møller & Myles, 2016). Whilst quantitative cumulative evidence and qualitative systematic reviews differ in

tools used (e.g., GRADE and ConQual, respectively), it is not appropriate to use given the review includes both designs and mixed designs (Munn, Porritt, Lockwood, Aromataris, & Pearson, 2014).

3.3 Results

3.3.1 Study selection

Searches on the databases were run on 02/06/2023. The date of publication of the studies between all the databases that reported on this ranged between 1910 and 2021. At the full-text review stage, 88.9% (k = 0.70) between reviewers was obtained. In total, eight studies were included in the synthesis. The PRISMA flow study outlines the identification, screening, and inclusion of studies for the systematic review. See Figure 3.

An additional search was conducted in June 2024. This was a supplementary search to identify any new literature that may influence conclusions drawn from the 2023 search. See Appendix J for the 2024 supplementary search.

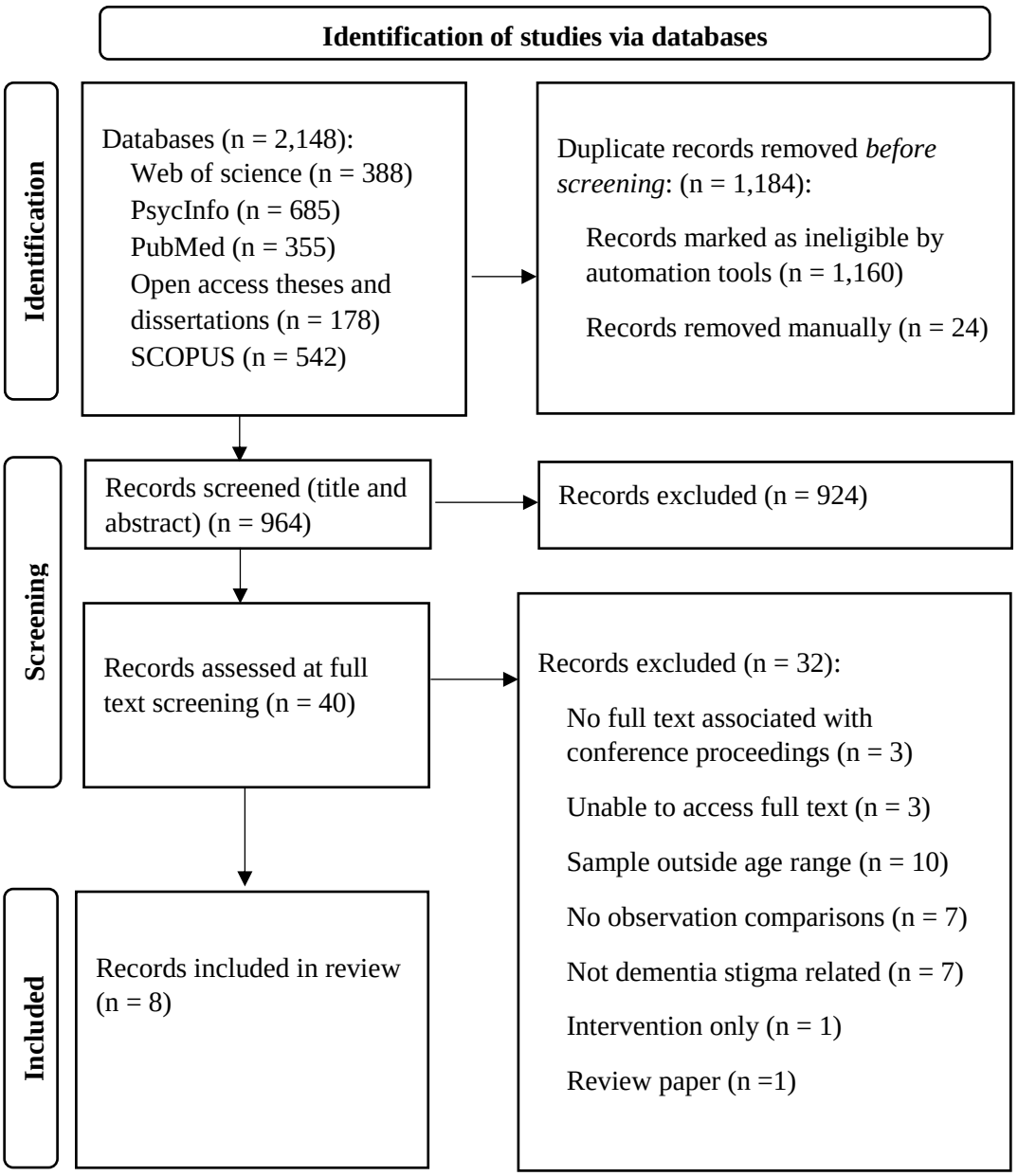

Figure 3 – PRISMA study flow char for systematic review

Figure 3 presents the process by which articles were identified initially through databases (n = 2,148), the number of titles and abstracts screened (n = 964), the number of full texts screened (n = 40), and the final number of articles included in this systematic review (n = 8).

Of the 2,148 articles identified, 964 were eligible for title and abstract screening. In the training mode, EH reviewed 116 articles (13%), rejecting 80 articles and screening

11 articles consecutively before concluding the screening stage. Forty studies were deemed eligible for full-text screening. Three articles were excluded at the start of the full-text screening stage due to having no abstracts or full texts to screen. EH, and a second reviewer independently reviewed the remaining full texts. Cohen's kappa coefficient (κ) for checking interrater reliability for the full-text stage was $\kappa = 0.70$ (88.9% agreement), indicating substantial agreement between the reviewers. Eight studies were eligible for full-text extraction, excluding 32 studies. The most common reasons for exclusion included not having observation comparisons (baseline), comprising exclusively university students, and not being DRA related. Corresponding authors of articles without full-text access were contacted and excluded if full texts were unavailable.

3.3.2 Quality assessment

Six studies were categorised as quantitative descriptive studies, one as qualitative (Baker et al., 2018a), and one with qualitative and quantitative components. However, it was not a mixed-methods design. Therefore, it was categorised under the qualitative and quantitative descriptive categories (Felc, Leskošek, & Felc, 2021).

Only one study was judged to meet all five methodological criteria (Baker et al., 2018a). Two studies met four of the five criteria (Baker et al., 2018b; Farina et al., 2020a) with four studies judged as meeting less than three of the five criteria (Felc et al., 2021; Fuh et al., 2005; Fox, 2020; Werner et al., 2017). It was a common theme across studies for a lack of reporting clarity, making judgments unclear. The common methodological issues observed amongst the studies included inability to judge on the non-response bias criteria confidently where in several studies, reasons for non-response in participants were not reported (Baker et al., 2018b; Felc et al., 2021; Fox, 2020; Fuh et al., 2005; Lo et al., 2020; Werner et al., 2017), as well as little indication on samples being representative of the target population due to the lack of inclusion/exclusion criteria made available (Felc et al., 2021; Fox, 2020; Fuh et al., 2005; Lo et al., 2020; Werner et al., 2017). Studies utilising validated measures were judged to have higher research quality (Baker et al., 2018b; Farina et al., 2020a). Most studies had statistical analyses that were appropriate to answering the research question. The qualitative study (Baker et al., 2018b) was assessed as being of high

quality, where rationale, sampling, and qualitative techniques were justified and adequate, with clear links between data, analysis, and descriptive themes well integrated throughout.

The most common reasons for low-quality MMAT scores included insufficient reporting on sampling strategies, lack of inclusion and exclusion criteria for participant recruitment, and lack of validated measures being used. Researchers should aim to address these issues in future research. For example, researchers should robustly report sampling procedures, explicitly state their inclusion and exclusion criteria for participant recruitment, and adopt measures that have been psychometrically evaluated. These may help improve the overall quality of the research. A summary score of the MMAT for each article is presented in Table 15. The MMAT matrix completed by reviewers is located in Appendix I.

3.3.3 Studies characteristics

Study Characteristics

Table 15 provides an overview of the characteristics of the eight synthesised studies. Demographic characteristics were also grouped to provide commentary on the similarities across the studies on these characteristics.

Of the eight studies, six had a quantitative design, one a qualitative design and one with a separate qualitative and quantitative design. Most studies used a survey (seven out of the eight). The qualitative study used interviews and a focus group (Baker et al., 2018a). Only one study had a cross-cultural comparison design (Werner et al., 2017). Studies were mostly conducted in the United Kingdom (k=2) and Australia (k=2), with one study each from Slovenia, Taiwan, Macao, and Israel. Many of the studies did not report on ethnicity (k=5), and where ethnicity was reported, samples were mostly white British (>75%) (Farina et al., 2020a; Fox, 2020). Only one other study reported on ethnicity, in which participants were Jewish and Israeli Arab (Werner et al., 2017). Seven studies recruited participants from schools. One study recruited from scout groups (Baker et al., 2018a). There was some variability in the number of schools recruited, ranging from two (Fox, 2020; Werner et al., 2017) to 20 (Felc et al., 2021).

The median sample size was 460 across the studies. There were more female (52.9%) than male participants (47.1%) overall. The sample size was extracted by including only the sample (n) in the data analysis. DRA was the dependent variable/the associated outcome and included those under 18. The sample size had a considerable range across the studies, with the smallest sample size of 28 (22 scouts and six grandchildren) in one study (Baker et al., 2018a) and the largest sample size of 5,515 (Fuh et al., 2005). The mean age range across the studies was 13 years old (the mean was reported in seven studies). Across the studies, there were more female than male participants overall.

Table 15 - Characteristics of included studies (k=8). A summary score of study quality is reported for each study using the Mixed Methods Appraisal Tool.

Author and year of publication	Study design	Country	Recruitment setting	Sample size †	Age range (m)	Ethnicity	MMAT score
Baker et al. (2018a)	Qualitative	Australia	Two scout groups and grandchildren of relatives with dementia	22 scouts and six grandchildren	9-12 years old (scouts; m=10.5, grandchildren; m=11)	NR	**** (100%)
Baker et al. (2018b)	Quantitative - scale development	Australia	Three schools	203	9-12 years old (m=10.49)	NR	*** (75%)
Farina et al. (2020a)	Quantitative - questionnaire	England	Four schools	901	13-18 years old (m=14.9)	80.0% White British	*** (75%)
Felc et al. (2021)	Quantitative and qualitative components	Slovenia	At least twenty schools	1128	14-19 years old (m=16)	NR	* (25%)

Continued. Table 15 - Characteristics of included studies (k=8). A summary score of study quality is reported for each study using the Mixed Methods Appraisal Tool continued.

Fox (2020)	Quantitative - questionnaire	United Kingdom	Two schools	120	6-11 years old. Children are divided into three groups. 6–7-year-olds (m=6.35); 8–9-year-olds (m=8.17); and 10–11-year-olds (m=10.35).	Majority White English (% NR)	* (25%)
Fuh et al. (2005)	Quantitative - questionnaire	Taiwan	Seven schools	5515	10-15 years old (m=13.4)	NR	** (50%)
Lo et al. (2020)	Quantitative - questionnaire	Macao	Ten schools	586	14-20 years old (m=16.5)	NR	*** (75%)
Werner et al. (2017)	Quantitative - questionnaire	Israel	Two schools	460	14-15 years old (mean NR)	64.6% Jewish; 35.4% Israeli Arab	** (50%)

† the sample size (n) represents those with complete outcome measures. NR = Not Reported. MMAT = Mixed Methods Appraisal Tool. MMAT overall quality score ; * = one criteria met (25%) - ** = all critiera was met (100%) (scores reflect the amount of criteria indicated by 'yes' was met).**

Measuring DRA

Five studies used validated measures as outlined in Table 16 (k=5). The most common type of quantitative measure was a Likert scale, which was mainly a 5-point Likert scale that ranged between strongly disagree (1) to strongly agree (5). There was a small minority of variation with one study adopting a 4-point Likert scale (Fuh et al., 2005), 6-point Likert (Farina et al., 2020a), and another study using a 9-point Likert scale (Werner et al., 2017). Other quantitative measures with limited face validity used multiple choice in one study (Fox, 2020) and a 'yes/no' category in another study (Fuh et al., 2005). There was also the use of a single-item open-ended question (Felc et al., 2021). All quantitative measures were explicit measures. No implicit attitudes were captured. The psychometric properties can be found in the scoping review Chapter (Chapter 2).

Qualitative methods (two studies) included open-ended questions about experiencing change in a person with dementia, with the narrative answers summarised into 12 categories (Felc et al., 2021). The other study adopted a qualitative inquiry through utilising interviews and focus groups. This was to better understand the attitudes of children and people with personal experience of dementia (Baker et al., 2020a). This study used content analysis with responses coded into cognitive, affective, and behavioural themes (Baker et al., 2018a).

Table 16 - Validated measures identified in the systematic review

Measure	Developed by	Cited by
Adolescent Attitudes towards Dementia Scale (A-ADS)	Griffiths et al. (2018)	Farina et al. (2020a)
The Allophilia scale	Kinney et al. (2017)	Farina et al. (2020a)
Attribution Questionnaire 9 (AQ-9)	Corrigan et al. (2003)	Werner et al. (2017)
Kids Insight into Dementia Survey (KIDS)	Baker et al. (2018b)	Baker et al. (2018b)
Questionnaire of knowledge, attitude and preventive practice of dementia care	NR	Lo et al. (2020)

NR = not reported

Terminology

'Attitudes' towards dementia was the most referred to outcome in measuring an association between variables/themes (k=7), with one study using 'stigmatic beliefs' as the outcome (Werner et al., 2017). The studies did not typically report whether negative attitudes or stigma towards dementia were at a low, medium, or high level. Two studies reported that participants had optimistic attitudes about dementia (Fuh et al., 2005) or were mostly positive and neutral (Lo et al., 2020). Werner et al. (2017) reported that participants' stigmatic beliefs were low.

Theoretical frameworks

Three studies reported a theoretical underpinning. Two of the studies (Baker et al., 2018a; 2018b) incorporated the tripartite framework of attitudes (Eagly & Chaiken, 1993), and one study (Werner et al., 2017) adopted the public stigma towards mental illness model (Corrigan, et al., 2003). Both frameworks are similar in adopting the cognitive, affective (emotional), and behavioural components.

Although most reviewed studies did not report on a theoretical framework, there were common themes and measurable outcomes related to attitudes that exhibited elements of the tripartite model.

Cognitive component

In one study, ageism (negative attitudes) was found to be positively associated with cognitive dimensions of Alzheimer's disease stigma, whilst knowledge was found to be negatively associated with the cognitive dimension. The factor of majority-minority status (a subdivision of racial, ethnic/religious minorities) also significantly differed in levels of stigmatic beliefs in the cognitive dimensions of stigma between Jewish and Israeli Arabs (Werner et al., 2017).

Affective component

A qualitative theme in the affective dimension was the response of fear and unease towards people with dementia (Felc et al., 2021) with personal experience with

dementia found to be associated with more fear compared to less experience (Baker et al., 2018a; Felc et al., 2021). Measuring DRA is commonly done by eliciting the emotional response and feelings towards someone with dementia (Fox, 2020). Empathy as a factor was only drawn on by one qualitative study that highlighted participants with experience with dementia emphasised personhood (Baker et al., 2018a). This was also supported by a quantitative study that used a tripartite model which also captures personhood through the KIDS measure (Baker et al., 2018b). This is where children with a friend or family member with dementia scored higher on KIDS than children with little experience. Similarly, the A-ADS also captures empathy (Farina et al., 2020a).

Behavioural component

Ageism and familiarity with AD were found to be positively associated with the behavioural dimensions of AD stigma (Werner et al., 2017). The behavioural intent of helping was a common theme across the studies. One study found that in children with little/no experience of dementia, helping someone with dementia was the dominant behavioural intention (Baker et al., 2018a), which is also supported by another study that adolescents would help someone with dementia if they were struggling (Farina et al., 2020a).

3.3.4 Synthesis of factors: To identify factors that are and are not associated with DRA in adolescents

A summary of each synthesised factor associated with DRA is presented. The factors represent an integration of quantitative variables and qualitative themes identified in the reviewed studies. Seven factors were identified; age, ageism, empathy, ethnicity, gender, knowledge of dementia, and level of contact. A tabulation of statistical significance and associations from quantitative outcomes is presented in Table 17.

Age

Amongst the three studies reporting on age, there was limited evidence on whether age was associated with DRA. In the study supporting the association, younger

participants were found to have more negative dementia attitudes (Fuh et al., 2005), and felt embarrassed to invite classmates to their homes if they had a family with dementia (Fuh et al., 2005). Two studies reported no significant association between age and DRA (Fox, 2020; Lo et al., 2020). In the case of Fox (2020), there were no significant differences in participants' responses to social distance associated with diagnosis and participants' age and no age differences in the participant's emotional response to liking or feeling sorry for the principal characters in the vignette (i.e., a character with dementia) (Fox, 2020).

Ageism

One study reported on ageism (Werner et al., 2017). The authors incorporated a public stigma framework through the cognitive, emotional and behavioural dimensions. The authors reported a significant, positive association between avoidance behaviours (e.g., avoiding direct contact with elderly people) in the dimension of ageism with Alzheimer's disease stigma. The cognitive dimensions of Alzheimer's disease stigma and negative attitudes towards the elderly were also positively associated with ageism and the behavioural dimension of Alzheimer's disease stigma.

Empathy

There was a single qualitative study relating to empathy and DRA (Baker et al., 2018a). Empathy was one of the most common responses found in children in the community under the theme of 'affective response: concern and sympathy and empathy';

> "They can't help it, they just do it" (Baker et al., 2018a, p. 678)

and similarly, children with personal experience with dementia (grandchildren) also expressed empathetic reactions under the theme of 'personhood';

> "It is not the fault of the person with dementia, they cannot help or control what they do" (Baker et al., 2018a, p. 680).

Ethnicity

Only a single study reported variables relating to ethnicity (Werner et al., 2017), with Israeli Arab students having a higher level of stigma towards Alzheimer's disease compared to Jewish students.

Gender

Three out of four studies reported a significant association where females significantly held more positive attitudes than males (Farina et al., 2020a; Fuh et al., 2005; Lo et al., 2020). For example, females scored higher on both the A-ADS and the Allophilia scale for a majority of the scale items (see Farina et al., 2020a). In the study by Fuh et al. (2005), males reported feeling more embarrassed than females to invite a classmate to come home if they had a family member with dementia (8.5% versus 5.3%, respectively) (Fuh et al., 2005). There were no significant gender differences reported in the other study that explored the association between DRA and gender (Felc et al., 2021).

Knowledge of dementia

Three studies reported a significant association between dementia knowledge and DRA (Felc et al., 2021; Lo et al., 2020; Werner et al., 2017). In one study, two schools had more positive attitudes and dementia prevention knowledge in comparison to eight other schools. Narratively, the authors suggest these two schools had some form of dementia education (Lo et al., 2020). Further support of the association included a negative association between knowledge about Alzheimer's disease and Alzheimer's disease stigma (cognitive dimension) (Werner et al., 2017). Students who also had contact with relatives with dementia showed better knowledge of dementia, although, these students' attitudes were mostly negative (Felc et al., 2021). However, this was narratively reported with no formal analysis reported in the study.

Level of contact

There was a dichotomy under the factor ‘contact’. Level of contact was described as direct contact with dementia which included personal experience with dementia (i.e., familiarity), meeting someone with dementia, and/or living with someone with dementia, and also non-direct contact, which is observed as knowing or hearing about dementia via media (e.g., internet and TV). All four studies reporting on the level of contact and DRA supported an association (Baker et al., 2018a; Baker et al., 2018b; Felc et al., 2021; Werner et al., 2017). One study found an association between the level of contact and DRA (Baker et al., 2018b). This study found that children who had a high level of contact with people with dementia had a higher KIDS score compared to those having lower levels of contact. In the study by Baker et al. (2018b), the level of contact was based on children not having heard of dementia (34.5%), never seen someone with dementia (31%), having seen media about someone with dementia (36.9%), and having a family/or family friend living with dementia (23.6%) (Baker et al., 2018b). The highest level of contact children had with dementia was indirectly (via media). However, it is difficult to categorise whether the level of contact through media rather than direct contact with dementia leads to more or less positive attitudes.

Quantitatively, support for direct experience was reported by Werner et al. (2017) where the more familiarity students had with Alzheimer’s disease, the less stigma was held towards Alzheimer’s disease. There was a positive association reported in the behavioural dimension (social distance) of the AQ-9 measure. This association was only found to be associated with the behavioural dimension (social distancing), which may suggest that familiarity does not necessarily influence cognition or emotion towards AD, but does reduce the behavioural intention to socially distance themselves from the person with AD (Werner et al., 2017).

The qualitative studies identified ‘fear’ as a negative consequence of contact with people with dementia. It was found that personal experience with dementia was associated with fear (Baker et al., 2018a; Felc et al., 2021) with children in the community (i.e., those with less personal experience) displaying less fear compared to children with personal experience of people with dementia. This is demonstrated in the theme ‘teach how to relate to a person with dementia’ amongst the children with personal experience;

> "Well, it's really scary. Like, the first time I saw grandma with dementia I just backed off, like, who is this person? Like, it's really scary" (Baker et al., 2018a, p. 680).

Similarly, in a majority of students (55%) with a family member living with dementia, students expressed feelings of fear towards people with dementia. This is discussed under the theme of 'it is sad because they don't recognise their loved ones and mistake them for the decease; fear that your closest relatives with dementia will no longer recognize you';

> "A sadness and fear prevail in their attitudes towards dementia in half of the respondents with a relative with dementia" (Felc et al., 2021, p. 6).

These findings potentially indicate that despite better dementia knowledge through personal experience, contact through personal experience may lead to more negative attitudes.

Table 17 - Descriptive data derived from included studies that used quantitative analysis to report associations between independent variables and DRA.

Identified factors	Statistical significance	Reference	Variables
Age	F = 21.89; df=1, p <0.001	Fuh et al. (2005)	Younger males and dementia attitudes
	F (2, 117) = 2.93, η_p^2 = 0.05, p = 0.06,	Fox (2020a)	10-11-year-olds significantly higher scores than 6–7-year-olds. 8–9-year-olds did not differ significantly from either age group
	r = 0.05, p > 0.05	Lo et al. (2020)	Positive relationship between attitudes and age
Ageism	β = 0.11, 0.44, and 0.36, p's < 0.01	Werner et al. (2017)	Positive association between avoidance dimension of ageism in the cognitive, emotional and behavioural dimensions of AD stigma
Ethnicity	β = 0.27, 0.14, and 0.16, p's <0.01	Werner et al. (2017)	Majority-minority status (Jewish and Israeli Arabs) and cognitive, emotional and behavioural dimensions of AD stigma. Arabs had higher level of stigma.
Gender	All individual Allophilia items (χ^2), p <0.05 15 of 23 items of A-ADS (χ^2), p <0.05	Farina et al. (2020a)	Gender and attitudes (females more positive compared to males)
	F = 21.89; df=1, p <0.001	Fuh et al. (2005)	Gender and attitudes towards dementia (males more negative than females)
	t = 5.66, p < 0.001	Lo et al. (2020)	Gender and attitudes towards dementia (female students more positive than male students)

Continued. Table 17 - Descriptive data derived from included studies that used quantitative analysis to report associations between independent variables and DRA.

Knowledge	$\beta = -0.10$, $p < 0.05$	Werner et al. (2017)	Negative relationship between knowledge about AD and cognitive dimension of AD stigma
	$r = 0.27$, $p < 0.001$	Lo et al. (2020)	Positive relationship between knowledge and attitude
	$r = 0.25$, $p < 0.001$	Lo et al. (2020)	Positive relationship between preventive practice and attitude
Level of Contact	$\beta = 0.15$, $p < 0 .001$	Werner et al. (2017)	Positive relationship between familiarity with the disease and behavioural dimension of AD stigma
	t (109) = -5.40, $p < 0.001$	Baker et al. (2018b)	Level of contact with people with dementia and KIDS score (more contact associated with better attitudes than lower contact)

***F* = ANOVA; *β* = Beta regression coefficient; χ^2 = Chi-Squared; *r* = Pearson's correlation; *t* = t-test; *Z* = Z test.**

N.B. Statistical coefficients and p-values are summarised. Independent variables are grouped into summary factors.

3.3.5 Summary of Association

To fulfil objective two of the systematic review, 'to investigate the strength of association between identified factors with DRA in adolescents', the overall summary of association was calculated for all factors derived from variables where DRA was a dependent variable. Variables were synthesised by grouping them into a main category to determine overall association. The summary includes factors from both qualitative and quantitative associations.

The summary of association is broken down in Table 18. The table demonstrates which factors are most associated with DRA. The lowest association with DRA and how many studies were deemed related, unrelated or unclear within each factor was used to calculate the overall association score (number of related studies / total number of studies X 100 = %).

Three factors were strongly related to DRA; gender, knowledge and level of contact. Current evidence indicates that age is unrelated to DRA, while no summary of association was reported for ageism, ethnicity, and empathy as only one study was reported on each of these factors. Empathy was the only factor that was derived exclusively from qualitative data.

Table 18 - Overall summary of the association between factors and DRA in adolescents.

Identified factors	Statistically related	Statistically unrelated	Qualitatively supported	Total studies	%	Overall association
Age	Fuh et al. (2005)	Fox (2020) Lo et al. (2020)	NR	3	33.3%	Unrelated: 0-33% of studies supporting an association
Ageism	Werner et al. (2017)	-	NR	1		
Empathy	-	-	Baker et al. (2018a) (Y)	1		
Ethnicity	Werner et al. (2017)	-	NR	1		
Gender	Farina et al. (2020a) Fuh et al. (2005) Lo et al. (2020)	-	Felc et al. (2021) (N)	4	75%	Related: 60-100% of studies supporting association
Knowledge	Werner et al. (2017) Lo et al. (2020)	-	Felc et al. (2021) (Y)	3	100%	Related: 60-100% of studies supporting association
Level of contact	Werner et al. (2017) Baker et al. (2018b)	-	Felc et al. (2021) (Y) Baker et al. (2018a) (Y)	4	100%	Related: 60-100% of studies supporting association

No summary of association factors with only one study. Overall association categorised by Related: 60-100% of studies supporting association; Unclear: 34-59% of studies supporting an association; Unrelated: 0-33% of studies supporting association. NR = not reported; (Y) = supported; (N) = not supported.

3.4 Discussion

The main aim of this systematic review was to identify what factors are associated with DRA in adolescents. This systematic review is the first in the DRA literature to gather evidence on the factors associated with DRA in adolescents. Three factors were identified as strongly related to DRA: gender, knowledge, and level of contact. By identifying these factors, we can better understand which groups are at the greatest risk of holding negative DRA. To address the third objective of this systematic review, key findings are evaluated below, drawing on the strength of associations, potential explanations for the findings, and gaps identified in this systematic review for future work.

3.4.1 Key Findings

Factors associated with DRA

Gender

Evidence from quantitative studies supported the association between gender and DRA in adolescents. In line with the general dementia literature (Blay & Peluso, 2010; Cheng et al., 2011), broader mental health (Bradbury, 2020), and ageing literature (Randler, Vollmer, Wilhelm, Flessner, & Hummel, 2013), females were found to have more positive attitudes than males (Farina et al., 2020a; Lo et al., 2020). There was no statistical significance from reviewed studies that suggested males had more positive attitudes than females. However, there is little evidence as to why there are gender differences in DRA and which factors are significant in this. Some explanations for why this could be the case include females maturing quicker than males (Lo et al., 2020), females being more likely to have contact with people with dementia (Cheston et al., 2019), and females scoring higher on explicit self-report empathy measures (Muncer & Ling, 2006). Female adolescents having more contact with people with dementia is also supported (Farina et al., 2020a). Farina and colleagues demonstrated that females had more positive attitudes and had higher levels of contact with dementia than males. The authors highlight that this makes it difficult to interpret whether the gender difference is from improved attitudes or whether this comes down to personal experience (Farina et al., 2020a). Future work could unravel this.

From the empathy lens, females self-reporting attitudes tend to score higher on empathy. Socio-cognitive developmental theories suggest that empathy underlies the development of prejudice (Miklikowska, 2018). Prosocial behaviour towards others (a form of positive motivation-action) appears to increase over childhood and mid-adolescence but declines after this period (Van der Graaff et al., 2018). If empathy is associated with positive DRA, this would suggest that it is even more important to target young people. This is because prosocial behaviour is likely at this stage of development. Interestingly, the difference between genders on attitudes appears to be much narrower when using implicit measures (Muncer & Ling, 2006), which may dampen the strength of association. Nevertheless, future work could explore the mediatory mechanisms of empathy, gender and DRA.

Knowledge

Knowledge of dementia was strongly associated with DRA (Lo et al., 2020; Werner et al., 2017). Evidence from the mental health literature supports the findings with 'myth-busting' interventions seen to positively alter high school students' attitudes towards mental illness (Martínez-Zambrano et al., 2013). The TPB may help explain how knowledge reduces stigma. The theory suggests that subjectively held beliefs are linked to positive or negative behaviour outcomes. When providing relevant information that challenges those specific beliefs and conflicts with the anticipated behaviour can lead to the formation of new beliefs (Ajzen, 2011). However, information being effective in modifying beliefs may depend on the type of knowledge presented. For example, a public attitude survey suggested that biological causal explanations of mental illness in the general population negatively impact attitudes (Schomerus et al., 2012). It is also unclear how much knowledge is needed to modify attitudes. Evidence from a dementia awareness intervention in adolescence demonstrated that a one-off advocacy session was insufficient to change attitudes long-term (Farina et al., 2020b). This is supported by studies that found a significant improvement in dementia knowledge through knowing someone with dementia (Carpenter, Zoller, Balsis, Otilingam, & Gatz, 2011; Cheston et al., 2016). However, it was not a convincing indicator of having more positive attitudes (McParland et al., 2012). Contrary evidence found that having a relative with dementia provides

adolescents with basic knowledge of dementia and that this strengthens positive DRA (Felc et al., 2021).

Given that the studies indicate a strong relationship between dementia knowledge and DRA, it will be important to assess where dementia knowledge in students comes from and whether these mitigate positive or negative DRA. This is relevant due to studies highlighting a lack of dementia knowledge and awareness (Cahill et al., 2015), with less than half the questions on dementia knowledge answered correctly in one study from England (Isaac et al., 2017). Given that very little is being taught in schools currently in England (66.4% of adolescents had never been taught dementia in school) (Farina, 2020), and little change in public awareness of dementia over the years argued by some researchers (Olsen et al., 2020), knowledge about dementia may come from a host of factors. Identifying these sources may help tackle DRA.

Level of contact

This systematic review identified that level of contact was the most reported factor associated with DRA in adolescents. It indicated that contact with people with dementia and dementia familiarity were associated with more positive DRA than those with lower contact (e.g., Baker et al., 2018a; Baker et al., 2018b). These findings are in line with the dementia literature on public stigma in older students (Lokon et al., 2017) and the mental health literature (Aromaa, Tolvanen, Tuulari, & Wahlbeck, 2011). For example, direct contact with dementia mediated more positive DRA compared to those with little/no experience with dementia. This is echoed in healthcare students such as nurses, where increased contact also led to more positive attitudes (Lokon et al., 2017). These findings may be explained by the intergroup contact theory, which suggests that direct and positive contact between groups in certain situations can help reduce prejudice (Allport, 1954). However, findings from the qualitative research indicate that the relationship between the level of contact and DRA may be more nuanced than "more contact is better", not least because it can instigate feelings of fear (Baker et al., 2018a). Thus, it is important to explore further the relationship between the type and frequency of contact, and its effect on adolescents' DRA.

Several terms fell under this category, such as 'familiarity', 'acquaintance', 'personal experience', and 'contact'. There was a lack of definition by authors that made it difficult to assess what the authors intended construct was. For example, one study uses the term' familiarity' in the context of contact (Werner et al., 2017). The need for clearly defined variables leaves room for misinterpretation, limiting the studies. Future work should clearly define variables, particularly where cross-cultural comparisons are made, as this may differ amongst cultures and lead to different interpretations of the terms used.

Interestingly, the highest level of contact young people had with dementia was through the media (indirect contact) (Farina et al., 2020a). However, it is difficult to categorise whether the level of contact through indirect means rather than direct contact leads to more or less positive attitudes. While media was not a factor explored by studies in this systematic review, Lo et al. (2020) suggested that students in their study tended to get information about diseases through media such as TV and websites (Lo et al., 2020). This is further supported by another study in the systematic review that found adolescents' level of contact with dementia was mostly through adverts (80.2%) (Farina et al., 2020a). Therefore, the media may affect how dementia is perceived through information and portrayal. However, the extent of influence of film and media on adolescent's perception of dementia remains limited currently. Indirect contact through media has yet to be investigated robustly in young people despite evidence in the dementia literature that demonstrated media negatively perpetuating dementia (Cheston et al., 2019).

Knowing someone with dementia, such as a relative, can also strengthen positive DRA (Felc et al., 2021). Recent studies on adolescents have shown that approximately one-quarter to a third of adolescents in Slovenia and England know someone with dementia (Felc et al., 2021; Farina et al., 2020a), providing further support for the strength of these findings.

Qualitatively, there was a lack of notable difference in empathy between the community focus group and the grandchildren with personal experience of dementia (Baker et al., 2018a). It may have been likely to suspect that the grandchildren with personal experience may have displayed more levels of empathy due to the likelihood

of having more direct contact. A possible explanation for this could be that 12 of the 22 children in the community focus group reported having a family member who behaved a similar way to a person with dementia in the videos. As such, these children may have frequent direct contact with such family members, therefore mitigating worse attitudes (Baker et al., 2018a). Alternatively, the children may have been desensitised to the behaviour in the video due to frequent exposure to such behaviour already. Given the strength of the association, future research could establish interactions with other variables that influence DRA. Further work on the relationship between direct and indirect contact and DRA, would be insightful.

Unclear associations between factors and DRA

Several factors (age, ageism, empathy, and ethnicity) had an unclear association or an insufficient number of studies to form conclusions. Other similar fields of study have established greater consensus on these factors. These literatures include mental illness stigma (Fox, Earnshaw, Taverna, & Vogt, 2018; Tanaka, Inadomi, Kikuchi, & Ohta, 2004) and ageism (Cooney, Minahan, & Siedlecki, 2021).

Age

The studies focusing on ages 10-18 did not support age differences as widely as the current adult dementia literature (Wu et al., 2022), or provide enough data to compare differences between those at the start and those towards the end of adolescence. This may be useful to observe longitudinally, given theoretical positions that there is attitude flexibility at the start of adolescence (Allport, 1954). Theoretically, it is argued that there is a maximum strength of negative attitudes that takes place in early puberty (start of adolescence), with attitude flexibly changing until this point, supporting that younger children may have more positive attitudes and become more negative as they get older (Allport, 1954). While developmental theories support that older young people have more negative negatives, this is contradicted by findings that demonstrate that greater knowledge of dementia is associated with better attitudes (Lo et al., 2020; Werner et al., 2017). It is more likely that older adolescents have more life experience, which leads to acquiring more knowledge of dementia than younger adolescents (Wu et al., 2022). Attitude formation and stability may explain this (Albarracin et al., 2014;

Prislin, 1996). Adolescents gain more life experience as they get older, which can shape and reinforce their attitudes over time (Hjerm, Eger, & Danell, 2018). Adolescents also gain cognitive maturity with age (Birch & Birch, 1997, p. 204), where they can better process and integrate new information, which allows them to critically evaluate their beliefs and resolve conflicting attitudes (Ma, Westhoff & Van Duijvenvoorde, 2020). Older adolescents may have undergone more extensive socialisation compared to younger adolescents. As a consequence, older adolescents, with more sophisticated understanding (Glück & Bluck, 2013), observe and understand the negative aspects of dementia through familial contact (Baker et al., 2018a).

Ageism

A stand-alone study suggested an association between ageism and DRA (Werner et al., 2017), thus warranting further investigation to establish the strength of the association.

Age is a highly salient categorisation that people use (Ayalon & Tesch-Römer, 2018). *Ageism* is a prejudice or discrimination based on chronological age (Abrams & Swift, 2012; Rahman & Hyden, 2020). This entails stereotyping, discrimination, and prejudice against individuals or groups based on age, which leads to negative attitudes and behaviours towards individuals or groups (World Health Organization, 2021a). Studies have previously demonstrated that young people hold positive (e.g., Teater & Chonody, 2017) and negative feelings towards older individuals (e.g., John, 2013). Dementia often intersects with negative attitudes towards ageing, with people living with dementia often experiencing 'double stigma', with the beliefs about dementia itself layered on top of ageist stereotypes (Evans, 2018). Ageism and DRA are likely separate entities that can often become blurred due to ageist stereotypes held towards people with dementia (ADI, 2019). For example, some negative DRA can be influenced by the false belief that dementia is caused by normal ageing. Ageist views of older people do create challenges for those living with dementia (ADI, 2019) and, therefore, are thought to be associated with DRA (Werner et al., 2017). Those with more ageist attitudes are thought to be associated with having higher levels of stigma

towards those living with dementia, while lower ageism is associated with less stigma towards people living with dementia (Baumgartner, 2017).

Negative attitudes towards ageing are usually adopted at an early age (John, 2013). They are directed as negative attitudes towards an outgroup (older adults) that become self-relevant when individuals reach later in life (Wu et al., 2022). The Social identity theory suggests that adolescents are motivated to seek positive distinctiveness from older outgroups by asserting more valued characteristics for younger people (Tarrant, 2002).

Within the context of DRA, there is research support for the role of ageism. Molden and Maxfield (2017) demonstrated that even low levels of exposure to negative ageing stereotypes increase the level of dementia worry in adult participants (Molden & Maxfield, 2017). Evidence suggests that exposure to negative ageing stereotypes can often come from dementia depiction in film and media, which is usually negative and fear-inducing (Evans, 2018; Zeilig, 2015). This is supported by evidence that the media is viewed as a potential driver of dementia attitudes through presenting age-related stereotypes and portrayals of dementia (Hillman & Latimer, 2017), which could worsen stigma towards people living with dementia (Harper et al., 2019; Mukadam & Livingston, 2012). However, there is contradictory evidence that there is greater empathy towards people living with dementia largely driven by awareness raised by high-profile celebrities on the news (Milne, 2010; Olsen et al., 2020; Zeilig, 2015).

Empathy

Empathy was qualitatively found to be associated with DRA in both participants who had experience with people with dementia and in the children in the community (Baker et al., 2018a). Unfortunately, no quantitative evidence was identified to support or refute this association. A potential explanation as to why empathy may not have greatly differed between the two groups of children in the paper by Baker and colleagues is that in the community focus group, 12 of the 22 children reported having a family member who behaved a similar way to the person with dementia in the videos

and therefore familial contact could help explain why there were similar levels of empathy in the grandchildren (Baker et al., 2018a).

Conceptually, empathy is multi-faceted and includes various constructs (e.g., affective and cognitive) that can be measured. One study could be tapping into a single component of empathy, while another could be broadly tapping into several components (e.g., contagion and empathetic concern versus compassion). This reflects that the empathy construct has no exact agreed definition (Engelen & Röttger-Rössler, 2012; Telle & Pfister, 2016). However, empathy is thought to consist of cognitive and affective components, which are generally accepted (Batchelder, Brosnan, & Ashwin, 2017). It is not well understood which components of empathy are more important in influencing attitudes (e.g., cognitive or affective) or whether they are inter-connected. Some research has indicated that perspective-taking (cognitive) did not predict prosocial behaviour, while empathetic concern (affective) serves as a better predictor for prosocial behaviour (Batson et al., 1991; Carlo, Mestre, Samper, Tur, & Armenta, 2010).

From a theoretical perspective, the social cognitive theory (Bandura, 2001) may help explain the role of empathy in DRA. Empathy has a key role in the attitude learning process (e.g., via observation) by allowing vicarious experiences of emotions and perspectives of others (Telle & Pfister, 2016). For example, if an individual empathises with someone experiencing challenges relating to dementia, the individual may develop more positive DRA through feelings of compassion. Another perspective is the social identity theory (Tajfel & Turner, 1986 cited in Harwood, 2020), which states that social categorisation and group membership shape attitudes. Empathy in this capacity facilitates positive intergroup relations by closing the psychological distance between in-groups and outgroups (Bernstein et al., 2018). When an individual empathises with members of other groups, they are more likely to perceive shared experiences, leading to more positive attitudes towards the group (Dovidio et al., 2010; Levine, Prosser, Evans, & Reicher, 2005). In the paper by Baker and colleagues, children reported having family members who behaved similarly to the person with dementia. This shared experience can lead to more positive attitudes. However, this is situational. Negative shared experiences may elicit negative responses that dull empathy. For example, the paper also noted that the children cited feeling fear. There

may be common behaviours of various outgroups (e.g., people in aged care facilities) that remind young people of the behaviours of someone with dementia (Baker et al., 2018a).

Given the potential role of empathy in attitudes, it is useful to understand whether empathy is fixed or malleable in these contexts. This would be useful to understand when designing effective interventions that tackle DRA, particularly if interventions aim to illicit empathy in such interventions (i.e., perspective-taking) or promote empathy (i.e., understanding). Research suggests that empathy is situational, individualistic, and not entirely fixed. Empathy is thought to increase during adolescence, reflecting changes in socio-emotional and cognitive capacity that increase perspective-taking ability (Van der Graaff et al., 2018). Nevertheless, empathy as a factor associated with DRA warrants further investigation to establish the strength of association, particularly quantitatively, given the lack of studies exploring the relationship in adolescents. Given the potential interaction between contact and empathy to DRA as outlined by the social contact theories, the mediatory relationship between contact, empathy, and DRA could also be useful to unpick.

Ethnicity

A single study included ethnicity as a variable. The study by Werner and colleagues uses the term 'majority-minority status,' which is defined as a subgroup where racial, ethnic, or religious minorities are the majority within the local population (Werner et al., 2017).

In the dementia literature, cultural beliefs are seen to have a significant influence on the conceptualisation of dementia in the general public (Algahtani et al., 2020) and is viewed differently cross-culturally (Berwald et al., 2016; Hulko, 2009; Young et al., 2019). Minority-majority status research is still relatively limited in this literature (Cohen, Werner, & Azaiza, 2009; Werner et al., 2017), albeit there is some research in other literatures, such as mental illness stigma (Eylem et al., 2020; Misra et al., 2021). Werner and colleagues, similarly aligned with other majority-minority status literature, demonstrate that minorities have more stigmatising attitudes compared to those with the majority status (Abdullah & Brown, 2011; Werner et al., 2017).

However, there are imperative implications to consider with the above findings and why this may be the case. It should be acknowledged that often, stigmatising attitudes in minority groups are attributed to their 'culture' or a poor understanding of dementia (Fletcher, Zubair, & Roche, 2022) rather than the responsibility of institutions and services. Language barriers and lack of information, for example, could be due to information not being made available in different languages by services rather than actual cultural attitudes (Fletcher et al., 2022). With only one study reporting on ethnicity (Werner et al., 2017), forming conclusions is limited. The lack of reporting on ethnicity, in general, makes it difficult to confer its role in DRA. This is particularly since there is a generalisability issue with the homogenous nature of participants, especially in UK-based studies. In these studies, samples are predominantly White British. There is a greater level of evidence provided in the adult population within the dementia DRA literature, where cultural beliefs are influential in the conceptualisation of dementia amongst the general public (Algahtani et al., 2020; Ar & Karanci, 2019; Hanssen & Tran, 2019).

Methodological considerations

Attitudes were the most referred to construct when associating variables/themes with DRA. Different outcomes are possible depending on the aspect of DRA that is the focus, usually driven by a theoretical model based on whether DRA is based on public stigma or other forms of stigma, such as self-stigma (Bhatt, Stoner, Scior, & Charlesworth, 2021). In regards to the DRA, Corrigan and Watson's (2002) stigma framework is typically adopted in assessing public behaviour and DRA (Rüsch et al., 2005), although this was scarcely mentioned or adopted in adolescent DRA studies. Interestingly, the underlying concept of cognitive, affective and behavioural components was seen in measures that mirrored studies that had intentionally incorporated theoretical frameworks. This can be demonstrated in the study by Fox (2020), where trait attribution, emotional response, and behavioural intent were measured, but lacked a theoretical model to explain the findings. However, this does not necessarily mean these studies did not incorporate a framework; they merely did not report on it.

Three studies reported the use of a theoretical framework (Baker et al., 2018a; 2018b; Werner et al., 2017). Werner et al. (2017) adopted the public stigma towards the mental illness model (Corrigan & Watson, 2002; Corrigan et al., 2003), in line with the general literature (Werner et al., 2020) where the cognitive, emotional and behavioural components are central to the model. This aligns with the tripartite framework of attitudes (Eagly & Chaiken, 2007). The public stigma towards mental illness model builds on Eagly and Chaiken's (1993) model (Corrigan & Watson, 2002; Eagly & Chaiken, 2007), with further focus on stereotypes and discrimination. Unsurprisingly, the studies adopting either framework display similarities by drawing on the cognitive, affective and behavioural components as a means to measure DRA.

There was a lack of gold standard use of validated measures and reporting of psychometric properties in the studies. From the DRA measures, four studies used a validated measure (Baker et al., 2018b; Farina et al., 2020a; Lo et al., 2020; Werner et al., 2017). Noted in the scoping review conducted in this thesis (Chapter 2), these measures were identified as having good psychometric properties (A-ADS, AQ-9, KIDS, ADQ, Questionnaire of knowledge, attitude and preventive practice of dementia care and the Allophilia scale). The A-ADS (Griffiths et al., 2018) and KIDS (Baker et al., 2018b) were specifically designed for children and adolescents, which makes them ideal tools for DRA in the context of further establishing factors associated with DRA in adolescents. Greater accuracy in capturing the strength of the association of such factors would be important as researchers could miss targeting factors within the adolescent population, which would lead to initiatives being less effective if they are not targeting what they should be.

Lastly, recruiting from one geographic location could lead to a lack of diverse ethnic groups in the studies. This was the case for many of the studies. For example, geographic locations of Warwickshire and Sussex (Fox, 2020; Farina et al., 2020a) tend to be mostly populations of White, more affluent, and the middle-class. It is therefore important that studies transparently report ethnicity and region. Future work could consider surveying DRA across other geographic locations to increase recruitment to address the homogeneity of participants observed in these studies.

3.4.2 Strengths and limitations of the systematic review

Strengths

First, this systematic review is novel in identifying factors associated with DRA in adolescents, integrating evidence from quantitative, qualitative, and mixed methods studies. The textual narrative synthesis enriches the findings by combining statistical support with real-world context through qualitative descriptions and quotes (Barnett-Page & Thomas, 2009), This approach highlights gaps in the literature, providing the foundations for future research.

Second, the systematic review method was vigorous with a well-tested search strategy designed to optimise answering the research question. The publication of the systematic review protocol (Hassan et al., 2021) provides transparency in the research process. It also reduces bias in the review process by specifying pre-determined inclusion and exclusion criteria, reducing the risk of post hoc alterations to the review methodology (Booth, Rees, & Beecroft, 2010). Carefully considering the number and types of databases used, enhances the likelihood of including as many relevant studies as possible. This was guided by evidence in the literature that found Web of Science, PubMed and APA PsycINFO as the most used databases in the social sciences (Chapman, 2021; Wanyama et al., 2021). Although no grey literature met the criteria, its inclusion broadened the scope for identifying further relevant studies (Mahood, Van Eerd, & Irvin, 2014).

Last, using ASreview software minimised researcher bias and improved efficiency in the screening process through its machine learning (van de Schoot et al., 2020). The MMAT was chosen over other appraisal tools for its ability to appraise qualitative, quantitative, and mixed-method studies (Souto et al., 2015), and provide a detailed descriptive overview of research quality without excluding lower-quality studies. This offers a richer synthesis of the research's quality, strengths, and limitations instead of a reductionist quality score (Hong et al., 2018).

Limitations

First, relatively few studies met this review's inclusion criteria. Many studies were also judged as poor quality, so interpretations may change with the addition of more high-quality research. As this was an exploratory review with no time period restrictions, it is important to acknowledge societal and cultural shifts, such as increased public awareness of dementia in the past decade (Mukadam & Livingston, 2012; Zeilig, 2015). Future reviews could benefit from meta-regression once more studies are available (Higgins et al., 2022).

Second, there was an overlap between variables such as familiarity and knowledge, making it difficult to categorise them clearly due to a lack of clear definitions. Some interpretation was required, which could introduce bias, though this was minimised by having two reviewer's complete data extraction and assess variable categorisation.

Third, although this thesis focuses on adolescents, the limited literature meant there was less room to disregard studies that included participants under ten. Including younger children might reduce the relevance to adolescents, as measures may need to be simplified. While theories such as Allport's (1954), suggest attitude flexibility during early adolescence, it is important to consider how DRA may be influenced by early childhood knowledge (Allport, 1954; Wahl, Susin, Kaplan, Lax, & Zatina, 2011).

Last, while statistical p-values assist with the interpretation of associations, they are often misused (Gibson, 2021) or studies are underpowered to detect significant associations (Jia, Lim, Kwong, & Xu, 2021). As such, findings should be considered alongside study quality, recognising that statistical significance does not always imply meaningful associations.

3.5 Conclusion

This systematic review is the first in the DRA literature to collate the evidence on factors associated with DRA, specific to adolescents. This addresses a knowledge gap in the literature where previous systematic reviews have focused on the general adult population, healthcare workers, and university students. Out of the seven factors identified, gender, knowledge, and level of contact were commonly associated with

DRA in adolescents. Therefore, these factors may be good target candidates for future anti-stigma initiatives. The knowledge gained also provides foundational knowledge for researchers to build upon in testing the strength of these associations in well-designed and heterogeneous cohorts, to better establish their usefulness as targets. Across the studies, there was an absence of how or why these factors may have formed in the first place, which would be an important avenue for future work on those factors strongly implicated in DRA. Other identified factors such as ageism, ethnicity, and empathy, while potentially relevant, currently do not yet have an established evidence base and warrant further investigation. The absence of evidence is not evidence of absence, particularly considering issues related to reporting bias. Therefore, there is a general need to investigate these relationships further in well-powered cohorts.

While the systematic review was approached with a bivariate lens and was not intended to establish interactions between factors and DRA, there is future scope to test interactions such as gender, empathy, and other potential mediating factors to provide a more nuanced picture of how identified factors may drive DRA in the first place, providing an evidence-base for tailored anti-stigma dementia initiatives.

Chapter 4 The socio-demographic and modifiable factors associated with dementia-related attitudes in an adolescent cohort: Structural equation modelling

This Chapter presents a secondary data analysis of the factors associated with adolescent DRA. This consists of two phases. Phase I explores the association between variables (i.e., age, gender, ethnicity, level of contact, and empathy) and DRA. Phase II explores the mediatory influences on DRA, and uses an exploratory structural equation model (SEM) to assess the best model fit. The associated publication is the first to use SEM to explore DRA factors in adolescents. This approach offers a deeper understanding of how these factors interact to influence DRA in this population;

Hassan, E., Hicks, B., Tabet, N., & Farina, N. (2023a). Factors associated with dementia attitudes in an adolescent cohort: structural equation modelling. *Cogent psychology, 10*(1), 2235125.

4.1 Aims and Objectives

This secondary data analysis aimed to explore factors associated with DRA among adolescents (see Table 19). By employing regression analyses (phase I), the study took an exploratory approach to assess the effects of factors such as gender, ethnicity, and empathy on adolescents' DRA. This was to explore which factors were most strongly associated with DRA in adolescents, and which socio-demographic groups are most susceptible to negative DRA. As a novel component, the study aimed to investigate mediation relationships (phase II), mainly focusing on whether variables like empathy mediate the association between other factors and DRA. Regression analyses allow for the examination of the direct relationships between predictor variables (e.g., gender, ethnicity) and the outcome variable (DRA), providing insight into the unique contributions of each factor. SEM enables a more comprehensive exploration of mediation relationships by assessing direct and indirect effects among variables. By employing SEM, the study investigates complex pathways through which variables influence DRA. See Chapter 1, section 1.8 for an overview of the factors and discussion of their potential interactions. Exploring mediatory interactions may help begin to explain how DRA forms in the first place in adolescents and help identify

which factors may be most useful to target in DRA initiatives. Understanding all these factors together are important since various experiences (e.g., socially and developmentally) co-occur in adolescents' lives (Sisk & Gee, 2022).

The objective of the phase II was to obtain the best-fitting SEM. The relationship between DRA, predictor variables, and willingness to work with dementia (behaviour intention) was explored using regression analyses and included in the SEM. In this thesis, 'willingness to work with people with dementia' is one of the outcome variables. Building the model fit was based on findings from phase I of the analysis and the broader theorised relationships discussed in the research background (Chapter 1, section 1.8 and Chapter 3, section 3.4.1) (i.e., the empathy altruism hypothesis, social role theory, and the intergroup contact hypothesis).

The ABC model and TPB framework were selected for this study. The ABC model overlaps conceptually (i.e., affective, behavioural, and cognitive constructs) with attitude, contact, and empathy theories (Ostrom, 1969). The TPB helps contextualise the motivational aspects underlying behavioural intentions that are influenced by some of these factors (Montano & Kasprzyk, 2015). This is demonstrated by a recent study that examined the role of contact, empathy, and stigma with the preference for working with mental illness. The study adopted the TPB and the contact hypothesis as the underlying frameworks (Méndez Fernández et al., 2022). Level of contact, empathy, and gender (see section 1.8) are also thought to be associated with willingness to work with people with dementia in healthcare students (Hebditch et al., 2020). Thus, these two frameworks can provide insight into the interplay of factors influencing young people's DRA and willingness to work with dementia. The TPB does not specify where beliefs originate from, however, it does indicate that socio-demographic variables may influence and interact with such psychological constructs (Ajzen, 2011).

This study addresses the underutilisation of validated outcome measures in previous research by adopting psychometrically sound measures, specifically designed for adolescents. The Brief A-ADS (Farina et al., 2022) and the KIDS (Baker et al., 2018b) are the most psychometrically comprehensive and ideal tools for measuring DRA in adolescents (as explored in Chapter 2 of this thesis). This may bolster the reliability

and validity of the study, enhancing the credibility and robustness of the study findings.

Table 19 - Rationale for inclusion of factors in the analysis (Chapter 4)

Factors	Finding (see Chapter 3, section 3.4.1)	Justification for exploring in the analysis
Gender	A majority of studies identified that females appear to have more positive DRA than males.	We are unsure on the mechanisms as to why this is the case. Males have less contact with dementia and lower reported levels of empathy. Empathy, contact and gender may interact.
Empathy	Only one study (Baker et al., 2018a) exploring empathy and DRA in adolescents	Has not been quantitatively captured yet. Understanding which constructs of empathy are stronger predictors of attitudes (affective, cognitive, prosocial) would mean researchers could tap into the 'right' kind of empathy in anti-stigma initiatives that could elicit more effective prejudice reduction.
Contact	Has a somewhat confident consensus on association with DRA in young people	Studies on contact capture frequency of contact with dementia. Unclear what type of contact is more influential (direct versus indirect contact) (Parveen, Griffiths, & Farina, 2020b). If direct contact is more dominant in influencing DRA in young people, interventions utilising this approach may have a better chance at changing DRA in this demographic.
Age and ethnicity	Age (Fox, 2020; Fuh et al., 2005; Lo et al., 2020) - has contradictory findings. Ethnicity (Werner et al., 2017) - currently does not have an established evidence base	Difficult to determine strength of association with DRA in adolescents. Warrants further investigation into their association with DRA.

N.b. DRA = Dementia-related attitudes

4.2 Methods

4.2.1 Study design

This is a secondary data analysis of the baseline cross-sectional data collected by Farina et al. (2020b). The study was a quasi-experimental design with a pre-/post-design. Data was collected in secondary schools in England from adolescents aged 12-15 years old. Participants were assigned to either receive Dementia Friends (see Chapter 1, section 1.7) or education as usual. All participants completed a series of validated questionnaires pre- and post-intervention, related to dementia attitudes (Brief A-ADS and KIDS) as well as demographic information (Farina et al., 2020b). This secondary analysis treats the group as single cohort using the cross-sectional (pre-intervention) data collected. The variables are further outlined below in section 4.2.3.

4.2.2 Study setting and sample

Participants were recruited from three secondary schools geographically close to Brighton and Hove (England). Schools were identified on the basis they had previously expressed interest in being involved in dementia awareness initiatives, as well as through publicly available information. Senior staff provided consent for the research to occur within the schools. Participants were required to be between 12-15 years old (n = 470). There were no other formal exclusion criteria. Due to the busy school environment, headteachers were able to select which classes and pupils were involved in the research. Participants were recruited from three mixed-gender schools. School one was an academy-sponsored led mainstream school. Schools two and three were community schools. None of the schools provided dementia education to their pupils.

4.2.3 Measures

See Appendix K for the coding syntax for all measures listed.

Predictor variables

Demographic variables: *Age:* student's age (12, 13, 14, and 15) was treated as a continuous variable in the analysis due to the participants narrow age range.

There is a lack of evidence for age differences (Fox, 2020) at the mid-adolescent development stage (Van der Graaf et al., 2018). *Gender:* there were three categories assigned; male, female, and other. Gender was dichotomised as 0 = female, and 1 = male. *Ethnicity:* consisted of eight ethnicity categories (white British, white Gypsy, white Irish, white other, Black, Asian, mixed, and other). Ethnicity was recoded into dummy variables and dichotomised into the categories White British = 1, and non-White British = 0.

Single item about *whether participants have heard of the word dementia or Alzheimer's disease before*: This consisted of the following responses; whether they have heard of either dementia or Alzheimer's disease, have heard of both terms, or have heard of neither term. The variable was dichotomised as 'heard of dementia or Alzheimer's disease' (heard of either or both terms: yes = 1) and neither terms (no = 0).

Level of Contact: Adolescent Level of Contact of Dementia Questionnaire (ALOCD) is a validated measure on the level of contact adolescents have with dementia (Parveen et al., 2020b). The scale consists of 10 items and provides a score for both direct (i.e., "I have spent time with a family member living with dementia") and indirect (i.e., "I have searched for information on dementia on the interest") contact. Items are on a 5-point Likert scale that ranges from '1 – Never' to '5 – A great deal'. Higher scores indicate more contact with people with dementia. For the analysis, ALOCD was split into its subscales; direct contact (five items) and indirect contact (five items). The measure demonstrates adequate internal consistency ($\alpha = 0.89$; $\alpha = 0.62$, respectively) in the original measure (Parveen et al., 2020b). The internal consistency within this secondary data analysis was adequate ($\alpha = 0.90$; $\alpha = 0.68$, respectively, with $\alpha = 0.80$ for the total ALOCD score).

Empathy*:* The Empathy Questionnaire for Children and Adolescents (EmQue-CA) (Overgaauw, Rieffe, Broekhof, Crone, & Güroğlu, 2017) is a validated measure of adolescent empathy that consists of three subscales of empathy; 'affective empathy', 'cognitive empathy', and 'intention to comfort'. Intention to comfort indicates prosocial motivation (intention). The measure consists of

18 items (i.e., 'If a friend is sad, I also feel sad'). Each item on a 3-point Likert response scale that ranges between 'not true', 'sometimes true' and 'often true'. The subscales were treated as separate to determine which components of empathy are more influential on DRA. The subscales demonstrate good internal consistency ($\alpha = 0.70$, $\alpha = 0.70$, and $\alpha = 0.74$, respectively). Totals were scored adhering to the guidance of the EmQue-CA syntax (Rieffe, Ketelaar, & Wiefferink, 2010). Higher scores indicated a higher level of empathy. The total score demonstrated adequate internal consistency within the sample for this thesis ($\alpha = .86$) and the subscales (prosocial: $\alpha = 0.77$, cognitive: $\alpha = 0.70$, and affective: $\alpha = 0.62$).

Outcome variables:

Willingness to work in a dementia-related career paths: a single item ("I would be willing to work with people with dementia") captures behavioural intention to pursue a career working with people with dementia. Guidance on the type of job role this entails was not provided to the participants. The item was rated on a 5-point Likert scale with the response scale ranging between '1 – strongly disagree' and '5 – strongly agree'. Higher scores indicated more willingness to work in a dementia-related career. The variable was dichotomised to create a categorical variable where agree and strongly agree responses were coded as 1 (yes) and all other responses coded as 0 (no).

The Brief version of the Adolescent Attitudes towards Dementia Scale (Brief A-ADS): this validated measure is a shortened version (13-items) (Farina et al., 2022) of the 23-item A-ADS (Griffiths et al., 2018). The brief version of the A-ADS was adopted due to having more comprehensive psychometric properties than the 23-item measure (as identified in Chapter 2 of this thesis). The measure has demonstrated very good internal consistency ($\alpha = 0.82$) (Farina et al., 2022). Each item (e.g., "people with dementia can be creative") is on a 5-point Likert scale with the response scale ranging between '1 – strongly disagree' and '5 – strongly agree'. Higher scores indicated more positive attitudes towards dementia. Scores were calculated according to the Brief A-ADS syntax. Two items (2 and 13) were negatively worded and

required reverse scoring (e.g., “I would avoid a person with dementia who was all worked up”). This was in accordance with the Brief A-ADS syntax. The measure demonstrated good internal consistency (α = 0.82) in this thesis sample.

The Kids Insight into Dementia Survey (KIDS): this 14-item validated measure captures children’s perceptions of dementia with three constructs captured ‘personhood’, ‘stigma’, and ‘dementia understanding’ (Baker et al., 2018b). The KIDS has demonstrated very good internal consistency (α = 0.83). Each item (e.g., “spending time with people with dementia can be fun”) is on a 5-point Likert scale with the response scale ranging between ‘5 – agree a lot’ to ‘1 – disagree a lot’. Higher scores indicated more positive attitudes and understanding of dementia. Scores were calculated according to the KIDS syntax. The KIDS total score was calculated for the analysis. Six items (8, 9, 10, 11, 3 and 5) were negatively worded (e.g., “people with dementia can be creepy”). These underwent reverse scoring. The KIDS demonstrated good internal consistency (α = 0.77) in this thesis sample.

4.2.4 Procedure

School senior staff provided consent for the research to occur within the school and indicated which classes/pupils should be approached for participation. There were approximately 30 adolescents in each class. All potential participants were provided with information about the study, and an opportunity to opt out of participation. All participants received a standard set of measures related to demographic information, and DRA at baseline which were completed at a similar time within each school. The questionnaires were completed via pen and paper in normal lesson time with the adolescent’s teachers. Data collection was undertaken between late 2018 and early 2019. For the thesis, the data used was further cleaned and prepared for analysis by the doctoral researcher EH. The study by Farina et al. (2020b) obtained ethical approval by Brighton and Sussex Research Governance and Ethics Committee. For this thesis, the use of the data from the study did not need further ethical approval since the data was used for secondary data analysis purposes.

4.2.5 Phase I data analysis

A data analysis plan was developed in consultation with a statistician. SPSS (version 26) (IBM, New York, USA) was used to analyse the data. Insufficient error response (IER) and missing data were handled first with the Maximum Longstring Index analysis for detecting IER (Wertheimer, 2017). This is where the maximum number of consecutive values were calculated (participants providing identical responses to many consecutive items) for items within the KIDS and Brief A-ADS. Checks for IER was carried out due to evidence indicating that a respondent's motivation, the survey length, and distractions, can lead to IER. This is a validity threat to the data (Meade & Craig, 2012). All cases that were two standard deviations above the mean were indications of IER. Consequently, these cases were removed (Wertheimer, 2017).

The Brief A-ADS and KIDS underwent variable transformation for reverse coding and then the total scores for these measures were summed. The scoring of the items was reverse coded as follows; 1 = 5, 2 = 4, 3 = 3, 4 = 2, and 5 = 1. Each of the ALOCD subscales was summed separately (direct contact and indirect contact). Each of the three subscales of the EmQue-CA were also summed separately (affective, cognitive, and prosocial intention).

A missing values analysis was used to detect the likelihood of data being missing at random. The assumption of random missingness is determined by $p>0.05$. Extreme outliers were excluded if they fell outside the interquartile ranges of -1.5 and +1.5. Multiple imputation (MI) was used to handle missing data. MI was selected due to its superiority to other techniques of handling data such as single imputation to retain the statistical power of the sample size (Harel, Perkins, & Schisterman, 2014). MI works by producing complete data sets from incomplete data by imputing the missing data a certain number of times (based on theoretical grounds, five imputed data sets are said to be a sufficient number of times depending on the amount of missingness) (Li, Yu, & Rubin, 2012). MI was used to detect the number of missing values for the KIDS, the Brief A-ADS, the subscales of the EmQue-Ca, and the subscales of the ALOCD. Variables with more than 0.01% missing values were checked. As less than 10% of data was missing, five imputation iterations were chosen. The Markov chain Monte Carlo (MCMC) method of MI (Bodner, 2008; Jakobsen, Gluud, Wetterslev, & Winkel,

2017) was automatically selected as the data was missing at random. The final iteration was used to interpret the data which provided a full data set. This was necessary for consistency, as not all the analyses following the MI had pooled data available to use.

Descriptive statistics, cross-tabulations, and checks for normality (skewness: -1 +1, kurtosis: -2 +2, histograms for a normal distribution curve, plots, and Shapiro-Wilk test) (Ghasemi & Zahediasl, 2012) were obtained. As the data was not normally distributed (skewed), the non-parametric equivalent analyses for a bivariate correlation was used. The Spearman's Rho (two-tailed significance) was used for validity checks between the Brief A-ADS and the KIDS. Data for the skewed variables were not transformed as the distribution of the variable and the relationship between the variable and other imputed variables changed. This can lead to imputing outliers and further bias (Lee & Carlin, 2017).

Assumptions for running a Spearman's Rho and regressions were met: 1) the Brief A-ADS and the KIDS are measured on an ordinal, interval, or ratio scale, 2) the Brief A-ADS and the KIDS represented paired observations, 3) there was a monotonic relationship between the Brief A-ADS and the KIDS, and 4) there were no extreme outliers. Multiple linear regressions were used to assess which variables (age, gender, indirect contact, direct contact, affective empathy, cognitive empathy, prosocial intention empathy, ethnicity, and whether participants have heard of dementia or Alzheimer's disease before) were associated with DRA. The variables were entered simultaneously into the models. The Brief A-ADS (model 1) or the KIDS (model 2) served as a dependent variable. Assumptions to run the regression were met (Durbin-Watson statistic values were all between 1.5 and 2.5, and plots and multicollinearity were checked with VIF values less than ten). An alpha of 0.05 was used to denote statistical significance.

As willingness to work with people with dementia was a dichotomous variable, a multivariate logistic regression (model 3) was conducted instead. The group membership for this outcome variable was set to the value one, indicating the likelihood of being willing to work with dementia (1 = yes). For the dichotomous predictor variables, a value of zero was set as the comparator. The odds ratio was used to obtain percentages of whether participants would be more or less willing to work

with people with dementia. Assumptions to run the regression were met (the outcome variable is dichotomous, no extreme outliers in the continuous variables, and no multicollinearity).

4.2.6 Phase II Data Analysis

To explore mediation effects between factors, a non-recursive path analysis was conducted via SEM using the Maximum Likelihood Estimation (CB-SEM) approach. This method was selected due to its robustness in handling complex models and its ability to manage non-normal data distributions when paired with bootstrapping techniques (Nevitt & Hancock, 2001). The analysis was performed using IBM SPSS Amos Graphics (version 28).

The factors included in the model were determined based on the strongest predictors identified in the regression analyses, as well as theoretical relationships supported by the literature (Grønneberg & Foldnes, 2018). Attitudes, contact, and empathy were set as latent variables (unobserved endogenous) with their associated scales set as observed endogenous variables; attitudes (Brief A-ADS and KIDS), contact (direct and indirect contact subscales), and empathy (affective, cognitive and prosocial intention subscales). Gender (observed exogenous) and willingness to work with people with dementia (observed endogenous) were set as observed variables. The term ‘career interest’ was used in the SEM figures to represent the ‘willingness to work with people with dementia’ variable due to the word limit in the SEM. ‘Career interest’ is only used in the SEM (figures 4 to 12) as a term to represent willingness to work with people with dementia rather than used as an interpretation of the variable. The scales connected with latent variables were parcelled with the total score of each participant rather than individual scale items. Thus, a total score of each scale was used and treated as continuous.

Path analysis was conducted using the maximum likelihood estimation (MLE) method, with the data being fitted to both the saturated and independent models. Given that the data was not normally distributed, a bootstrapping procedure was applied. This procedure involved 10,000 resamples, which allowed for the calculation of bias-corrected confidence intervals (BsCI) for the direct and indirect effects within the

model. The decision to use 10,000 bootstrap samples was based on research indicating that this number provides a more accurate estimate of confidence interval limits than fewer bootstrap samples, particularly in larger sample sizes like the one used in this study (n=432) (Efron, 1987; Fitrianto & Cing, 2014).

A Bollen-Stine bootstrap was used to obtain a goodness-of-fit statistic (at 10,000 bootstrap samples) to provide the model fit. The Bollen-Stine can correct for standard error and fit statistical bias that may occur in SEM due to non-normal data (Corrêa Ferraz, Maydeu-Olivares, & Shi, 2022) (see Appendix L). A *p*-value of above 0.05 indicates a good fit (Walker & Smith, 2017). Table 20 provides the indexes used as indicators of the exploratory model fit including $\chi 2$ *p* value. The User-defined estimand function was used to create specific indirect effects and indirect serial effects by adding paths to the parameters.

The SEM had four stages. These included testing a measurement model to optimise and check for misspecifications of the model, model identification to assess initial model fit modifications to the preliminary model, model fitting and checking for directionality (direct effects), and lastly, obtaining specific indirect effects by creating parameter paths.

For further methodological specifics, including the rationale behind choosing CB-SEM and model complexity, please refer to Appendix L.

Table 20 - Indexes and values used to judge whether the model fit is acceptable.

Indexes	**Indication for acceptable model fit**
Chi-square ($\chi 2$) *p* value	$p \geq .05$
Degrees of freedom (df)	> 3
Goodness-of-fit index (GFI)	≥ .90
Adjusted goodness-of-fit index (AGFI)	≥ .90
Comparative fit index (CFI)	≥ .90
Tucker–Lewis index (TLI)	≥ .90
Root mean square error of approximation (RMSEA)	≤ .05 (close fit)
Pclose	> .05 (close fit)
Bollen-Stine bootstrap – GFI	p > .05

***p* = p-value (statistical significance) (Smith & McMillan, 2001)**

4.3 Results – Phase I

4.3.1 Descriptive statistics

There were 470 students recorded at baseline. Following data cleaning (i.e., IER: n = 21, m = 7.67 ± SD = 4.77), 432 students remained in the analysis. The Little's MCAR test (missing values analysis) indicated that the data was missing at random, χ^2 (170) = 166.16, $p > 0.05$. On average, participants were 12.6 years old (SD. = 0.78), female (55.6%), and predominantly White British (75.7%). Table 21 outlines the descriptive statistics obtained.

Table 21 - Descriptive statistics for the secondary data analysis (Chapter 4)

Characteristics		N	%	Mean ± Std.
Age		432		12.62 ± 0.78
Gender	Male	183	42.4%	
	Female	240	55.6%	
	Other	9	2.1%	
Ethnicity	White British	327	75.7%	
	Other ethnic groups	105	24.3%	
Heard of dementia or Alzheimer's disease	Not heard	17	3.9%	
	Alzheimer's Disease only	8	1.9%	
	Dementia only	124	28.7%	
	Heard of both	275	63.7%	
	Missing	8	1.8%	
I would be willing to work with people with dementia	Yes	205	47.5%	
	No	227	52.5%	
School	School 1	48	11.1%	
	School 2	194	44.9%	
	School 3	190	44.0%	
Brief A-ADS		432		45.40 ± 5.42
KIDS		432		52.99 ± 5.97
ALOCD subscales	Direct contact	432		11.29 ± 5.69
	Indirect contact	432		11.51 ± 3.94
EmQueCa subscales	Affective empathy	432		8.05 ± 2.73
	Cognitive empathy	432		7.18 ± 1.93
	Prosocial intention empathy	432		9.86 ± 2.20

4.3.2 Validity checks

There was a significant, positive, moderate correlation between the Brief A-ADS and KIDS, demonstrating good reliability between the two measures ($r_s = .52$, $p<0.001$).

4.3.3 Regression models: Dementia attitudes

The multiple linear regression of all predictor variables (k = 9) significantly fitted to the model where the Brief A-ADS was the outcome, $F(1, 422) = 13.738$, $p < 0.001$. A small but significant amount of variance in the Brief A-ADS scores was explained by the model, R^2 adjusted = .210. Increased prosocial intention empathy ($p<0.001$), higher levels of direct contact ($p < 0.001$), higher levels of indirect contact ($p<0.001$), and being female ($p = 0.03$) were the only significant factors associated with higher Brief A-ADS scores. Within the models, males denoted significantly poorer attitudes.

The multiple linear regression of all predictor variables (k = 9) significantly fitted to the model where the KIDS was the outcome, $F(1, 422) = 14.169$, $p<0.001$. A small but significant amount of variance in the KIDS scores was explained by the model fit, R^2 adjusted = .216. Within the model, increased prosocial intention empathy ($p = .002$), higher levels of direct contact ($p<0.001$), and being female ($p = .02$) were the only significant predictors of the KIDS scores. Table 22 provides the multivariate linear regression for the Brief A-ADS and the KIDS.

Table 22 - Multiple linear regression for variables predicting Brief A-ADS and the KIDS attitude scores

	Multiple linear regression (n = 422)					
	Brief A-ADS			KIDS		
	β	**B**	**CI [95%]**	**β**	**B**	**CI [95%]**
Age	-0.03	-0.18	-0.78 – 0.42	-0.01	-0.11	-0.76 – 0.55
Gender: Male	-0.10*****	-1.09	-2.05 – -0.12	-0.11*****	-1.28	-2.34 – -0.23
Ethnicity: White British	-0.05	-0.57	-1.65 – 0.51	0.03	0.36	-0.82 – 1.55
Affective empathy	0.08	0.17	-0.06 – 0.39	-0.03	-0.06	-0.30 – 0.19
Cognitive empathy	-0.09	-0.26	-0.55 – 0.04	-0.03	-0.10	-0.42 – 0.22
Prosocial intention empathy	0.25*******	0.61	0.32 – 0.90	0.18******	0.49	0.18 – 0.82
Direct contact	0.20*******	0.19	0.10 – 0.28	0.40*******	0.42	0.32 – 0.52
Indirect contact	0.20*******	0.28	0.15 – 0.41	0.10	0.28	-0.11 – 0.17
Heard of dementia or Alzheimer's: Yes	-0.07	-2.05	-4.45 – 0.35	0.06	1.81	-0.82 – 4.45

Outcome variable: Brief A-ADS and the KIDS. Statistical significance: * = $p < 0.05$; ** = $p < 0.01$; *** $p = < 0.001$. Dichotomous variables are coded as 0 versus 1. *B* = unstandardised beta coefficient, β = standardised beta coefficient; CI = confidence interval (lower – upper bound) [95%]

4.3.4 Regression models: Willingness to work with people with dementia

All nine variables were entered into a multiple logistic regression model which revealed a good fit, $\chi^2(9, 432) = 46.775$, $p < 0.001$. The model accounted for approximately 13.7% (Nagelkerke R^2) of the variance in willingness to work with people with dementia. The model correctly classified 65.5% of cases. Prosocial intention empathy ($p = .01$), direct contact ($p = .002$) and indirect contact ($p = .004$) remained positively associated with willingness to work with people with dementia. Gender and affective empathy were not significant within the model ($p > .05$). Table 23 presents the outcomes of the multiple logistic regression.

Table 23 - Multiple logistic regression for variables predicting the likelihood of willingness to work with people with dementia.

Predictors	Multiple logistic regression (n = 432)		
	B	**Odds ratio: Exp (B)**	**CI [95%]**
Affective empathy	-0.03	0.97	0.88 – 1.07
Cognitive empathy	-0.08	0.93	0.81 – 1.05
Prosocial intention empathy	0.18*	1.20	1.05 – 1.36
Direct level of contact	0.06**	1.07	1.02 – 1.11
Indirect level of contact	0.09**	1.09	1.03 – 1.15
Gender: Male	-0.37	0.69	0.45 – 1.05
Age	-0.10	0.90	0.69 – 1.17
Ethnicity: White British	0.10	1.11	0.69 – 1.77
Heard of dementia or Alzheimer's: Yes	-0.50	0.61	0.22 – 1.70

Outcome variable: Willingness to work with people with dementia. Statistical significance: * = $p < 0.05$; ** = $p < 0.01$; *** $p = < 0.001$. Dichotomous variables are coded as 0 versus 1. B = unstandardised beta coefficient; Exp (B) = odds ratio; CI = confidence interval (lower – upper bound).

4.3.5 Summary

Overall, the regression models indicated that prosocial intention empathy, direct contact, indirect contact, and gender were significant factors of DRA. Univariate linear regressions (see Appendix M) also revealed a relationship between affective empathy and DRA, and willingness to work with people with dementia measures. Based on these findings and theoretical support, the following latent factors were considered at the initial exploratory SEM building stage: gender, empathy, and level of contact, along with the outcome variables; Brief A-ADS, KIDS, and willingness to work with people with dementia (labelled as career interest). As a majority of the empathy domains were associated across the outcomes, all domains of empathy were included in the latent variable empathy for the SEM. Due to the lack of statistical or theoretical support, age, ethnicity, and whether participants have heard of dementia or Alzheimer's disease were not included in the SEM.

4.4 Results – Phase II

4.4.1 SEM - testing a measurement model

The overall fit for the model was poor, $\chi^2(11) = 64.562$, $p < 0.001$. Other indicators also indicated poor fit; AGFI = .89, RMSEA = .11, Pclose = .00, TLI = .86. Only two indicators suggested adequate fit; GFI = .96 and CFI = .93. Figure 4 provides the standardised estimates for the measurement model.

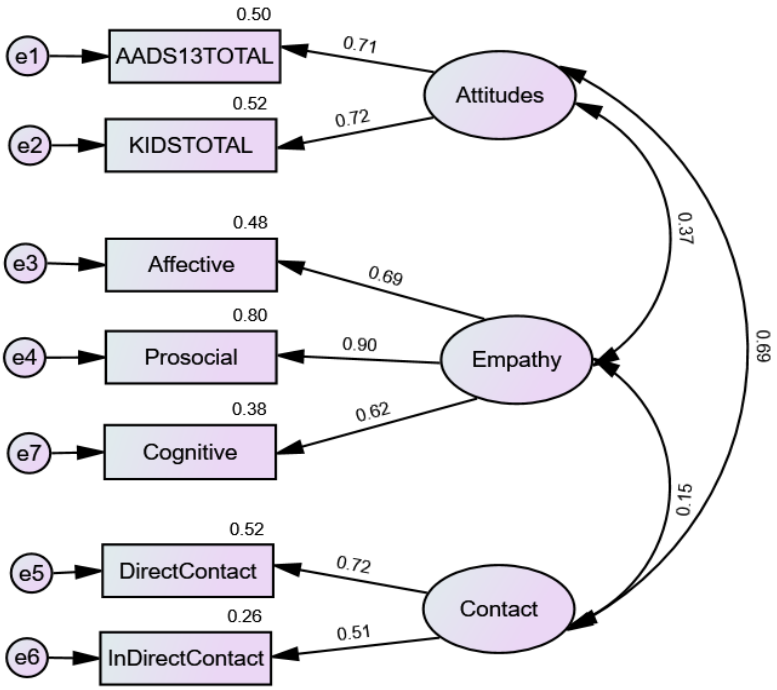

Figure 4 - Measurement model I with standardised coefficients.

Measurement model I displays the pathway between latent variables (attitudes, empathy, and contact) and the measures relating to those constructs. The standardised coefficients represent the strength and direction between the latent variables and their corresponding variables. There is a bidirectional arrow between the latent constructs which represents correlation or covariance between the constructs.

Modification indices were checked and applied to the measurement model before assessing how well the indicators were measuring their latent variable constructs. Only selecting the correlations that impact the model the most is advised. Adding all covariates can lead to overfitting the model, which can be misleading (Bollen 1989; Greenland & Pearce, 2015). The following error terms were covaried with each other; e1 and e5, e2 and e5 and e3 and e6 as displayed in Figure 5. The theoretical measurement justifications include that both the Brief A-ADS and the KIDS similarly tap into direct contact (e.g., Brief A-ADS: “I would volunteer to spend time with people with dementia” and KIDS: “I feel confident around people with dementia”). Another example from the KIDS includes “spending time with people with dementia can be fun”. This is similar to some of the direct contact items of the ALOCD (e.g., ‘I

have come across people with dementia' and "I have spent time with people living with dementia").

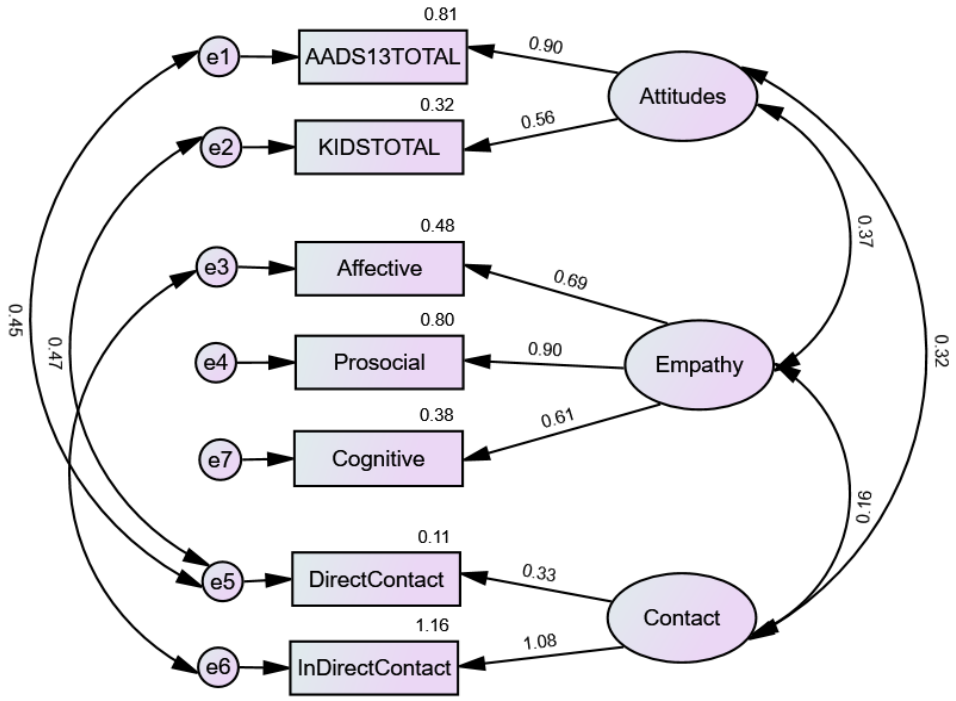

Figure 5 – Measurement model II with standardised coefficients.

Measurement model II displays the pathway between latent variables (attitudes, empathy, and contact) and the measures relating to those constructs. The standardised coefficients represent the strength and direction between the latent variables and their corresponding variables. There is a bidirectional arrow between the latent constructs which represents correlation or covariance between the constructs. Covaried error terms (e.g., e1 and e5) represent that some items from 'AADS13 TOTAL' and 'DirectContact' share similarities in the dimensions of attitudes and contact they are capturing.

The overall fit for the model was acceptable with the modifications, $\chi^2(8) = 16.406$, $p = .04$. Other indicators were checked and further confirmed an acceptable model; GFI = .99, AGFI = .96, TLI = .97, RMSEA = .05 and Pclose = .46. This indicated a good measurement model to proceed with running the path models. The maximum likelihood estimates suggested that the factor loadings were statistically significant

between the indicator variables and their respective factors for the following; attitudes (KIDS and the Brief A-ADS), $p < 0.001$, and empathy (affective, cognitive, and prosocial intention), $p < 0.001$. Level of contact (direct and indirect contact) was not significant, $p = .26$. Squared multiple correlations suggest that the latent variable 'contact' accounted for a small proportion of variance in direct contact (r = .11) but a large proportion of variance in indirect contact (r = 1.16). All other observed variables were found to be adequate indicators of their latent factors (all other factor loadings ranged in magnitude from .32 to 1.16, all with $p < 0.001$). As the model fit was acceptable overall, the measurement model was accepted without further modifications.

4.4.2 Model building - Exploratory Model

The initial model building of the SEM was to test the model fit as seen in Figure 6, and to make further modifications if necessary before building the model to test the paths. The overall fit for the model was inadequate, $\chi^2(19) = 35.857$, $p = .01$. Other indicators such as the RMSEA suggested the fit was marginally inadequate; RMSEA = .05. Other indicators suggested the model was an adequate fit; GFI = .98, AGFI = .96, TLI = .96, CFI = .98, and Pclose = .60. However, the Bollen-Stine bootstrap (m=19.88, n = 10,000) suggested goodness of fit of the model was poor overall, $p = 0.02$.

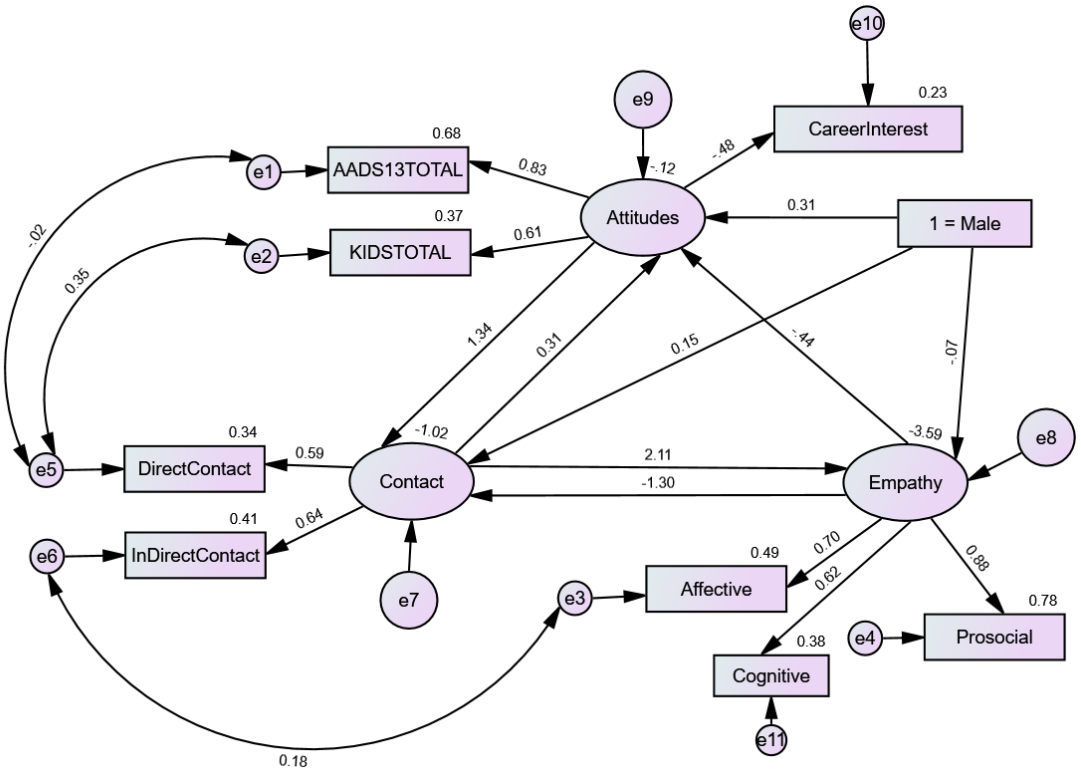

Figure 6 - Model building: exploratory model with standardised coefficients.

The exploratory model displays pathways between the latent variable attitudes, predictor variables, and error terms. Attitudes and contact have a direct pathway to each other. Contact and empathy have a direct pathway to each other. Empathy has a direct pathway to attitudes. Gender (male =1) has a direct pathway to attitudes, empathy, and contact. Note. 'CareerInterest' represents willingness to work with people with dementia.

Based on the model fit, the decision was made to modify the model by removing cognitive empathy to better fit the model. The variable was removed for the following reasons:

1. Cognitive empathy had the weakest association and influence on attitudes compared to the other variables at phase I of the analysis (regressions).

2. Theoretically, there is stronger support for prosocial intention related empathy (Van der Graaff et al., 2018).

3. Of the three subscales of empathy, the latent variable empathy at the measurement model stage accounted for the smallest proportion of variance in cognitive empathy, r = .38 compared to affective, r = .48, and prosocial intention related empathy, r = .80.

4.4.3 Accepted Model

With cognitive empathy removed from the model as indicated in Figure 7, the overall fit for the model was very good. Several indices indicated a very close fit, $\chi^2(16) = 16.913$, $p = .15$, CFI = .99, GFI = .99, AGFI = .97, TLI = .98, RMSEA = .03, and Pclose = .82. The Bollen-Stine bootstrap (m=12.44, n = 10,000) was not statistically significant, $p = .18$. This suggests that the goodness of fit of the model was good and that the null hypothesis is correct ($p > 0.05$). Thus, the null hypothesis for this model was accepted.

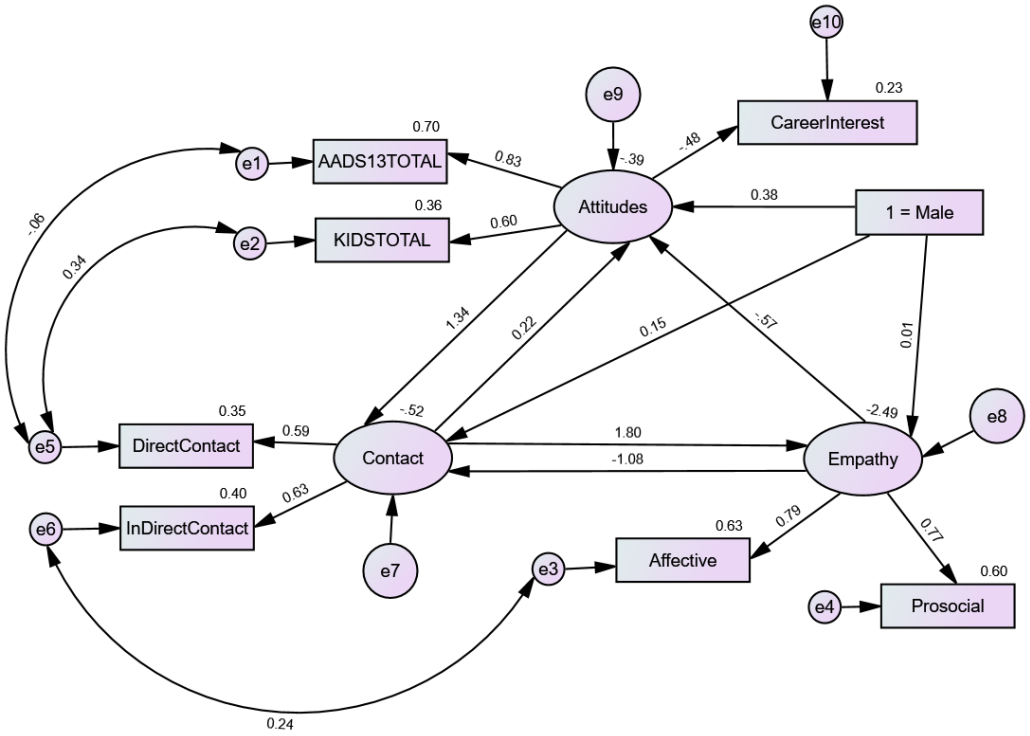

Figure 7 - Accepted model with standardised coefficients.

The accepted SEM displays removal of the cognitive variable and highlights the pathways between the latent variable attitudes, predictor variables and error terms. Attitudes and contact have a direct pathway to each other. Contact and empathy have a direct pathway to each other. Empathy has a direct pathway to attitudes. Gender (male =1) has a direct pathway to attitudes, empathy, and contact.

Note. 'CareerInterest' represents willingness to work with people with dementia.

Direct effects

There was a significant direct effect observed between the following paths; gender to attitudes p = .001, attitudes to willingness to work with people with dementia, p < 0.001, empathy to attitudes, p = .01, contact to empathy, p = .01, and empathy to contact, p < 0.001. The direct paths, gender to empathy (p = .98), and contact to attitudes (p = .64) were not significant. Table 24 reports the coefficients.

Table 24 - Unstandardised direct effects of the accepted model (Chapter 4)

Parameters			Estimate (B)	S.E	Lower CI [95%]	Upper CI [95%]
Attitudes	<---	Gender	3.44**	1.24	1.71	10.13
Empathy	<---	Gender	0.04	0.77	-5.14	1.25
Willingness to work with people with dementia	<---	Attitudes	-0.05**	0.01	-0.07	-0.04
Attitudes	<---	Empathy	-1.19*	0.67	-5.76	-0.25
Empathy	<---	Contact	1.16*	0.67	0.24	4.61
Contact	<---	Empathy	-1.68**	0.49	-3.26	-0.82
Attitudes	<---	Contact	0.29	0.45	-1.97	0.98

Estimate (B) = unstandardised beta regression coefficient; Statistical significance: * = $p < 0.05$; ** = $p < 0.01$; *** $p = < 0.001$. S.E = standard error of the regression weight estimate; CI = bias corrected (95%) confidence interval (lower and upper bound). If 0 falls between the lower and upper bound, the effect is not statistically significant. Estimates with (-) = negative relationship.

Indirect effects

The indirect pathway for contact to attitudes via empathy (contact > empathy > attitudes) was statistically significant and stronger than the direct pathway of contact to attitudes (contact > attitudes) ($p < 0.05$). There was no statistically significant indirect pathway between gender and attitudes (gender > empathy > contact > attitudes). The model also revealed that attitudes was a key mediator of willingness to work with people with dementia. Table 25 reports the coefficients for the mediation effects.

Table 25 - Unstandardised mediation effects of the accepted model (Chapter 4)

Parameters	*B*	Lower Bound CI [95]%	Upper Bound CI [95%]
Empathy > attitudes > willingness to work with people with dementia	0.06*****	0.01	0.29
Contact > attitudes > willingness to work with people with dementia	-0.02	-0.05	0.09
Empathy > contact > attitudes > willingness to work with people with dementia	0.03	-0.12	0.12
Contact > empathy > attitudes	-1.37*****	-17.31	-0.10
Contact > empathy > attitudes > willingness to work with people with dementia	0.07*	0.01	0.81

Estimate (*B*) = unstandardised beta regression coefficient. Two-tailed statistical significance: * = $p < 0.05$; ** = $p < 0.01$; *** $p = < 0.001$. CI = bias corrected [95%] confidence interval (lower and upper bound). If 0 falls between the lower and upper bound, the indirect effect is not statistically significant. Estimates with (-) = negative relationship.

4.5 Discussion

This is the first study to explore the factors associated with DRA in adolescents using SEM. The study highlighted that gender, empathy, and contact are important contributors to DRA. Adolescents' DRA was also a strong predictor of future behavioural intention to work with people with dementia. Being male was a risk factor

for developing negative DRA. Contact and empathy are potential modifiable factors that may be useful targets for anti-stigma interventions. Further empirical replication can strengthen the evidence of these findings. Cognitive empathy weakened the model and explained the data less well in the SEM, supporting the theory that other domains of empathy may have a more important role in DRA at this stage of adolescence (Carlo et al., 2010; Van der Graaff et al., 2018). The SEM also highlighted that indirect effects overall were stronger than direct effects and that empathy facilitated behavioural intention through DRA. Beyond the regressions, the SEM provides a better understanding about how these factors interact together in influencing DRA in adolescents.

4.5.1 Key findings

Gender

The SEM found a significant direct effect of gender on DRA. The findings in this study support prior literature on gender differences in adolescents (Farina et al., 2020a; Fuh et al., 2005; Lo et al., 2020), the general dementia literature (Blay & Peluso, 2010; Cheng et al., 2011), and broader mental illness literature (Bradbury, 2020). Investigating the mechanisms that contribute to the gender differences in DRA may involve exploring how socialisation processes (Chung & Rimal, 2016), personal experiences (Cheston et al., 2019), and societal expectations (Losada-Baltar et al., 2023) shape adolescents' perceptions and DRA differently based on gender. Longitudinal studies may be useful in determining the stability of gender differences in DRA over time to help unpick the mechanisms that take place in early adolescence through adulthood to understand how gender-related factors shape DRA.

As identified in the systematic review (Chapter 3), females are more likely to have contact with people with dementia than males (Cheston et al., 2019) which also corresponds with the association between contact and DRA (Baker et al., 2018b; Werner et al., 2017). The application of these findings includes consideration for gender-specific factors when devising interventions aimed at promoting positive DRA in adolescents. For example, employing different messaging, activities, or modes of delivery of the intervention can help engage male and female adolescents (Okoli,

Greaves, & Fagyas, 2013). Adolescent boys for example use video games up to five times more than girls, while girls use social media more (Leonhardt & Overå, 2021). Females also engage with health-related information online more so than males (Powell, Inglis, Ronnie, & Large, 2011). This can enhance the relevance and effectiveness of various interventions for socio-demographic groups. Gender differences in DRA also may reflect societal disparities in caregiving responsibilities generally (ADI, 2019). Therefore, future work could consider how cultural and contextual factors influence gender differences in DRA.

Empathy

There is a lack of quantitative evidence to support the association between empathy and DRA. It was unclear what the strength of this association is, and in what domains of empathy. This secondary data analysis provides quantitative evidence, supporting the qualitative relationship between empathy and DRA (Baker et al., 2018a). It also provides support for the empathy altruism hypothesis (Batson et al., 1991; 2002). Prosocial intention in the empathy domain consistently demonstrated a strong association with the DRA measures across the analyses. This is in line with evidence that found prosocial responding and empathy are associated with less prejudice (Dovidio et al., 2010). The findings also align with evidence that supports prosocial behaviour towards strangers increases during the mid-adolescent period as they begin to perspective take (Padilla-Walker, Carlo, & Memmott-Elison, 2018). This is one explanation as to why prosocial intention may have strongly correlated with DRA. A weaker, but significant association between affective empathy and DRA was found. Cognitive empathy had the weakest association in the regression models overall. Despite empathy inter-component relatedness (Overgaauw et al., 2017), identifying prosocial empathy as the most strongly associated dimension highlights the importance of considering different components of empathy when examining DRA. Why prosocial and affective empathy may have been stronger predictors of attitudes than cognitive empathy may be explained by research. Some studies highlight that that perspective-taking (cognitive) does not predict prosocial behaviour directly. Empathetic concern (affective) is a stronger predictor for prosocial action related behaviours (Batson et al., 1991; Carlo et al., 2010; Van der Graaff et al., 2018).

If empathy is an important driver of DRA, tapping into the 'right' kind of empathy could elicit more effective prejudice reduction. Given that prosocial intention (empathy) was more prominently associated with DRA, interventions aiming to reduce negative DRA could foster this by incorporating empathy-building activities into interventions (e.g., 'myShoes experiential dementia training') (Adefila, Graham, Clouder, Bluteau, & Ball, 2016). Prosocial intention related empathy is not only associated with altruistic behaviours, adolescents who possess prosocial empathy are also more likely to challenge stereotypes (Lay & Hoppmann, 2015), which can reduce discrimination. Adolescents who also develop strong prosocial related empathy skills are associated with being more likely to carry these traits into adulthood (Silke et al., 2018). Future work could compare the effectiveness of interventions utilising empathy versus other interventions (e.g., contact, and knowledge based).

The theoretical underpinning of each attitude measure may help provide an understanding to why cognitive empathy was not a significant predictor in KIDS but was for the Brief A-ADS scores. The conceptual development of the Brief A-ADS and KIDS are different, which may mean they capture slightly different underlying constructs. For example, the Brief A-ADS appears to have a greater number of motivation-action items that embody prosocial intention behaviours such as helping and empathetic concern (i.e., 'I would volunteer to spend time with people with dementia' and 'If I saw someone with dementia struggling to do something, I would help them'). This could be an issue if this creates ambiguity as it is difficult to determine whether scores truly reflect attitudes or behavioural intention. If the Brief A-ADS conflates attitudes as behavioural intentions, interventions aimed at improving DRA may inadvertently promote specific behaviours instead of addressing underlying beliefs. Behavioural intention is however an important intermediator between attitudes and behaviour (Bagozzi & Yi, 1989). In the case of the KIDS, the measure did not include any perspective-taking items which may be why cognitive empathy is less prominent in the model. It could mean that cognitive empathy was not adequately captured by the outcome measures, as opposed to being genuinely less influential compared to affective and prosocial intention empathy. The measurement model of SEM reported in phase II analysis supports this notion. The latent variable empathy accounted for the smallest portion of variance in the cognitive domain.

Level of contact

Contact is one of the factors identified as more strongly associated with DRA quantitatively (Cheston et al., 2016; Werner et al., 2017) and qualitatively (Baker et al., 2018a). The findings from the regressions suggested that overall, direct contact was more influential in the model than indirect contact. This supports the intergroup contact theory (Allport, 1954). In line with the dementia literature, evidence reveals direct contact with dementia mediated more positive DRA in comparison to those with little/no experience of dementia in university students (Scott, Kugelman, & Tulloch, 2019) and healthcare students (Lokon et al., 2017). With research indicating that approximately one-quarter to a third of adolescents in England know someone with dementia (Farina et al., 2020a), it is perhaps not remarkable that direct contact was a significant predictor of attitudes. However, evidence suggests that the greatest level of contact that young people have with dementia is through media (indirect contact) (Baker et al., 2018b; Farina et al., 2020a). Although media was not a variable in this thesis study, the findings may allude to the fact that direct contact is of higher quality of contact than indirect means. However, the extent of media influence on adolescent's perception of dementia is still limited currently and the quality of contact is yet to be investigated robustly in young people.

Another potential explanation as to why indirect contact was not a significant predictor of KIDS in the multiple regression model could be that the outcome measures contain more direct contact items than indirect contact. Both the Brief A-ADS and the KIDS refer to spending time, being friends with, and having met someone with dementia (Baker et al., 2018b; Farina et al., 2022). The authors of the ALOCD also demonstrate that the direct contact subscale has better internal reliability, construct validity, and discriminant validity than the indirect contact subscale (Parveen et al., 2020b). This means it is likely capturing direct contact more appropriately than indirect contact.

One strength of the ALOCD is that it addresses level of contact on a continuum which provides the extent of contact rather than mere exposure. However, in this study the ALOCD was dichotomised. Whilst this was necessary to determine which form of contact was more influential, it meant the extent of contact was not captured, limiting how much information can be conferred from this. Understanding this distinction is

important as anti-stigma strategies involving indirect contact whilst cost-effective, may fail to have a significant effect on attitude change. On the other hand, direct contact may be costlier in terms of time and finances. Providing an evidence base for this allows for the appropriate allocation and justification of resources that make the anti-stigma intervention more effective.

In the SEM, empathy and contact both had a mediatory effect on attitudes. It is therefore reasonable to suspect that initiatives employing one without the other may not be strong enough to change stereotypes (i.e., intergroup contact theory, Allport, 1954). Evidence from the broader adolescent (7-16 years old) disability literature found that greater empathy was a partial mediator between contact and attitudes, and that empathy was an important factor to consider when developing interventions based on contact (Armstrong, Morris, Abraham, & Tarrant, 2017). Likewise, intergroup contact led to increased empathy in another programme, supporting the stance that empathy may be malleable (Adefila et al., 2016; Barbot & Kaufman, 2020). Facilitating meaningful contact between people with dementia and young people may be difficult due to red tape, such as the need for thorough background checks for those interacting with vulnerable populations (Lipman & Manthorpe, 2016). These can complicate efforts to create opportunities for direct interaction. Virtual reality (VR) could be one way to tap into empathy (Schutte & Stilinović, 2017) without having direct contact with a person with dementia. VR offers a promising avenue for positively impacting DRA by challenging stereotypes and fostering empathy. For example, inter-generational video gaming in VR can create positive portrayals of dementia (Makri & Tsolaki, 2022). This approach is particularly appealing to young populations (Hicks, Konovalova, Myers, Falconer, & Board, 2021) and has been shown to support the development of empathy. However, while VR is effective in this regard, it may come at the cost of losing the direct voices of people with dementia.

Other factors

Ethnicity was not a significant predictor of DRA. This is in contrast to one study reported on ethnicity in the systematic review (Chapter 3) (Werner et al., 2017), the general DRA literature including adults (Algahtani et al., 2020; Cheston et al., 2016; Kafadar et al., 2021; Lawrence et al., 2008; Mukadam et al., 2011), and the broader

adolescent mental health literature (DuPont-Reyes, Villatoro, Phelan, Painter, & Link, 2020). These studies typically report that White participants exhibit more positive attitudes than other ethnic groups (Cheston et al., 2016). In this secondary data analysis, samples were mostly White British (75%). The homogenous nature of the data makes it difficult to generalise the results and confer the true extent of influence of ethnicity in DRA, since there was not enough data to conduct a subgroup analysis. Other studies reporting on ethnicity tend to have a larger age range (Cheston et al., 2016), which may be why significant differences are found in DRA and ethnicity between different generations. Future work will need to ensure inclusive efforts to recruit various ethnic backgrounds. A more granular focus on different ethnic groups could also help better understand these findings.

Similarly, age was not found to be associated with DRA. Drawing on the mental illness literature, there are differences between children aged seven in their thinking about mental illness compared to those aged 10-11 years old (Fox, 2020; Fox, Buchanan-Barrow, & Barrett, 2010). Similarly, differences in DRA are demonstrated between those aged 18 years old and above and those under 18 years old (Wu et al., 2022). Given there are key developmental milestones in maturity, understanding of the world, and empathy differences at the start of adolescence, and the mid-adolescent period (Allport, 1954; Van der Graaff et al., 2018), age differences might be more likely observable between age groups with a wider age gap. Given the sample had a mean age of 12.6 years old, it may not wholly represent much older adolescents' attitudes. As a result, a comparison of those at the start of adolescence and those towards the end of adolescence may be more useful.

Whether participants had heard of dementia or Alzheimer's disease before was not a significant predictor overall. It was only significant in the univariate regression model (see Appendix M) where KIDS was the outcome. Whilst the item did not provide context on where participants heard the terms, the participants were provided with a vignette that explains a scenario of someone with dementia, which may tap into memory constructs of attitudes. For the participants who had not heard of the terms before, the vignette would have been their first impression. Yet, participants may still have an accessible evaluation of dementia through the retrieval of other beliefs and content that closely matches a particular belief in memory (e.g., a person with mental

illness) (Vogel & Wanke, 2016). Since the KIDS items tap into the construct of knowledge, participants may have been attributing the terms ‘dementia’ and ‘Alzheimer’s disease’ to other similar categories that are stored in long-term memory.

Willingness to work with people with dementia

Overall, a majority of participants expressed being unsure or unwilling to work with people with dementia. This is in line with work by Hebditch and colleagues, where interest in geriatrics was ranked low by healthcare students (Hebditch et al., 2022). These negative attitudes held by this generation of young people may adversely influence their willingness to take up careers relating to gerontology or older care services. However, the results should be interpreted with caution since the item did not prompt the type of career. This could entail several careers (e.g., charity work and commercial sector). This makes it difficult to assess how participants interpreted the item. From the perspective of the TPB where perception of barriers influence behavioural intention, adolescents may have had negative attitudes towards the idea of working with people with dementia if they perceive that judgements from others could be negative. Alternatively, they may feel that they cannot achieve a career involving dementia due to perceptions around qualifications. Schools could consider the integration of dementia education in school subjects such as health and social care, and psychology to foster more positive attitudes towards working with people with dementia. Future work could further explore the mediators influencing willingness to work with dementia which may help researchers to understand its underlying determinants. This would also be important for policymakers if they are to address predicted shortages in the dementia care workforce (NHS England, 2023).

The findings from the logistic regressions revealed the likelihood of participants willing to work with people with dementia was highest in the prosocial domain (17%). Since this outcome variable is related to motivated-related action, it is not a surprising finding that the prosocial domain was the strongest predictor of willingness to work with people living with dementia. Enhancing prosocial related empathy skills in young people may increase their willingness to work with people living with dementia.

The relationship between willingness to work with people with dementia and gender suggests that are gender disparities. Males were 41% less likely to express willingness to work with people with dementia than females (59%). This is supported by research where females have a higher preference for dementia-related careers (Hebditch et al., 2020; Ní Chróinín et al., 2013). Future work could explore the factors contributing to these disparities to encourage more males to consider careers in dementia.

ALOCD scores also increased the likelihood of participants' willingness to work with people with dementia, particularly for indirect level of contact rather than direct contact (13% vs 8%). A hypothetical explanation for this could be that those with personal experience of dementia via direct contact (e.g., family members with dementia) may have observed some level of dementia care. Young people may associate working with people with dementia with negative care elements. Studies have shown that adolescents display avoidance and negative emotions in their interactions with grandparents diagnosed with dementia (Liao et al., 2022). Increasing opportunities for young people to engage in meaningful interactions with people living with dementia (e.g., volunteering opportunities or intergenerational activities), could be ways to address this, thereby increasing willingness to work with people with dementia.

4.5.2 Strengths and limitations

Strengths

First, this study is the first to explore associations between multiple socio-demographic and modifiable factors and DRA in young people within the SEM context. Past research has been limited to reporting an association with no indication of the directionality of the association. This study adds further context to how these factors may interact with each other, specific to this target age group.

Second, all the measures used are validated in children and adolescents and psychometrically evaluated in subsequent studies. Chapter 2 of this thesis highlighted the scarce number of validated measures created specifically for young people. It also

highlighted the poor quality of studies that used non-validated measures. This sub-study therefore addresses this limitation.

Third, the findings consolidate that adolescents are a worthwhile age group to target given that prosocial intention related empathy is optimal in adolescents (Van der Graaff et al., 2018). This was supported in the regressions and the SEM.

Last, there were several methodological strengths in this study. The detection of IER minimises extreme outliers and systematic bias that could exaggerate potential correlations that can occur (Huang, Curran, Keeney, Poposki, & DeShon, 2012). It is advised that researchers should look at IER in their data so that findings are not limited due to the issues relating to it (Ward & Meade, 2023). Whilst the maximum Longstring index was used to determine IER, it is important to note that this gives an indication for IER likelihood and does not necessarily mean that these participants are all IER. Moreover, the use of MI for handling missing data meant a greater retention of sample size and power. The advantage of MI is that it is more likely to give unbiased results when the data is assumed missing at random compared to other methods (de Goeij et al., 2013).

Limitations

First, the data is cross-sectional. This makes it difficult to make causal inferences about the data and how variables influence each other. Whilst statistical p-values and confidence intervals are useful in supporting interpretations of associations, statistical associations does not necessarily equate to meaningful associations. A cross-sectional design is justified in this secondary analysis as it enabled the exploratory establishment of relatedness of several variables (Spector, 2019).

Second, explicit attitude measures are prone to social desirability bias that threatens internal validity (Ross & Bibler Zaidi, 2019). Due to the nature of secondary data, it was not possible to adopt methods that could address this issue (e.g., implicit measures and tests for social desirability).

Third, dichotomising oversimplifies data. In research, gender is often dichotomised into male and female sex categories. This binary approach fails to capture the complexity of individual gender and can take meaning away from data (Cost et al., 2022).

Fourth, due to using secondary data, not all the factors from the systematic review could be explored. The factors examined in this secondary analysis are not definitive and it did not take into consideration their influence on attitudes in the context of other potential factors that are involved. The model's variance percentages indicate that there are other unobserved variables. Future work will need to establish more complex models to include other variables. This includes variables such as level of dementia knowledge (Felc et al., 2021; Lo et al., 2020; Werner et al., 2017), which was supported in its association with DRA in Chapter 3. However, its interaction with other factors is yet to be explored.

Fifth, multiple tests of associations between variables were conducted and the significance level was not adjusted which increases the risk of Type I error (Lee & Lee, 2018). As the analysis was exploratory in nature, adjusting for multiple comparisons (e.g., with Bonferroni correction) can increase the risk of Type II errors, given the Bonferroni correction for example, can be overly conservative. This could overlook potentially important associations (Barnett, Doroudgar, Khosraviani, & Ip, 2022). Thus, maintaining sensitivity to detect associations was prioritised alongside the use of confidence intervals to aid interpretation. However, findings should be interpreted with caution, recognising the risk of Type I error. Future studies should consider the need for appropriate adjustments to the significance level to minimise the risk of Type I error.

Last, differences observed in the regression models could be due to measurement differences. The Brief A-ADS and the KIDS only moderately correlate with each other. The KIDS factor structure may be subject to varying interpretations. For example, under factor three (knowledge: dementia understanding), an example item is 'Dementia is unpredictable; families of people with dementia need to expect the unexpected'. This item could be viewed as an attitude, while in factor two (stigma), items such as 'you can catch dementia from other people' appear more knowledge-

based. The consistency of strength and direction of associations across the Brief A-ADS and KIDS, however, provides reassurance that they capture overlapping domains.

4.6 Conclusion

The purpose of this study was to explore factors associated with DRA in adolescents and establish a best model fit to the data. Prosocial intention related empathy appears to be a key mediator between contact, DRA, and ultimately behavioural intention in adolescents. The findings suggest that empathy and contact are factors that may be useful targets for anti-stigma initiatives for adolescents. This thesis Chapter sets the theoretical justifications and evidence for the subsequent Chapter that explores how these factors influence DRA in adolescents in a more complex SEM. Future studies should recruit more heterogenous samples to confirm or disprove the findings of this SEM, and explore other potential factors that may interact with those factors that are better established within this analysis.

Chapter 5: A cross-sectional study on the determinants of dementia-related attitudes in British adolescents

This Chapter consists of a novel cross-sectional study on the determinants of DRA in British adolescents and builds on existing evidence with a diverse sample of British adolescents.

5.1 Aims and Objectives

This study aimed to contribute new knowledge on the factors that have not been previously explored in SEM in the context of DRA and willingness to work with people with dementia in young people. These include ageism and level of dementia knowledge. This study aimed to be more representative, by recruiting more regions of England. This study will help inform interventions aimed at reducing dementia stigma among adolescents. By identifying at-risk demographic groups and understanding how attitudes may develop, targeted anti-stigma initiatives can be designed more effectively. Using SEM to explore novel mediatory mechanisms of these factors deepens the understanding of the complex interplay between demographic factors, modifiable factors, and DRA (see Chapter 1, section 1.8, 1.8.1. and 1.8.2).

In an exploratory capacity, the experiences and knowledge of dementia was also explored descriptively, using frequencies and cross-tabulations to contextualise the sample of British adolescents. This may improve our understanding of DRA by providing novel insight into whether various experiences of dementia that young people encounter, are generally positive or negative. This is currently not known quantitatively (see Chapter 1, section 1.8.1 – 'contact'). Ideally, measures of dementia contact would capture frequency, quality, duration, and type of contact. However, there is not a dementia contact measure that captures all these components currently. Thus, in this chapter, type of contact and quality of contact is captured in an exploratory capacity. Understanding the current level of dementia knowledge in British adolescents also provides insight into the baseline knowledge held by this demographic (see Chapter 1, section 1.8.1 and Chapter 3, section 3.3.4), which may be useful for dementia awareness advocacy in schools, in line with UK policy (Policy

paper: Department of Health and Social Care, 2015). Prior data on this was only collected from one region of England (Isaac et al., 2017).

One limitation of using explicit measures to assess attitudes is their susceptibility to social desirability bias. Including measures of social desirability bias in studies is essential to assess the validity of the findings (Van de Mortel, 2008). This approach may help determine the extent to which the responses from young people are influenced by the desire to conform to socially acceptable norms (Camerini & Schulz, 2018). As a result, the association between a social desirability bias measure and DRA measures are assessed in this study.

The main objective of this exploratory cross-sectional study was to assess the determinants of DRA in British adolescents using descriptive statistics, regression analyses, and SEM.

The primary objectives of this study were:

1. To identify demographic groups that are more susceptible to negative DRA.

2. To establish whether there are modifiable factors associated with DRA.

The secondary objectives of this study were:

1. To determine the relationship between ageist beliefs and DRA.

2. To report the agreement between different measures of DRA.

3. To identify the quantity of contact with dementia and whether different contact experiences are generally positive or negative.

4. To establish the level of dementia knowledge in British adolescents.

5.2 Hypotheses

The models are guided by theorised relationships and frameworks from prior chapters, and findings from Chapter 4. Thus, modifiable factors are hypothesised to be more

influential than non-modifiable factors. Chapter 4 also demonstrated that affective and prosocial intention related empathy were more strongly associated with DRA than cognitive empathy. This aligned with the developmental literature on empathy, and with the empathy-altruism hypothesis (Batson et al., 1991; Van de Graaff et al., 2018). It is hypothesised that this finding will be replicated (Hassan et al., 2023a). Moreover, contact and empathy are expected to be key mediators, replicating the findings from Chapter 4. If contact and empathy are key mediators, this would underscore its importance in DRA and its potential role in future anti-stigma initiatives. Appendix N provides a full list of hypotheses and the theoretical frameworks underlying the selected SEM pathways for this study.

5.3 Methods

5.3.1 Study design

The study is a quantitative cross-sectional design consisting of a series of explicit questionnaires administered between February 2023 and April 2023. Adolescents aged 11-18 from secondary schools across England completed a series of questionnaires relating to DRA and demographic information.

5.3.2 Study setting and sample

The inclusion criteria for participants were: A) aged 11-18 years, reflecting the ages of secondary and sixth-form pupils in England; B) attending a mainstream secondary school/sixth-form in England (with consent from a gatekeeper such as a headteacher), and C) having obtained parental consent (opt-in/opt-out) to participate in the study. Exclusion criteria were adolescents: A) in non-mainstream schools (e.g., special educational needs schools) and B) those unable to consent (as determined by the school). Schools were initially contacted via email using public contact information. An inclusive recruitment criterion was employed to address the homogeneity limitation in the literature (see Chapter 3, section 3.4.1 – methodological considerations), by seeking diverse ethnic groups, socioeconomic status, and attainment, to increase the generalisability of findings. The age range was selected to reflect the definition of adolescence in the context of secondary and sixth forms in

England (UK Government, 2014). Schools from regions with established research collaboration links and prior outreach contacts were also included.

Of the 305 schools contacted, 273 schools did not respond to the invitation between November 2022 and March 2023, while 21 schools refused to participate. Reasons given were lack of capacity to support the study due to staff shortages (nine schools), and time pressures resulting from a tight curriculum (three schools).

In total, 11 schools initially consented to participate in the study. However, two of these schools later withdrew without providing a reason. As a result, nine schools across six regions of England participated (see Appendix P for school characteristics). In total, 1,625 adolescents aged 11-18 were approached, with 1,453 providing written consent to participate. Of these, 134 participants opened the questionnaire link but did not complete it. There were 120 participants who did not consent to data processing or participation. Only three of the nine participating schools included students under the age of 13 due to opt-in requirements. Five schools distributed the questionnaires opportunistically, while four selected specific classes (tutor groups or PSHE classes). From the parental opt-out procedures, only one parent opted out. Questionnaires were considered valid for data processing if the consent form was completed.

5.3.3 Public Patient Involvement (PPI) and pilot testing

Two groups were consulted in the study design; 1) Individuals with dementia experience (n=6) through the Sussex Partnership NHS Trust lived experience advisory panel (LEAP), and 2) adolescents (n=3). These groups guided outcome choices and suggested adding resources to the debrief form for participants interested in learning more about dementia. Both groups were compensated for their time. The consultation involved an online meeting organised by the Sussex PPI lead, covering study design, the wording and appropriateness of the information sheet for gatekeepers and guardians, and the debrief form. The two groups felt that contextualising experiences of dementia in adolescents would also be useful. As a result, this was an added outcome in an exploratory and descriptive way. After data collection, the LEAP and the youth panel reflected on the findings and discussed dissemination plans, fostering an intergenerational collaborative space.

The young people panel (aged 12, 13, and 15) were recruited through the PPI dementia café initiative to pilot the questionnaire, aiming to maximise response rates and minimise psychological harm. The panel assessed the questionnaire's length, design, interpretability, potential distress, appropriateness of debriefing resources, and readability, addressing limitations identified in the scoping review in Chapter 2. The young people panel included individuals with personal experience of dementia (n=2) and one without (n=1). Minor adjustments were made to ensure inclusive language, such as using ‘them’ instead of ‘he’ or ‘she’. The group found the questionnaire and topic neither distressing nor overly emotive.

5.3.4 Ethical considerations

The study was approved by the Brighton and Sussex Medical School Research Governance and Ethics Committee (ER/BSMS9PCH/1). See Appendix C.

There were four main ethical issues to consider when recruiting adolescents. School headteachers and other senior school staff, school governors, and borough council members were consulted for their expertise on conducting such a study within the school context. Ethical considerations entailed recognising appropriate safeguarding procedures when having direct contact with adolescents, opt-in versus opt-out consent procedures, emotive topics, and strict anonymisation and confidentiality.

5.3.5 Study procedure

A total of 305 school gatekeepers were identified through publicly available information and sent an email invitation to participate in the study. Gatekeepers received a brief study overview, a detailed study information sheet, and consent procedures (UK Research Integrity Office, Code of Practice for Research, 2023). Gatekeepers provided written informed consent and facilitated survey distribution. Gatekeepers could distribute the survey online (via Qualtrics) or by pen and paper, depending on their school's resources. They also sent opt-in and opt-out consent forms (opt-in required for those under 13) and information sheets to parental guardians. The schools managed all communication with guardians and consent collection. The questionnaire link (or paper copy) was provided to participants a week before data collection (see Appendix O for participant materials). Gatekeepers determined which

year groups and classes would participate and coordinated with EH on convenient dates and times. They also specified whether data collection would be in person or remote. Two schools opted for in-person data collection with EH. A risk assessment for in-person data collection was completed by EH for each school.

On the study day, participants received an information sheet explaining their rights, including withdrawal and the risks and benefits of participation. Consent was required for participation, with participants ticking boxes on the consent form. The self-completion questionnaire included demographic information and DRA-related questions. The questionnaire took approximately 10-15 minutes to complete. All materials were in English.

Participants were given up to one month after data collection to withdraw from the study. They could do so via a withdrawal link, where they entered their unique identifier to delete their record. At the end of the questionnaire, participants received a debrief form and were entered into a prize draw for vouchers (value of £20). The use of incentives, specifically a larger number of small voucher prizes (60 prizes per time point), was intended to increase response rates without affecting data quality. This is to minimise potential coercion (Laurie & Lynn, 2009).

5.3.6 Data management

Participants created a unique identifier to enable data withdrawal, protect anonymity, and maintain confidentiality in compliance with data protection legislation (Data Protection Act, 2018 and General Data Protection Regulation, 2023 cited in UK Research Integrity of Office, 2023). The identifier included sex, birth month, number of older brothers and sisters, the second letter of their first name, and the first letter of their surname. These were chosen based on prior research demonstrating their memorability and suitability for self-generated ID studies with adolescents (Agley et al., 2021; Brändle, & Pläschke, 2024). Names and contact details were not collected to prevent direct identification. Participating schools were also anonymised and assigned a number (i.e., school 1, school 2), with only the broader region of the schools used in analyses.

5.3.7 Variables

Questionnaires were scored adhering to the guidance of their corresponding syntax (all scoring syntax information is located in Appendix K).

Demographic variables: age, sex, ethnicity, religion, and region. Age consisted of the following ages: 11, 12, 13, 14, 15, 16, 17, and 18. Participants were asked what sex they were assigned to at birth (male or female). The variable sex was categorical and dichotomous. Categories for ethnicity comprised of White British, Black, South Asian, East Asian, Middle Eastern, Mixed background, Other ethnic background, and 'I do not want to answer'. The categories selected were based on the UK government census (Office for National Statistics, 2023a,b,c). The categories for religion consisted of no religion, Christian, Muslim, Sikh, Hindu, Buddhist, Jewish, other religion, and 'I do not want to answer'. Categories for the region included Bedfordshire, Hertfordshire, East Sussex, Devon, West Midlands, and Leicestershire.

Heard of dementia: a single-item question asking participants whether they have heard of the term dementia or Alzheimer's disease before (Baker et al., 2019). Those who had not heard of these terms before were not required to complete the questionnaire to reduce the chance of social desirability responding. See Chapter 4, section 4.2.3 for further information about this measure.

The Adolescent Level of Contact with Dementia (ALOCD): ALOCD is a validated measure ($\alpha = .86$) on the level of contact adolescents have with dementia (Parveen et al., 2020b). See Chapter 4, section 4.2.3 for further information about this measure.

The Northern Ireland Life and Times Survey (NILTS): The NILTS (Dowds et al., 2010) captures a national representation of social attitudes. A module of the survey is 'Knowledge of dementia' which consists of true or false statements related to knowledge of dementia. Participants select either 'True', 'False' or 'Don't Know' (McParland et al., 2012). Seven true or false statements relating to dementia knowledge were used. Other knowledge scales such as the Alzheimer's Disease Knowledge Scale were not deemed appropriate for this study compared to the NILTS due to having a 30-item scale which would cause a disproportionate burden on young

people. Moreover, the NILTS was most appropriate in terms of simplistic wording and ability for the targeted demographic to understand.

The Empathy Questionnaire for Children and Adolescents (EmQue-CA): The EmQue-CA (Overgaauw et al., 2017) is a validated measure of adolescent empathy that consists of components, 'affective empathy', 'cognitive empathy' and 'intention to comfort'. See Chapter 4, section 4.2.3 for further information about this measure.

The Relational Ageism Scale (RAS): The 'collective affinity for older people' subscale of the Relational Ageism Scale (RAS) (Gendron, Inker, Andricosky, & Zanjani, 2020) is a 5-item measure of ageism. Each item is composed of a 5-point Likert response (1 – strongly agree to 5 – strongly disagree). The collective subscale is most in line with public stigma frameworks. An example question is 'I enjoy talking with older people'. Higher scores indicate higher levels of ageism. The measure demonstrates very good internal consistency ($\alpha = 0.88$) with the collective ageism subscale specifically demonstrating internal consistency ($\alpha = 0.83$).

The Brief version of the Adolescent Attitudes Towards Dementia Scale (Brief A-ADS): The Brief A-ADS is a validated measure consisting of 13 items (Farina et al., 2022). See Chapter 4, section 4.2.3 for further information about this measure.

Attribution Questionnaire Children's version (AQ-8-C): the AQ-8-C is a shorter, modified eight-item children's version of the validated AQ-27 Attribution questionnaire of public stigma towards mental illness (Corrigan et al., 2003), designed for ages 10-18 years old (Watson et al., 2004). The AQ-8-C represents the attribution constructs (i.e., beliefs, emotional, and behavioural) on a nine-point Likert scale ranging from 1 (not at all) to 9 (very much). Higher scores indicate more stigmatising attitudes. Participants responded to the items about a vignette (see Appendix O) that was adapted from the AQ-8-C. This is where 'mental illnesses' was replaced with 'dementia' and 'a new student' replaced with 'an older family friend'. The attribution questionnaire demonstrated generally acceptable internal and test-retest reliability in college-age students ($\alpha = .55$ to $\alpha = .87$) (Corrigan, Watson, Warpinski, & Garcia, 2004). Since there are no standard dementia-specific theoretical frameworks, the

Attribution framework of mental illness is most commonly used and adapted to make it relevant to dementia.

Willingness to work in dementia-related career paths: a single item ("I would be willing to work with people with dementia") captures behavioural intention to pursue a career working with people with dementia. See Chapter 4, section 4.2.3 for further information about this measure.

Experience of dementia (quality of contact with dementia): No existing validated measures capture the quality of adolescents' contact with dementia (whether it is a generally positive or negative experience). To address this, a 5-item survey was created for this thesis. Participants indicated whether their experience of dementia was generally positive or negative across five statements, such as 'My experience of looking after someone living with dementia is...'. Two items assessed how dementia is represented in the media, given its potential influence on attitudes. Participants responded on a 4-point Likert scale ranging from 0 = 'I have not experienced' to 3 = 'Don't know'. The five items showed good internal consistency (α = .70). The statements derived from the ALOCD items (items 2,5,6,8, and 10) and PPI feedback.

Brief Social Desirability Scale (BSDS): The BSDS (Haghighat, 2007) is a validated, reliable instrument, free from sex specificity and designed to measure social desirability in attitudinal questionnaires. It consists of four items on a two-point Likert scale ('Yes' or 'No'). It is ideal for minimising participant burden compared to longer scales like the Children's Social Desirability Scale or the Marlowe-Crowne Inventory, which has 33 items (Loo & Thorpe, 2000). The BSDS has a Cronbach's Alpha of 0.70, indicating moderate reliability. Scoring more than two socially desirable answers suggests a high tendency toward social desirability. An example question is, 'If you say to people that you will do something, do you always keep your promise no matter how inconvenient it might be?'. The DRA measures are expected to positively correlate with BSDS due to explicit measures' vulnerability to social desirability bias (Van de Mortel, 2008).

5.3.8 Data analysis

A statistician was consulted on the data analysis plan. A priori sample size of 1,200 participants (allowing 20% missing data) was calculated to achieve 80% power for 5% statistical significance to detect a small effect size in the regressions and SEM. SPSS (version 28) (IMB, New York, USA) was used for data analysis. In the case of attrition, 11 variables with 850 participants could detect a small effect size (f2=0.02, GPower). IBM SPSS Amos Graphics (version 28) was used for SEM analysis. Participants who had never heard of dementia or Alzheimer's (n = 83) were excluded to remove those without formed opinions that could lead to increased social desirability responding.

To contextualise experiences and knowledge of dementia in adolescents, descriptive statistics, checks for normality, and cross-tabulations were obtained. For the variable region, the Index of Multiple Deprivation (IMD) of the Lower Layer Super Output Area (LSOA) geographic area in which the school is based, was used to classify schools into the 50% least (0) or most deprived (1) LSOAs in England (Ministry of Housing, Communities and Local Government, 2019). This was only for descriptive purposes.

Demographic categories were weighted to national data for ethnicity, sex, and age (Office for National Statistics, 2021 Census, 2023a,b,c) to ensure representation of the general public where possible. For weighting, age was categorised into two groups: 11-14 and 15-18. The weightings were grouped by sex, ethnicity, and age category (e.g., male, white British, 11-14 years old). Weighting was applied to ALOCD dichotomous items and NILTS dichotomous items to obtain 95% CI and prevalence estimates using the one-sample binominal non-parametric test. Prevalence estimates denote having had some level of contact with dementia (1). For the NILTS, prevalence estimates denote having a high level of knowledge (1).

Each statement of the ALOCD was analysed individually to determine the percentage of participants with direct/indirect contact with dementia and the frequency of that contact. For quality of contact with dementia, EH wanted to quantify the participants who had indicated that they had experience with dementia. For ease of interpretation, the quality of participants' dementia experience was dichotomised (0 = generally

negative, 1 = generally positive). For the level of dementia knowledge, each NILTS item (level of knowledge) was analysed using cross-tabulations to provide a valid percentage of how adolescents responded to each item of the NILTS. Each NILT statement was dichotomised as correct answer (1) versus other responses (0).

For the analysis concerning factors associated with DRA, insufficient error responding (IER) was managed first. The Longstring index (Wertheimer, 2017) on the Brief A-ADS was used. Cases two standard deviations above the mean (m = 6.94 ± SD. = 2.66) (n = 85) were excluded (Meade & Craig, 2012). IER cases were checked for consistency across the entire questionnaire. A missing patterns analysis using the MCAR test indicated that the Brief A-ADS, ALOCD, EmQue-CA, and AQ-8-C were statistically significant. This indicated that the data was not missing at random. This suggests monotonicity in the data, requiring multiple imputations for missing data ($p<.05$). In such cases, this can increase the likelihood of bias. A monotone method of multiple imputation was therefore required to replace missing data to retain the statistical power of the sample size (Harel et al., 2014). Cases with substantial missing data (over 50% missing) were excluded from the analysis. This left 1,044 participants in the final analysis. With 4.35% missing values across total variables, 15 iterations were used for MI using the von Hippel formula. This uses the fraction of missing information and coefficient of variation calculation (Von Hippel, 2020). A reasonable number of imputations would be between 10 and 20 (Von Hippel, 2020). For consistency, iteration 15 was used to interpret the data, as pooled data was not always available.

Descriptive statistics, checks for normality, and cross-tabulations were obtained. Two variables (AQ-8-C and ALOCD direct contact) were positively skewed but normalised with log transformation. The Brief A-ADS was not normally distributed and could not be transformed simply. However, it was still analysed due to the large sample size. To calculate whether participants had a positive or negative DRA overall, the Brief A-ADS numerical values were used to (1=strongly disagree, 5=strongly agree) calculate the mean response score. This was then converted into a percentage (dividing mean score by maximum score and multiplying by 100). Social desirability (BSDS) was reported only for descriptive purposes due to its low reliability (α) and for the purposive of reporting the level of social desirability responding in the sample.

Validity and internal consistency checks were performed for each measure. Categorical variables were recoded into dummy variables (e.g., White British = 1, other ethnic backgrounds = 0). See Table 26. A multivariate linear regression assessed which variables (age, sex, ethnicity, religion, knowledge, direct contact, indirect contact, affective empathy, cognitive empathy, prosocial intention related empathy, and whether participants have heard of dementia or Alzheimer's disease before) were associated with DRA outcomes. The Brief A-ADS or AQ-8-C was the dependent variable. Assumptions for the regressions were met (Durbin-Watson statistic values were all between 1.5 and 2.5, plots and multicollinearity was checked, with the VIF values less than ten). An alpha of 0.05 denoted statistical significance. A bivariate Spearman's Rho (two-tailed significance) assessed associations between dependent variables (Brief A-ADS and AQ-8-C) and ageist beliefs. Assumptions for Spearman's Rho were met (the Brief A-ADS measured on an ordinal or interval scale, represented paired observations with a monotonic relationship, and there were no extreme outliers).

A multivariate logistic regression was conducted to assess willingness to work with people with dementia (dichotomous variable). The odds ratio provided percentages indicating the likelihood of willingness to work with dementia (1 = yes). Assumptions to run the regression were met (Durbin-Watson statistic values were all between 1.5 and 2.5 indicating observations are independent, and plots indicated the data was homoscedastic, with plot residuals indicating normal distribution. Multicollinearity was checked, with the VIF values less than ten). An alpha of 0.05 denoted statistical significance.

SEM

To explore direct and indirect (mediation) effects between factors, a recursive path analysis via SEM using maximum likelihood estimation (CB-SEM) was employed. The model building was guided by theoretical justifications, focusing on factors most strongly predicting attitudes in earlier regression models and broader relationships outlined in previous chapters (Grønneberg & Foldnes, 2018). Having undergone multiple imputation earlier, the dataset contained no further missing values. The model incorporated three main frameworks. This includes the empathy-altruism hypothesis

(Batson et al., 1991), the intergroup contact hypothesis (Allport, 1954), and the Attribution Model of stigma (Weiner & Weiner, 1985). These frameworks underpinned the selection of latent variables: attitudes (Brief A-ADS and AQ-8-C), contact (direct and indirect ALOCD), and empathy (affective, cognitive, and prosocial EmQue-CA).

The SEM had four stages. This included testing a measurement model, model identification to assess initial model fit, model fitting following modifications and checking for direct effects, and obtaining specific indirect effects by creating specific parameter paths. Before testing the measurement model, the AQ-8-C scale was reversed to align its scoring with the Brief A-ADS, as higher scores on AQ-8-C indicated more stigmatising attitudes while higher Brief A-ADS scores indicated fewer stigmatising attitudes. This alignment allowed both scales to contribute meaningfully to a unified latent variable. Additionally, there was a significant but weak correlation between AQ-8-C and Brief A-ADS, highlighting the two measure their own unique constructs. Since the attitude latent variable was insignificant, indicating the latent variable did not adequately capture the underlying constructs of attitudes and stigma, the AQ-8-C underwent principal component analysis. This was to remove three poorly loaded items and increase alpha reliability from 0.62 to 0.82. This adjustment of the AQ-8-C from eight to five items allowed the latent variable to represent attitudes significantly. However, with more items, the Brief A-ADS contributed more variance to the construct. This was likely due to the Brief A-ADS comprising of 13 items versus five items from AQ-8-C.

Attitudes, contact and empathy were then set as latent variables (unobserved endogenous) with their associated scales set as observed endogenous variables: attitudes (Brief A-ADS and AQ-8-C), contact (direct and indirect contact subscales) and empathy (affective, cognitive and prosocial subscales). Sex (observed exogenous) and willingness to work with people with dementia (observed endogenous) were set as observed variables. A categorical item indicated sex and willingness to work with people with dementia, while ageism, age, and knowledge were continuous variables (in line with the regressions).

To manage measurement error, error terms were added to all variables except sex. Covariance decisions for error terms were based on modification indices provided by AMOS, and theoretical justification (Bollen, 1989). For example, AQ-8-C was covaried with NILTS due to overlapping constructs related to understanding, and prosocial intention related empathy was covaried with willingness to work with people with dementia, reflecting their shared focus on prosocial motivation.

Due to non-normal data, a bootstrapping procedure (100,000 samples) was applied (Nevitt & Hancock, 2001). Standardised coefficients, standard error, and 95% bias-corrected CI (100,000 bootstrap samples) were reported for direct and indirect effects (Cheung & Lau, 2008), and to obtain more accurate estimations of the low and upper limits of the CI (Wagstaff, Elek, Kulis, & Marsiglia, 2009). Parallel to the SEM in Chapter 4, assessing the overall model fit was the central purpose of SEM (Grønneberg & Foldnes, 2019). As latent variables were used, the path analysis via SEM was applied using the maximum likelihood estimation with the data set to fit the saturated and independent models. The Bollen-Stine bootstrap was utilised to provide a goodness-of-fit statistic for the model fit (100,000 bootstrap samples). A p-value above 0.05 indicates a good fit (Corrêa Ferraz et al., 2022).

For further methodological specifics, please refer to Appendix Q.

5.4 Results

5.4.1 Descriptives

There were 1,625 participants recruited for the study. After removing non-consents, and those who had not heard of dementia or Alzheimer's disease before (n = 83), 1,371 participants remained eligible in the analysis. Out of 1,371 participants, 994 participants had 100% questionnaire completion rate. At this stage of the analysis, participants were 14 years old on average (SD = 1.04) and roughly an equal number of females (48.1%, n = 660) and males (51.9%, n = 711). 55.9% (n = 767) identified as White British followed by South Asian (22.2%, n = 304). Adolescents were predominantly from neighbourhoods in regions that ranked amongst the 10-50% most deprived LSOAs (70.6%, n = 959) compared to the adolescents amongst the 20-50%

least deprived LSOAs (29.4%, n = 412). Nearly half of the adolescents identified as having no religious beliefs (48.0%, n = 654). See Table 26.

From 1,209 adolescents, weighted prevalence estimates demonstrated that 69% of adolescents (n = 834, 95%CI .66 to .72) have come across people living with dementia. The most frequent affirmative responses were related to watching a TV show or movie about dementia where from 1206 adolescents, 75% of adolescents (n = 905, 95%CI .73 to .78) indicated they had. Additionally, from 1,204 adolescents, 75% of adolescents (n = 903, 95%CI .72 to .77) indicated they had come across adverts about dementia. The least frequently reported experience of dementia was looking after someone with dementia where from 1205 adolescents, 30% of adolescents (n = 362, 95%CI .27 to .32) indicated they had. See Table 27 (weighting was applied to ALOCD dichotomous items).

Of those who indicated that they had previous experience with dementia, the majority of people who spent time with someone with dementia felt it was generally a positive experience (90.8%, n = 394). Similar positive experiences were held for people who have looked after someone with dementia (82.3%, n = 214). However, far fewer had positive experiences when speaking to family and friends about dementia (47.0%, n = 255). See Table 28. Of the 518 adolescents who had come across dementia via social media, just under a third of adolescents (31.7%, n = 164) felt the representation of dementia on social media was generally negative. Out of 555 adolescents who had indicated that they had seen a person with dementia represented in TV or film, a greater number of adolescents reported that representation was generally negative (54.2%, n =301). See Table 29.

Adolescents correctly answered just under half of the NILTS statements (m = 48%, SD = .20). 57.3% (n = 785) of adolescents answered more than four items correctly (weighted prevalence estimates for those with high dementia knowledge = .57, n = 1,329, 95%CI .54 – .59). The item most frequently correctly answered was that dementia is a disease of the brain (72.1%, n = 989). The item least frequently answered correctly was dementia is a mental illness (30.0%, n = 411). See Table 30 (weighting was applied to NILTS dichotomous items).

Table 26 - Chapter 5 Demographics and Descriptive statistics (n=1371)

Demographics		Valid %	M ± SD	N
Region				**1371**
	50% most deprived LSOAs – Bedfordshire, Leicester, Devon, and West Midlands (1)	70.6%,		959
	50% least deprived LSOAs – East Sussex and Hertfordshire (0)	29.4%		412
	Bedfordshire	52.2%		716
	Leicestershire	5.9%		81
	East Sussex	23.2%		318
	Hertfordshire	6.9%		94
	Devon	10.6%		146
	West Midlands	1.2%		16
School				**1371**
	School 1	33.0%		452
	School 2	16.1%		221
	School 3	3.1%		43
	School 4	8.4%		115
	School 5	6.9%		94
	School 6	10.6%		146
	School 7	14.8%		203
	School 8	5.9%		81
	School 9	1.2%		16
Sex				**1371**
	Female	48.1%		660
	Male	51.9%		711
Age			14.28 ± 1.04	**1366**
	11	1.1%		15
	12	0.7%		9
	13	20.4%		278
	14	38.1%		521
	15	28%		382
	16	11.1%		152
	17	0.1%		2
	18	0.5%		7

Continued. Table 26 - Chapter 5 Demographics and Descriptive statistics (n=1371)

Ethnicity			**1371**
	White	55.9%	767
	Black	5.1%	70
	South Asian	22.2%	304
	East Asian	2%	28
	Middle Eastern	1.5%	21
	Mixed or multiple ethnic backgrounds	7.3%	100
	Other	2.3%	31
	I do not want to answer	3.6%	50
Religion			**1363**
	No religion	48%	654
	Christian	20.2%	275
	Buddhist	0.5%	7
	Hindu	7.6%	103
	Jewish	0.5%	7
	Muslim	14.2%	195
	Sikh	1.4%	19
	Other religion	0.6%	8
	I do not want to answer	7%	95

Table 27 - Level of contact percentage breakdown of responses

	Response							One sample binominal test prevalence estimate		
ALOCD items	**Never**	**Rarely**	**Occasionally**	**A moderate amount**	**A great deal**	**N**	**Missing**	**Yes (1)**	**Prevalence Weighted**	**95% CI Weighted**
I have come across people living with dementia	35.5% (n = 429)	28.5% (n = 345)	20.3% (n = 246)	8.8% (n = 106)	6.9% (n = 83)	1209	162	.65 (n = 780)	.69	.66 – .72
I have spent time with people living with dementia	54.3% (n= 656)	18.5% (n = 223)	11.6% (n = 140)	8.1% (n = 98)	7.5% (n = 90)	1207	164	.46 (n = 511)	.52	.49 – .55
I have spent time with a family friend who is living with dementia	67.6% (n = 814)	16.0% (n = 193)	7.7% (n = 93)	4.1% (n = 49)	4.6% (n = 56)	1205	166	.32 (n = 391)	.36	.33 – .38
I have spent time with a family member living with dementia	58.5% (n = 706)	14.6% (n = 176)	10% (n = 121)	8.6% (n = 104)	8.2% (n = 99)	1206	165	.42 (n = 500)	.48	.45 – .51
I have looked after someone living with dementia	73.4% (n = 884)	12.0% (n = 144)	5.8% (n = 70)	4.2% (n = 51)	4.6% (n = 56)	1205	166	.27 (n = 321)	.30	.27 – .32
I have watched TV shows or movies in which the character has dementia	26.4% (n = 318)	32.3% (n = 388)	23.5% (n = 284)	10.5% (n = 127)	7.4% (n = 89)	1206	165	.74 (n = 888)	.75	.73 – .78
I have come across adverts about dementia	28.8% (n = 347)	28.6% (n = 344)	26.8% (n = 323)	11.2% (n = 135)	4.6% (n = 55)	1204	167	.71 (n = 857)	.75	.72 – .77
I have come across people living with dementia on social media	33.1% (n = 398)	29.0% (n = 350)	22.8% (n = 275)	11% (n = 133)	4.1% (n = 50)	1206	165	.67 (n = 808)	.69	.66 – .71
I have searched for information on dementia on the internet	54.1% (n = 651)	23.8% (n = 287)	14.8% (n = 178)	5.1% (n = 62)	2.2% (n = 27)	1205	166	.46 (n = 554)	.46	.44 – .49
I have spoken with family or friends about dementia	46.3% (n = 559)	17.9% (n = 216)	19.1% (n = 231)	10.8% (n = 130)	5.9% (n = 71)	1207	164	.54 (n = 648)	.58	.55 – .61

Note. ALOCD (Adolescents level of contact with dementia). The percentage frequencies denote valid percent. Each item was dichotomised as yes (1) versus never (0). One sample binominal test prevalence estimate for 'Yes' (1) is the unweighted proportion. The prevalence estimate and 95% CI is weighted.

Table 28 - Cross-tabulation of the responses for negative and positive quality of contact with dementia items

		Cross tabulation		
Contact type	**Quality of contact with dementia item**	**Generally Negative (0)**	**Generally Positive (1)**	**Total n**
Direct contact	When I have spent time with people with dementia my experience has been:	9.2% (n = 40)	90.8% (n = 394)	434
	My experience of looking after someone living with dementia:	17.7% (n = 46)	82.3% (n = 214)	260
	When I have heard family or friends talk about dementia it is:	53.0% (n = 287)	47.0% (n = 255)	542
Indirect contact	When I have come across dementia on social media, the person is represented:	31.7% (n = 164)	68.3% (n = 354)	518
	In tv or film I feel that the person with dementia was represented as:	54.2% (n = 301)	45.8% (n = 254)	555

Note. % = valid percentage in cross tabulations. Outcome variable: Quality of contact with dementia items. N = sample size. Dichotomous variables coded as 0 versus 1.

Table 29 - Percentages of how adolescents responded to each item of the NILTS

NILTS statements	Correct answer (1)	Other response (0)	Total N	One sample binominal test weighted estimate (n = 1329)	95% CI
1. Dementia is a disease of the brain (T)	72.1% (n = 989)	27.9% (n = 382)	1349	.75	.72 – .77
2. Dementia is a mental illness (F)	30.0% (n = 411)	70.0% (n = 960)	1340	.32	.29 – .34
3. Dementia is a normal process of ageing (F)	52.9% (n = 725)	47.1% (n = 646)	1340	.58	.55 – .60
4. Dementia is another term for Alzheimer's Disease (F)	36.0% (n = 493)	64.0% (n = 878)	1342	.40	.38 – .43
5. People who eat healthily and exercise are less likely to get dementia (T)	46.0% (n = 631)	54.0% (n = 740)	1342	.42	.39 – .45
6. There are many different kinds of dementia (T)	39.7% (n = 544)	60.3% (n = 827)	1342	.51	.48 – .54
7. Dementia can be cured (F)	59.6% (n = 817)	40.4% (n = 554)	1341	.67	.65 – .70

Note. NILTS (Northern Ireland's Life and Times Survey). (T) = True, (F) = False. The percentage frequencies denote valid percent. Each NILT statement was dichotomised as correct answer (1) versus other responses (0).
The sample number is presented as (n). Weighted prevalence estimates with 95% confidence intervals (CI) are presented for each statement.

Following data cleaning procedures, 1,044 students remained in the next stage of the analysis (regressions and SEM). The Little's MCAR test (missing values analysis) suggested that the data was not missing at random (χ^2, $p > 0.05$). On average, participants were 14.3 years old (SD = 1.00), roughly equal number of females (50.6%) and males (49.4%), and 58.7% identified as White British. Over half of the adolescents identified as having no religious beliefs (52%). Table 30 outlines the descriptive statistics obtained.

Table 30 - Chapter 5 Descriptive statistics (n = 1044)

Variables	Categories	N (valid %)	M ± SD
Region			
	Bedfordshire	551 (52.8%)	
	Leicestershire	76 (7.3%)	
	East Sussex	257 (24.6%)	
	Hertfordshire	69 (6.6%)	
	Devon	78 (7.5%)	
	West Midlands	13 (1.2%)	
School			
	School 1	375 (35.9%)	
	School 2	138 (13.2%)	
	School 3	38 (3.6%)	
	School 4	95 (9.1%)	
	School 5	69 (6.6%)	
	School 6	78 (7.5%)	
	School 7	162 (15.5%)	
	School 8	76 (7.3%)	
	School 9	13 (1.2%)	
Sex			
	Female (0)	528 (50.6%)	
	Male (1)	516 (49.4%)	

Continued. Table 30 - Chapter 5 Descriptive statistics (n = 1044)

Age			14.32 ± 1.00
	11	7 (0.7%)	
	12	8 (0.8%)	
	13	204 (19.5%)	
	14	397 (36.3%)	
	15	316 (30.3%)	
	16	127 (12.2%)	
	17	2 (0.2%)	
	18	1 (0.1%)	
Ethnicity (dichotomised)			
	White (1)	613 (58.7%)	
	All other ethnic background (0):	431 (41.3%)	
	Black	46 (4.4%)	
	South Asian	235 (22.5%)	
	East Asian	20 (1.9%)	
	Middle Eastern	14 (1.3%)	
	Mixed or multiple ethnic backgrounds	77 (7.4%)	
	Other	18 (1.7%)	
	‘I do not want to answer’	21 (2.1%)	
Religion (dichotomised)			
	No religion (1)	52%	
	All other religions (0):	48%	
	Christian	199 (19.1%)	
	Buddhist	3 (0.3%)	
	Hindu	89 (8.5%)	
	Jewish	5 (0.5%)	
	Muslim	130 (12.5%)	
	Sikh	15 (1.4%)	
	Other religion	5 (0.5%)	
	‘I do not want to answer’	55 (5.2%)	

Continued. Table 30 - Chapter 5 Descriptive statistics (n = 1044)

Whether participants have heard of either Alzheimer's Disease or Dementia (dichotomised)	I have heard of only one of these terms (0)	223 (21.4%)	
	I have heard of both terms (1)	821 (78.6%)	
Empathy: The Empathy Questionnaire for Children and Adolescents	EmQue-CA total		23.42 ± 6.41
Contact: Adolescent level of contact towards dementia scale	ALOCD total		19.90 ± 7.56
Ageism: The Relational Ageism Scale	RAS total		11.10 ± 3.76
Knowledge: Northern Irelands life and times survey	NILTS total correct %		53% (0.53 ± 0.21)
	Low knowledge (below 50%)	453 (43.4%)	
	Good knowledge (above 50%)	591 (56.6%)	
Stigma: Attribution questionnaire 8 items – children's version	AQ-8-C total		28.07 ± 8.32
	AQ-8-C Log^{10} transformed total		1.43 ± 0.12
Brief Adolescent attitudes towards dementia scale	Brief A-ADS total		48.2 ± 6.67
Brief Social Desirability Scale (dichotomised)	BSDS (low social desirability tendency)	873 (83.6%)	
	BSDS (high social desirability tendency)	171 (16.4%)	

5.4.2 Internal consistency

The AQ-8-C (α = .66) and BSDS (α = .39) demonstrated inadequate internal consistency. All other measures demonstrated good or excellent reliability. See Table 31.

Table 31 - Internal consistency of measures (Chapter 5)

Measures	Cronbach's Alpha	Cronbach's Alpha (Standardised Items)	Items (n)
Brief A-ADS	.86	.86	14
ALOCD Total	.86	.86	10
ALOCD (direct contact)	.91	.91	5
ALOCD (indirect contact)	.74	.74	5
Experience of Dementia	.78	.78	5
EmQue-Ca	.88	.88	18
RAS	.90	.90	5
AQ-8-C	.63	.66	8
BSDS	.40	.39	4

Note. Brief A-ADS: Brief Adolescent attitudes towards dementia scale; ALOCD; Adolescent level of contact towards dementia scale; EmQue-Ca: The Empathy Questionnaire for Children and Adolescents; RAS: Relational Ageism Scale; AQ-8-C: Attribution Questionnaire-8 items Children's version; BSDS: Brief Social Desirability Scale. Cronbach's Alpha (α) of .70 or above indicates good to excellent internal consistency.

5.4.3 The agreement between different measures of DRA

The AQ-8-C and Brief A-ADS demonstrated a weak negative correlation (r_s = -.13, p<0.001).

5.4.4 Determining the relationship between ageist beliefs and DRA

With a sample of 1044, the bivariate Spearman's Rho correlation revealed a significant negative association between RAS and the Brief A-ADS, r_s = -.44, p<.001, 95% CI -.49 – -.39. A Pearson's correlation revealed that the RAS and AQ-8-C were significantly, positively associated (r = .08, p = .01, 95% CI .02 – .14).

5.4.5 Identifying demographic groups who are more susceptible to negative DRA and establish whether there are modifiable factors associated with DRA

Regression model: Brief A-ADS

The multiple linear regression of all predictor variables (k = 12; sex, age, indirect contact, direct contact, affective empathy, cognitive empathy, prosocial intention related empathy, ageism, knowledge, ethnicity, religion, and whether have heard of the terms Alzheimer's or Dementia) significantly fitted to the model where the Brief A-ADS was the outcome, $F(12, 1031) = 38.70$, $p<.001$. A small but significant amount of variance in the Brief A-ADS scores were explained by the model fit, R^2 adjusted = .30. Within the model, being older was associated with having negative dementia attitudes (Brief A-ADS*;* $p<.001$). Higher levels of dementia knowledge ($p<.001$), higher levels of affective ($p = .01$) and prosocial intention related empathy ($p = .00$), and higher levels of indirect contact ($p<.001$) were significantly, positively associated with Brief A-ADS. Higher levels of ageist beliefs were associated with negative dementia attitudes ($p<.001$).

Regression model: AQ-8-C

The multiple linear regression of all predictor variables (k = 12; sex, age, indirect contact, direct contact, affective empathy, cognitive empathy, prosocial intention related empathy, ageism, knowledge, ethnicity, religion, and whether have heard of the terms Alzheimer's or Dementia) significantly fitted to the model where the AQ-8-C was the outcome, $F(12, 1031) = 3.78$, $p<.001$. A small but significant amount of variance in the AQ-8-C scores were explained by the model fit, R^2 adjusted = .03. Within the model, increasing age ($p<.001$), higher levels of indirect contact ($p = .01$), increased affective empathy ($p = .00$), and lower levels of ageism ($p = .00$) had positive relationships with AQ-8-C. Within the model, being older denoted significantly higher levels of stigma towards dementia.

Table 32 provides the multivariate linear regression for the Brief A-ADS and the AQ-8-C.

Table 32 - Multivariate linear regression for variables predicting Brief A-ADS and the AQ-8-C scores

Predictor variables	Multivariate linear regression (n = 1043)							
	Brief A-ADS (*p*<.001)				AQ-8-C (*p*<.001)			
	β	**B**	***p***	**CI [95%]**	**β**	**B**	***p***	**CI [95%]**
Sex: Male	-.04	-.46	.21	-1.18 – .26	-.03	-.01	.44	-.02 – .01
Age	-.06	-.38	.03*	-.72 – -.03	.11	.01	<.001***	.01 – .02
Indirect contact	.21	.36	<.001***	.26 – .46	.10	.00	.001**	.00 – .01
Affective empathy	.10	1.78	.01*	.54 – 3.01	.13	.04	.00**	.01 – .07
Prosocial intention empathy	.12	1.97	.00**	.70 – 3.24	-.08	-.03	.07	-.05 – .00
Cognitive empathy	.05	.73	.25	-.52 – 1.98	-.08	-.02	.09	-.05 – .00
Ageism	-.33	-.58	<.001***	-.67 – -.48	.10	.00	.00**	.00 – .01
Direct contact	.00	.05	.96	-1.83 – 1.92	-.05	-.03	.15	-.07 – .01
Knowledge	.13	4.11	<.001***	2.37 – 5.85	.05	.03	.12	-.01 – .07
Ethnicity: all other ethnic backgrounds	.02	.32	.46	-.53 – 1.17	-.03	-.01	.47	-.03 – .01
Religion: all other religions	-.06	-.80	.06	-1.62 – .03	.01	.00	.79	-.02 – .02
Heard of dementia or Alzheimer's: heard of both terms	-.05	-.79	.07	-1.66 – .08	-.00	-.00	.92	-.02 – .02

Outcome variable: Brief A-ADS and AQ-8-C. Statistical significance (*p*): * = *p* < 0.05; ** = *p* < 0.01; * *p* = < 0.001. Dichotomous variables are coded as 0 versus 1 (1 denotes the comparator). *B* = unstandardised beta coefficient, *β* = standardised beta coefficient; CI = confidence interval (lower – upper bound) [95%]**

5.4.6 Willingness to work with people with dementia

All 12 variables (sex, age, indirect contact, direct contact, affective empathy, cognitive empathy, prosocial intention related empathy, ageism, knowledge, ethnicity, religion, and whether have heard of the terms Alzheimer's or Dementia) were entered into a multiple logistic regression model which revealed a good fit, $\chi^2(12, 1044) = 140.04$, $p<0.001$. The model accounted for approximately 17% (Nagelkerke R^2) of the variance in willingness to work with people with dementia. The model correctly classified 69.2% of cases. Within the model, for each additional increase of one year in age is associated with 22% decrease in the odds of being willing to work with people with dementia ($p = .01$). Prosocial intention related empathy ($p = .03$) and indirect contact ($p<.001$) were positively associated with willingness to work people with dementia. Ageist beliefs and having heard of both Alzheimer's disease and dementia were statistically, negatively associated with willingness to work with people with dementia *(*$p<.001$ and $p= .03$, respectively). All other variables were not statistically significant ($p>0.5$). Table 33 provides the multivariate linear regression for this outcome variable.

Table 33 - Multivariate logistic regression for variables predicting the likelihood of willingness to work with people with dementia (Chapter 5)

	Multiple logistic regression (n = 1044)			
Predictor variables	**B**	**Odds ratio: Exp (B)**	***p***	**CI [95%]**
Sex: Male	-.25	.78	.09	.59 – 1.04
Age	-.18	.83	.01*	.73 – .96
Indirect contact	.11	1.11	<.001***	1.07 – 1.16
Affective empathy	-.39	.68	.11	.42 – 1.10
Prosocial intention empathy	.56	1.74	.03*	1.06 – 2.87
Cognitive empathy	.24	1.28	.34	.78 – 2.10
Ageism	-.16	.86	<.001***	.82 – .89
Direct contact	-.41	.67	.28	.32 – 1.39
Knowledge	.18	1.20	.60	.60 – 2.39
Ethnicity: all other ethnic backgrounds	-.27	.77	.12	.55 – 1.07
Religion: all other religions	-.06	.95	.74	.69 – 1.31
Heard of dementia or Alzheimer's: heard of both terms	-.38	.69	.03*	.49 – .96

Outcome variable: Willingness to work with people with dementia. Statistical significance (*p*): * = *p* < 0.05; ** = *p* < 0.01; * *p* = < 0.001. Dichotomous variables are coded as 0 versus 1. B = unstandardised beta coefficient; Exp (B) = odds ratio; CI = confidence interval (lower – upper bound).**

5.4.7 SEM

Due to their significance in the regression models, the following predictor variables were taken forward to the SEM: age, contact, empathy, ageism, and knowledge. Sex was also added to the model due to prior empirical evidence of the role of sex on attitudes through mediatory mechanisms (demonstrated in Chapter 4 – 'Gender', section 4.5.1).

5.4.7.1 SEM - testing a measurement model

The measurement model was recursive (n = 1044) (100,000 bootstraps). Overall fit for the model was marginally inadequate (see Table 20 for fit indices), $\chi^2(11) = 52.22$, $p < 0.001$. Other indicators suggested that the fit was good but could be improved overall; AGFI = .96, RMSEA = .06, Pclose = .14, TLI = .96, GFI = .99 and CFI = .98. Figure 8 provides the standardised estimates for the measurement model.

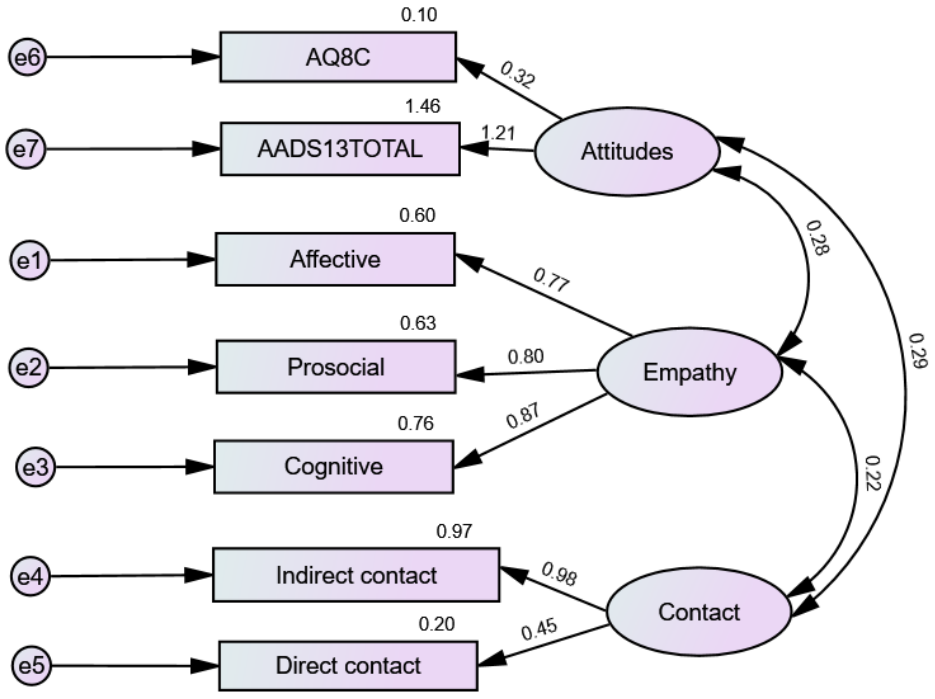

Figure 8 - Standardised estimates for the measurement model

The measurement model displays the pathway between latent variables (attitudes, empathy, and contact) and the measures relating to those constructs. The standardised coefficients represent the strength and direction between the latent variables and their corresponding variables. There is a bidirectional arrow between the latent constructs which represents correlation or covariance between the constructs.

As a result, modification indices were checked and applied to the measurement model before assessing how well the indicators were measuring their latent variable constructs. Only selecting the correlations that impact the model the most is advised as adding all covariates can lead to overfitting the model. This can be misleading (Bollen 1989). Thus, e6 and contact were covaried with each other, as well as e2 and contact, as seen in Figure 9. The theoretical measurement justification for these decisions include that the AQ-8-C has items such as "how likely is it you would help Charlie" which also shares the underpinning of prosocial motivation to 'help' in the latent empathy items such as prosocial intention related empathy. An example prosocial item is "if a friend has an argument, I try to help". In the AQ-8-C, the item "I would try to stay away from Charlie" insinuates contact with the person with dementia via avoidance behaviour. In the ALOCD, there are five items of direct contact with dementia. Moreover, theoretical frameworks help explain the theoretical justification for these decisions in the measurement model. The intergroup contact hypothesis (Allport, 1954) suggests contact can reduce prejudice (contact covaried with stigma). Contact with those with dementia can also lead to increased empathy, and reduced prejudice and stigma (contact covaried with prosocial intention related empathy).

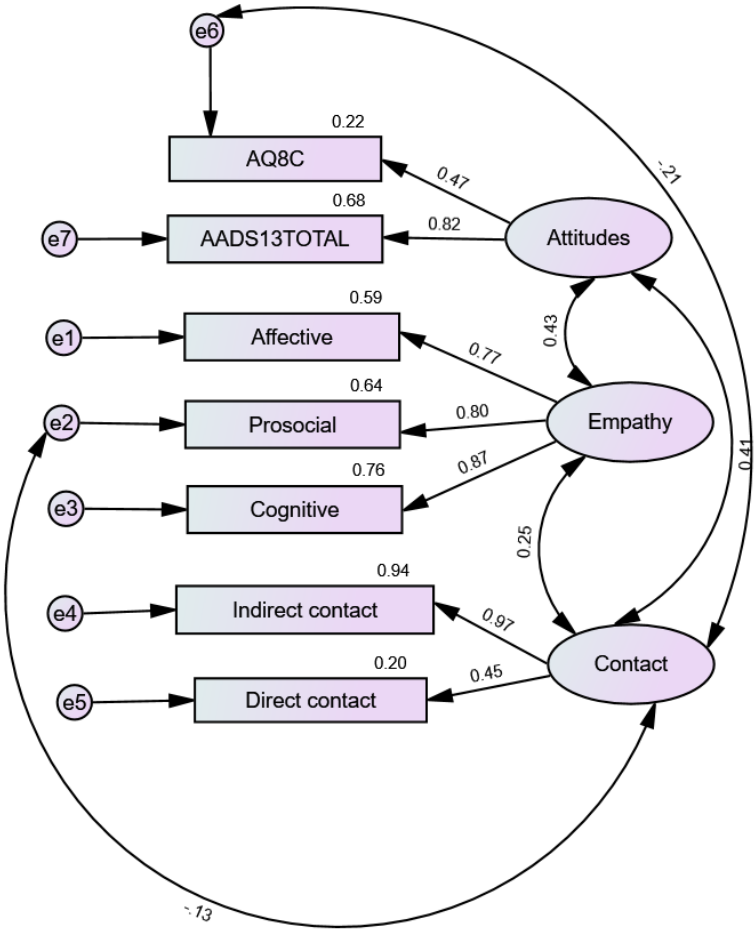

Figure 9 - Standardised estimates for the measurement model with the modifications

The modified measurement model displays the pathway between latent variables (attitudes, empathy, and contact) and the measures relating to those constructs. The standardised coefficients represent the strength and direction between the latent variables and their corresponding variables. There is a bidirectional arrow between the latent constructs which represents correlation or covariance between the constructs. There are covaried relationships between error terms and latent constructs (e.g., e2 and contact), highlighting that prosocial empathy items relate to the construct contact.

With the modifications, the overall fit of the model was very good with several indicators of a very close fit, $\chi^2(9) = 12.18$, $p = .20$, CMIN/DF = 1.35, CFI = 1.00, GFI = 1.00, AGFI = .99, TLI = 1.00, RMSEA = .02, Pclose = .99. The Bollen-Stine ($p = .23$) suggested that goodness of fit of the model was very good. The measurement model was accepted to proceed with running the path models. The maximum

likelihood estimates suggested that the factor loadings were statistically significant between the indicator variables and their respective factors (p<.001). All observed variables were found to be adequate indicators of their latent factors (all other factor loadings ranged in magnitude from .45 to .97, all with p < 0.001). Notably, squared multiple correlations suggested that the latent variable *attitudes* accounted for a higher proportion of variance in the Brief A-ADS (r = .68) compared to the AQ-8-C (r = .22). The latent variable *contact* accounted for a small proportion of variance in direct contact (r = .21) compared to indirect contact (r = .94). As the model fit was acceptable, the measurement model was accepted without further modifications.

5.4.7.2 Model building – exploratory model I

The initial model building of the SEM was to test the model fit and to make further modifications if necessary before accepting the model to test the direct and indirect paths. The overall fit for the model was inadequate, $\chi^2(44) = 170.75$, p <.001. Other indicators such as the RMSEA suggested the fit could be improved; RMSEA = .05. Other indicators suggested the model was a good fit; GFI = .97, AGFI = .95, TLI = .93, CFI = .95 and Pclose = .29. See Figure 10 on the model building.

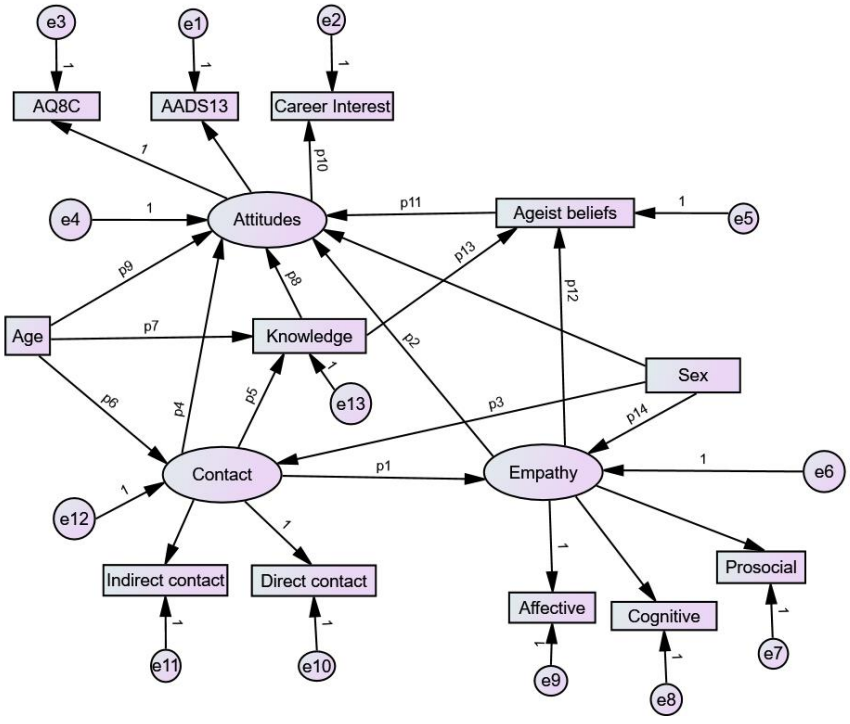

Figure 10 - Exploratory model building I

The exploratory model I displays pathways between the latent variable attitudes, predictor variables, and error terms. Contact, ageist beliefs, empathy, age, knowledge, and sex has a direct pathway to attitudes. Sex has a direct pathway to contact and empathy. Contact has a direct pathway to empathy and knowledge. Empathy has a direct pathway to ageist beliefs. Age has a direct pathway to knowledge and contact. Knowledge has a direct pathway to ageist beliefs.
Note. 'CareerInterest' represents willingness to work with people with dementia.

To improve the model fit, the initial modifications to the model included removing cognitive empathy. The variable was removed since cognitive empathy had the weakest association in the model, and with attitudes compared to the other variables (see regressions in section 5.4.5). Theoretically, this is in line with frameworks that demonstrate stronger support for prosocial intention and affective empathy (Van der Graaff et al., 2018). This is also in line with the SEM accepted in Chapter 4. While the removal of cognitive empathy improved the model as expected, the overall fit for the model was still inadequate, $\chi^2(34) = 128.56$, $p < .001$. Other indicators such as the RMSEA suggested the fit was good; RMSEA = .04. Other indicators suggested the model was a good and improved fit; GFI = .99, AGFI = .97, TLI = .96, CFI = .96, and Pclose = .97. The Bollen-Stine suggested a poor fit ($p = .000$). See Appendix R for the modified model findings.

The weakest pathways continued to be eliminated until an acceptable fit was achieved. For example, the direct pathways going from sex to attitudes ($p = .39$) and age to contact ($p = .16$) were the weakest associations in the model. This is in line with findings from Chapter 4 where sex had a stronger mediatory role in DRA rather than a direct effect when competing against non-sociodemographic variables in the model. Regressions in section 5.4.5 also did not support the association of sex to DRA. For the direct pathway of age to contact, a suppression effect may have occurred where variables such as knowledge or empathy suppress the influence of age on contact by explaining variance that age alone cannot account for. This may diminish the effect of age when competing against these variables.

Covaried error terms were added where there was theoretical justification to do so. This was to account for potential interdependencies between the constructs due to overlapping relationships between measure items (see section 5.4.3).

5.4.7.3 The Accepted Model I

Following the modifications, the overall fit for the model was good but not statistically significant, $\chi^2(26) = 42.91$, $p = .02$. Other indicators suggested the model fit was good and improved; RMSEA = .03, GFI = .99, AGFI = .98, TLI = .98, CFI = .99, and Pclose = 1.00. The Bollen-Stine suggested a good fit ($p = .07$). See Figure 11.

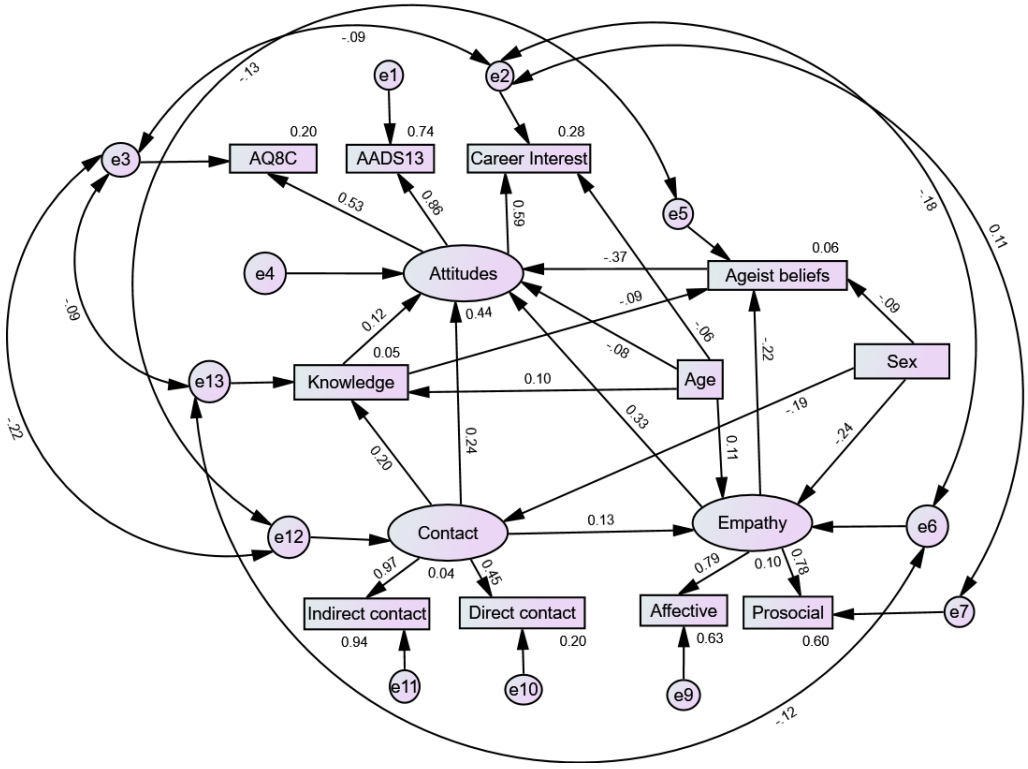

Figure 11 - Standardised coefficients for the accepted model I

The accepted model I displays pathways between the latent variable attitudes, predictor variables, and error terms. Contact, ageist beliefs, empathy, age, and knowledge has a direct pathway to attitudes. The pathway directly to attitudes from sex has been removed. Sex has a direct pathway to contact and empathy. Contact has a direct pathway to empathy and knowledge. Empathy has a direct pathway to ageist

beliefs. Age has a direct pathway to knowledge and empathy. Knowledge has a direct pathway to ageist beliefs. Error terms are covaried (e.g., e5 and e12), demonstrating ageist beliefs and contact have shared dimensions is what they are capturing. The added covaried arrows helps constrain the model.
Note. 'CareerInterest' represents willingness to work with people with dementia.

In the accepted model I SEM, all direct effects were statistically significant except the direct effect of age on behavioural intention (β = -.06, *p* = .05, 95%CIs -.12 to -.00). While sex did not have a direct relationship with attitudes, sex (being male) did have a significant negative direct effect on level of contact (β = -.19, *p* = .00, 95%CIs -.26 to -.13), levels of empathy (β = -.24, *p* = .00, 95%CIs -.31 to -.17), and higher levels of ageism (affinity towards older individuals) (β = -.09, *p* = .01, 95%CIs -.15 to -.02).

All indirect pathways in the SEM were statistically significant. Negative attitudes were associated with males via the mediator empathy (lower levels of empathy) (β = -.57, *p* = .00, 95%CIs -.85 to -.36). Negative attitudes were associated with males via the mediator contact (lower levels of contact with dementia) (β = -.33, *p* = .00, 95%CIs -.54 to -.19). A lower likelihood of willingness to work with dementia was associated with being male via the mediators contact and attitudes (lower levels of contact and less positive attitudes) (β = -.03, *p* = .00, 95%CIs -.04 to -.02). Lower levels of dementia knowledge were also associated with being male via the mediator contact (lower levels of contact with dementia) (β = -.02, *p* = .00, 95%CIs -.03 to -.01). Lastly, negative attitudes were associated with being male via the mediators contact and knowledge (lower levels of contact and knowledge) (β = -.03, *p* = .00, 95%CIs -.07 to -.02).

5.4.7.4 The accepted model II (best model fit)

Modifications to obtain the best model fit to the data led to the removal of the variable sex which led to the overall fit of the model being very good. Thus, the strongest variables predicting DRA were modifiable factors, with socio-demographic variables falling out of favour in the model when competing with the modifiable factors. Several indices indicated a very close fit, $\chi^2(19) = 26.72$, *p* = .11, CFI = 1.00, GFI = 1.00, AGFI = .99, TLI = .99, RMSEA = .02, Pclose = 1.00. The Bollen-Stine bootstrap (n = 100,000) was not statistically significant, *p* = .23. This suggests that the goodness of

fit of the model was good and that the null hypothesis is correct ($p > 0.05$). Thus, the null hypothesis for this model was accepted. See Figure 12.

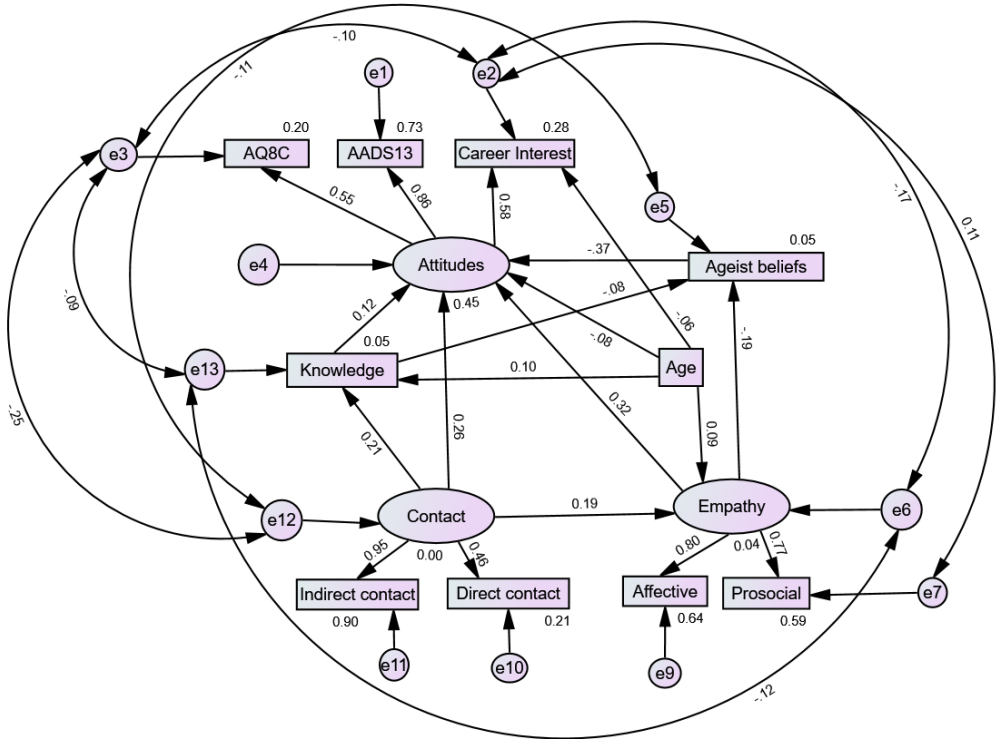

Figure 12 - Standardised coefficients for the accepted model II

The accepted model II (best model fit) displays pathways between the latent variable attitudes, predictor variables, and error terms. Contact, ageist beliefs, empathy, age, and knowledge has a direct pathway to attitudes. The variable sex has been removed from this model to see what the best model fit to the data is. Contact has a direct pathway to empathy and knowledge. Empathy has a direct pathway to ageist beliefs. Age has a direct pathway to knowledge and empathy. Knowledge has a direct pathway to ageist beliefs. Error terms are covaried (e.g., e5 and e12), demonstrating ageist beliefs and contact have shared dimensions is what they are capturing. The added covaried arrows helps constrain the model.

Note. 'CareerInterest' represents willingness to work with people with dementia.

5.4.7.5 Direct and mediatory effects

In the accepted SEM, all direct effects were statistically significant except the direct effect of age on behavioural intention ($\beta = -.06$, $p = .05$). The largest effects were

contact (β = .26) empathy (β = .32) and ageism (β = -.37). Table 34 reports the standardised coefficients and confidence intervals. All indirect pathways in the SEM were statistically significant. The strongest association was higher levels of empathy were associated with more positive attitudes via the mediator ageist beliefs (lower levels of ageist beliefs) (empathy > ageist beliefs > attitudes; β = .85, p<.001). Higher levels of dementia knowledge were associated with more positive attitudes via the mediator ageist beliefs (lower level of ageist beliefs) (knowledge > ageist beliefs > attitudes; β = .55, p = <.01). Table 35 reports the standardised coefficients for the mediation effects.

Table 34 - Direct effects of the accepted model II (Chapter 5)

Parameters			β	B	S.E	Lower CI [95%]	Upper CI [95%]
Empathy	←	Contact	.19***	.03	.04	.11	.27
Empathy	←	Age	.09*	.03	.04	.02	.16
Knowledge	←	Contact	.21***	.02	.04	.14	.28
Knowledge	←	Age	.10**	.02	.03	.04	.15
Ageist beliefs	←	Knowledge	-.08**	-1.48	.03	-.14	-.02
Ageist beliefs	←	Empathy	-.19***	-2.29	.04	-.27	-.11
Attitudes	←	Empathy	.32***	3.90	.04	.24	.41
Attitudes	←	Ageist beliefs	-.37***	-.37	.04	-.45	-.29
Attitudes	←	Knowledge	.12***	2.17	.03	.06	.18
Attitudes	←	Contact	.26***	.42	.04	.18	.35
Attitudes	←	Age	-.08*	-.31	.03	-.15	-.02
Willingness to work with people with dementia	←	Attitudes	.58***	.08	.03	.52	.65
Willingness to work with people with dementia	←	Age	-.06	-.03	.03	-.12	-.00

β = Standardised beta regression coefficient. Estimate (B) = unstandardised beta regression coefficient; Statistical significance: * = $p < 0.05$; ** = $p < 0.01$; *** $p = < 0.001$. S.E = standard error of the standardised regression weight estimate; CI = standardised bias-corrected (95%) confidence interval (lower and upper bound). If 0 falls between the lower and upper bound, the effect is not statistically significant. Estimates with (-) = negative relationship.

Table 35 - Mediation effects of the accepted model II (Chapter 5)

Parameters	β	S.E	Lower CI [95%]	Upper CI [95%]
Contact > empathy > attitudes > willingness to work with people with dementia	.01***	.00	.00	.01
Contact > empathy > attitudes	.10***	.03	.05	.17
Empathy > ageist beliefs > attitudes	.85***	.25	.44	1.42
Empathy > ageist beliefs > attitudes > willingness to work with people with dementia	.06***	.02	.03	.11
Empathy > attitudes > willingness to work with people with dementia	.30***	.05	.20	.41
Contact > knowledge > attitudes	.04***	.01	.02	.07
Contact > knowledge > attitudes > willingness to work with people with dementia	.00***	.00	.00	.01
Contact > knowledge > ageist beliefs > attitudes	.01**	.00	.00	.02
Knowledge > ageist beliefs > attitudes	.55**	.22	.16	1.04
Contact > attitudes > willingness to work with people with dementia	.03***	.01	.02	.04
Age > knowledge > attitudes	.05***	.02	.02	.09
Age > knowledge > ageist beliefs	-.03**	.02	-.07	-.01
Ageist beliefs > attitudes > willingness to work with people with dementia	-.03***	.00	-.04	-.02

Note. **β = standardised regression coefficient estimate. Two-tailed statistical significance: * = $p < 0.05$; ** = $p < 0.01$; *** $p = < 0.001$. S.E = standard error of the regression weight estimate. β CI = bias corrected [95%] confidence interval (lower and upper bound). If 0 falls between the lower and upper bound, the indirect effect is not statistically significant. Estimates with (-) = negative relationship.**

5.5 Discussion

This is the first study to explore several factors associated with DRA outcomes in a more diverse sample of adolescents in England, using SEM. The study highlights several mechanisms that influence DRA (see Discussion section 5.5.1). Modifiable factors such as level of contact, ageism, and empathy were the strongest factors in the model. The findings accept the hypothesis that modifiable DRA factors are more influential than demographic factors in adolescents. This aligns with the SEM conducted in Chapter 4. Notably, the findings indicate that stimulating empathetic responses through contact based anti-stigma initiatives, might be the most effective route to improving DRA.

Prior to this study, there was little understanding of what the experiences of dementia look like in adolescents. While this was only analysed in an exploratory and descriptive capacity in this thesis, the findings highlight that nearly half of the young people in the survey (46.0%) have spent time with someone with dementia in the past. Perhaps more significantly, over a quarter have looked after someone with dementia in the past (26.6%). While these findings are in line with those reported previously (i.e., 23% have provided some form of care, n = 901) (Farina et al., 2020b), it does appear to be far higher than the 1% reported in the National Children's Bureau survey (n = 51 young people identified from a total of 4,954 carers of all ages) (National Children's Bureau, 2016). Whilst this is concerning, it is important to note, that the majority of adolescents who had spent time with someone with dementia or looked after someone with dementia reported to have generally positive experiences of these interactions.

The findings also confirm that adolescents have had more indirect contact with dementia (via TV and film) than directly, supporting prior findings in the adolescent DRA literature (Farina et al., 2020a; Felc, 2022; Hwang, Kim, & Kim, 2013). Over 74% of the adolescents had watched TV shows or movies with a character who has dementia. A prior British survey of 11-14-year-olds found that 84% of adolescents had cited media as their main source of information on dementia, with some of the young people referring to the "dementors" in Harry Potter (Cowley, 2005). This thesis study adds to this body of work, providing quantitative context on how adolescents

experience the representation of dementia in the media. In this thesis study, a majority of British adolescents felt that dementia is represented generally negatively in TV and film. Cultivation theory suggests that the media's representation of a given topic can shape a person's perceptions, attitudes, and beliefs (Romer, Jamieson, Bleakley, & Jamieson, 2014; Shrum, 2017). Consideration of how young people will perceive dementia content when devising dementia awareness content is therefore important. It should be acknowledged that young people recognise that tackling the inaccurate portrayals in the media is an important policy focus and an area dementia charities could put greater effort into. This is because it is likely that public perceptions are, at least, partly shaped by the media which can contribute to stigma and misconceptions (Low & Purwaningrum, 2020). Whilst the association between adolescent's DRA and media was not captured, it is certainly a point of interest for future work.

A further objective of this exploratory analysis was to establish the level of dementia knowledge in British adolescents. The mean level of dementia knowledge in the study was just under 50%. The findings are in line with a prior study on adolescents in England (Isaac et al., 2017). This is a considerably lower level of dementia knowledge than the 71.5% achieved in Slovenian adolescents (Felc & Felc, 2020). The gaps in knowledge held by British adolescents are perhaps not a surprise given that dementia education is currently not embedded into the English curriculum (Farina, 2020). However, other factors could be influencing the level of dementia knowledge since dementia education is not widespread in Slovenia either (Felc & Felc, 2020). Comparison between these studies however is limited due to heterogeneity in dementia knowledge outcomes.

While DRA were generally positive across the sample (Brief A-ADS; m = 74%), which align with previous studies on British adolescents (Farina et al., 2020a; Isaac et al., 2017), the descriptive findings highlighted that adolescents continue to hold misconceptions about dementia that may feed into stigma. Nearly 70% of adolescents did not know or incorrectly believed that dementia is a mental illness. After weighting, this would equate to approximately 3.7 million adolescents in England and Wales. The prevalence of this misconception is perhaps unsurprising as it is common internationally amongst adults (ADI, 2019). From an awareness-raising point of view,

it is important that campaigns reiterate the distinctive characteristics of dementia and better emphasise it is not a mental illness. Although it is unclear what might be the repercussions of holding this misconception, stigma does still exist for mental illness (McCullock & Scrivano, 2023). Another common misconception is that dementia is a normal part of ageing (ADI, 2019). The current study indicated that 42% of adolescents (weighted by demography) incorrectly thought that dementia was a normal part of ageing, which would equate to 2.3 million adolescents in England and Wales. This could be an area that needs prioritising in dementia awareness-raising campaigns within this demographic.

5.5.1 Key findings relating to the factors associated with DRA in British adolescents

5.5.1.1 Non-modifiable factors and DRA

The main objective of this thesis study was to identify demographic groups that are more susceptible to negative DRA. The analysis of non-modifiable factors—age, sex, ethnicity, and religion, provides a nuanced understanding of their roles in shaping DRA among adolescents.

Age emerged as a significant factor (Fuh et al., 2005), with older adolescents displaying more negative DRA. In addition, the SEM revealed that age was indirectly related to the willingness to work with people living with dementia, demonstrating a 22% reduction in willingness for each additional year. DRA and ageism mediated this relationship. Both of these findings could be due to increased exposure to dementia through media, personal experiences, and societal stereotypes, which shape their attitudes more negatively (Sawyer et al., 2018). This finding contrasts with Chapter 4, where age was not linked to DRA, possibly due to the narrower age range (12-15 years). Studies with a wider age range such as this cross-sectional study (age 11 to 18 years old) support the observed age differences in attitudes towards both mental illness (age seven versus age 11) (Fox et al., 2010) and dementia (under 18 versus over 18-years old) (Wu et al., 2022). Interestingly, while older adolescents demonstrated higher levels of empathy, which aligns with developmental theories, this did not translate to more positive DRA. The SEM analysis revealed a complex relationship

between age and DRA. Despite higher empathy and increased knowledge about dementia among older adolescents, negative DRA still existed. This suggests that knowledge alone is not enough to counteract ingrained prejudices. This is supported by Allport's work, where implicit biases can persist despite exposure to knowledge. This is may be due to affective (emotional) experiences creating internal conflict if new knowledge contradict these experiences (Allport cited in Rich, 2011). Educational dementia initiatives must extend beyond information dissemination to build empathy and challenge stereotypes. Given these findings, younger adolescents might benefit from foundational education focused on empathy, whereas older adolescents may benefit from interventions that promote positive narratives of dementia (Baker et al., 2018a) to counteract negative stereotypes (e.g., DEALTS2 programme – this is explained below in section 5.5.1.2) (Heward, Board, Spriggs, & Murphy, 2020).

The regression analysis and SEM did not detect a significant direct relationship between sex and DRA, contrasting with earlier findings (Chapter 4, section 4.4.3; Farina et al., 2020a; Fuh et al., 2005; Lo et al., 2020). This discrepancy highlights the mixed evidence in the literature regarding sex and DRA (Cheston et al., 2016; Felc et al., 2021; Shulman & Adams, 2002). Since indirect contact was more influential in the models, it possibly counteracted the positive effects of direct contact, leading to no significant direct sex differences in DRA. In the SEM, sex was influential on DRA indirectly through contact with dementia, where males had less contact with dementia, which in turn led to less positive DRA. This aligns with gender social norms (Leonhardt & Overå, 2021) where females are more likely to have contact with dementia due to taking on caregiving roles, socialise with family members (Löffler & Greitemeyer, 2023; Revenson et al., 2016), and seek more health-related information (Goodyear et al., 2018) than males. These findings suggest the importance of increasing meaningful dementia-related interactions for both sexes. Anti-stigma initiatives that promote contact could particularly benefit males, who may have fewer natural opportunities for interaction with people with dementia. Understanding the cultural and social context of caregiving roles is crucial for future research. Given that females often serve as primary caregivers, addressing these dynamics could help tailor interventions to improve DRA across sexes (Arbel, Bingham, & Dawson, 2019).

Consistent with the findings from Chapter 4, ethnicity and religion did not show significant associations with DRA in this adolescent cohort. Although some prior studies reported ethnic differences in DRA, these studies often included older adults (Algahtani et al., 2020; Cheston et al., 2016; Lawrence et al., 2008; Mukadam et al., 2011). The lack of association in adolescents may be explained by potentially less pronounced cultural influences in this age group. This may lead to more uniform attitudes. This has been evidenced in research highlighting generational differences between first, second and third generation African Caribbean participants. The study reported that second and third generations hold less traditional views in the context of attitudes and carer roles (Lawrence et al., 2008). Thus, younger generations may have more homogeneous views, due to less pronounced cultural influences at this developmental stage. From the perspective of the eco-contextual model of adolescent attitude formation, this would mean the macrosystem (cultural influences and traditions) are less influential than the exosystem (immediate surroundings that impact the adolescent indirectly) (Petani, 2011).

In summary of the demographic factors, effective strategies should focus on enhancing positive contact experiences and empathy-building that are tailored to the specific developmental needs of different age groups, and acknowledging the indirect influences of sex-related factors. The absence of significant ethnic and religious differences indicates that broad-based interventions could be effective across diverse adolescent populations.

5.5.1.2 Modifiable Factors Associated with DRA

The main objective of this study was to establish whether modifiable factors are associated with DRA and determine the relationship between ageist beliefs and DRA. Overall, the findings highlight that modifiable factors such as contact, empathy, and knowledge, play a significant role in shaping DRA directly, and have a mediatory effect on it. The study also demonstrated that having high levels of negative ageist beliefs was associated with negative DRA. Both DRA and modifiable factors influenced behavioural intention in the SEM dominantly over demographic factors overall.

It was hypothesised that higher levels of contact with dementia would be associated with more positive DRA. The hypothesis was confirmed, reinforcing the role of direct and indirect interactions in shaping attitudes. These findings support the intergroup contact hypothesis (Allport, 1954; Pettigrew & Tropp, 2008) and align with previous quantitative (Cheston et al., 2016; Werner et al., 2017) and qualitative (Baker et al., 2018a) DRA studies on young people. The findings support contact as a potential modifiable factor for DRA initiatives, as identified in Chapter 4.

Indirect contact was more influential than direct contact in shaping attitudes, differing from Chapter 4 findings, where direct contact was more impactful. This discrepancy may be due to different measurement tools and contexts. In this study, the AQ-8-C measure, based on the Attribution Model of stigma (Corrigan et al., 2003), highlighted the significance of indirect contact through hypothetical scenarios, which engage cognitive and emotional (affective) processes, fostering empathy and reducing stigma (Crisp & Turner, 2012). The SEM findings supported the hypothesis that contact levels effect empathy. Empathy also directly impacted DRA (higher levels of empathy were associated with more positive DRA) and mediated the relationship between contact and DRA in the SEM. This further aligns with the Empathy Altruism Hypothesis (Batson et al., 1991; Batson et al., 2002) and the Intergroup Contact Hypothesis, where empathy towards a member of a stigmatised group reduces prejudice towards the outgroup (Batson et al., 1997; Dovidio et al., 2010). Alongside theoretical support, the findings align with both Baker and colleagues qualitative association of empathy with DRA (Baker et al., 2018a), and Chapter 4 findings of this thesis (Hassan et al., 2023a).

Thus, the findings suggest that stimulating empathetic responses through contact-based approaches may reduce prejudice. Together, these findings on contact and empathy also support the dual process model, where indirect contact can be as impactful as direct contact, especially when it involves scenarios that activate affective processing (Crisp & Turner, 2012). This supports the potential of indirect interventions to complement direct experiences in dementia anti-stigma initiatives. An example is the use of virtual reality to elicit empathy and reduce stigma through imagined contact (Hicks et al., 2021; Schutte & Stilinović, 2017) as an additional strategy to engage young people with dementia. However, a limitation of virtual reality

in eliciting empathy is that it can create a ‘tragedy discourse’ about dementia that may increase stigma (Hicks et al., 2021). Thus, virtual reality scenarios need to promote positive messages of dementia. The DEALTS2 programme, a simulation-based toolkit that helps participants understand the view of a person living with dementia, is a recent example of virtual reality scenarios promoting positive messages about dementia (Heward et al., 2020).

Furthermore, empathy's influence on DRA was more pronounced in the prosocial and affective domains compared to the cognitive domain. In the SEM, empathy accounted for a smaller portion of the variance in the cognitive domain, aligning with the findings from Chapter 4 of this thesis. Research from the developmental empathy literature also indicates that affective empathy drives prosocial actions more strongly than cognitive empathy (Batson et al., 1991; Carlo et al., 2010; Dovidio et al., 2010; Van der Graaff et al., 2018). Thus, cognitive empathy might not be as influential in shaping DRA in young people, or it may not be fully captured by the measures used. However, the latter is less likely in this scenario given the AQ-8-C measures cognitive and affective aspects of stigma. This reinforces the idea that fostering affective and prosocial intention empathy domains in anti-stigma initiatives may be useful in improving DRA in adolescents.

It was hypothesised that there would be an association between dementia knowledge and DRA. The hypothesis was supported, with dementia knowledge directly associated with more positive DRA. The findings align with the literature (Felc et al., 2021; Lo et al., 2020; Herrmann et al., 2018; Werner et al., 2017) presented in the systematic review of this thesis (Chapter 3). Yet, dementia knowledge as a mediator of DRA was not clear from prior research. The SEM analysis did reveal that knowledge had a mediatory capacity in the model. Notably, it mediated the relationship between contact and DRA. This suggests increasing knowledge through contact experiences may lead to more informed and positive DRA. Accurate information gained through contact can foster more empathetic and informed attitudes (Allport, 1954). Empirical evidence, such as the study by Isaac and colleagues, remarks that meaningful contact improves knowledge and DRA (Isaac et al., 2017). Intervention research supports this, showing that theatre and films (indirect contact)

can boost dementia knowledge and DRA in young people (Zheng et al., 2016). Initiatives like 'Adopt a Care Home' also demonstrate that direct contact effectively increases knowledge and improves DRA (Di Bona et al., 2019). These findings suggest that combining education with contact (Phillipson et al., 2019) may be an effective strategy for anti-stigma initiatives targeting young people (Chen et al., 2016). Future work could evaluate the effectiveness of standalone versus combined education and contact interventions longitudinally, particularly since standalone educational initiatives have shown limited effectiveness in changing DRA (Farina et al., 2020b). Public health campaigns must focus on providing accurate, accessible information about dementia to improve understanding and reduce stigma (Ebert et al., 2020). Developing a validated knowledge questionnaire for adolescents could also improve the measurement and effectiveness of dementia awareness programmes. The justification for selecting the NILTS is discussed in the methods (section 5.3.7), however, there is currently a lack of validated knowledge questionnaires designed for adolescents. There is a need for culturally relevant and validated knowledge measures for young people.

This Chapter also explored the relationship between ageist beliefs and DRA to assess whether addressing ageism could improve DRA in adolescents. This is because only one prior study examined this association in the DRA literature in adolescents (see Werner et al., 2017). In the SEM, the findings demonstrated that lower affinity to older adults was significantly associated with negative DRA, aligning with existing evidence (Werner et al., 2017) and the broader DRA literature (Baumgartner, 2017). This association was expected, as dementia is often linked to older adults (Ayalon & Tesch-Römer, 2018). Social identity theory explains that younger people seek positive distinctiveness from older out-groups, contributing to ageist beliefs. Negative attitudes towards ageing, often adopted at an early age, are directed at older adults as an out-group (Ayalon & Tesch-Römer, 2018).

Werner and colleagues validated the Attribution Model of stigma in explaining ageist beliefs related to DRA (Werner et al., 2017). The AQ-8-C measure, rooted in this framework, uses a vignette to assess whether dementia is perceived as beyond the control of those living with it (e.g., ‘I think Charlie is to blame for the dementia’). The

findings also align with the intergroup threat theory, where ageism arises from perceived threats (Swift, Abrams, Lamont, & Drury, 2017) (e.g., 'How dangerous would you feel Charlie is?'), influencing negative DRA.

Other notable relationships in the SEM relating to ageist beliefs included the mediatory pathway where contact increased knowledge, which reduced ageism and improved DRA. This suggests that increasing knowledge and facilitating meaningful interactions with dementia, could reduce ageist beliefs and improve DRA. Higher empathy levels also directly reduced ageist beliefs in the SEM. Overall, the prevalence of ageist attitudes in adolescents and its association with DRA highlights the need to incorporate anti-ageist elements in anti-stigma interventions that are contact and education based (e.g., "Instapals intervention: reducing ageism by facilitating intergenerational contact and providing aging education" - Lytle, Nowacek, & Levy, 2020). This may help tackle misconceptions about dementia effectively.

Overall, all these modifiable factors interact together, influencing not only DRA, but also behavioural intention (willingness to engage in dementia-related careers). The findings align with the TPB framework which emphasises that attitudes are crucial predictors of behavioural intentions (Ajzen, 1991; Ajzen et al., 2018). Despite a generally low willingness among adolescents, with 39.4% expressing interest, the SEM indicates that fostering positive DRA is key to influencing future career intentions in dementia.

5.5.2 Strengths and limitations

Strengths

First, the study addresses an important population gap by recruiting a substantial sample size (n>1000) from schools across six diverse regions of England that include different ethnic and religious groups, as well as regional deprivation, enhancing the generalisability of findings.

Second, this Chapter contributes to the existing body of work by building on the published work from Chapter 4, and incorporates factors identified in the systematic

review from Chapter 3 that were yet to be explored with the SEM methodology (i.e., ageism and level of dementia knowledge). This offers a more comprehensive understanding of factors relevant to anti-stigma initiatives for adolescents and helps build consensus on effective targets for such interventions.

Third, the SEM pathways were theoretically driven, based on evidence from the DRA literature, mental health stigma research, and developmental studies. Most measures used in this study were validated for younger populations, increasing the reliability of the findings.

Fourth, the findings have translational significance by offering practical insights for public health strategies aimed at reshaping societal attitudes and increasing dementia awareness among young people. These insights align with the national dementia strategy in England which emphasises improving dementia knowledge attitudes in young people (Department of Health and Social Care, 2015).

Fifth, it is important to acknowledge that in this thesis study, the item relating to whether young people have looked after someone living with dementia before, uses the term 'looked after' rather than 'care'. This distinction is important since arguably both reflect care, but the former is less stigmatising and may also better capture the concept of 'supervision' (Masterson-Algar et al., 2023). This could be useful in determining key demographics for initiatives that aim to raise awareness of dementia or that such individuals must be provided with support in caring for someone with dementia.

Last, there are methodological strengths. Data weighting was employed to reflect demographic characteristics more accurately, minimising potential bias. Construct validity was confirmed through significant correlations between measures. The majority of the measures also demonstrated good to excellent reliability, indicating the measures are consistent and the findings are more reliable (DeVon et al., 2007). The measures were pilot-tested by young people to ensure accessibility for the target demographic. Moreover, the study utilised PPI to ensure that the outcomes of the study aligned with real-world experiences, enhancing the study's relevance. Lastly, the use of robust SEM statistical methods, including bootstrapping procedures with 100,000

iterations for the SEM, enhances the reliability of the findings due to the increased precision of the parameter estimates (Efron, 1987; Fitrianto & Cing, 2014; Wolf, Harrington, Clark, & Miller, 2013). The SEM procedures were informed by key studies (Bodner, 2008; Harel et al., 2014; Li et al., 2012; Von Hippel, 2020) and in consultation with a statistician. The error terms in the SEM were also theoretically driven, ensuring that the SEM reflects established relationships, enhancing the interpretability of the findings (Bollen, 1989).

Limitations

First, the cross-sectional nature of the data limits causal inferences and makes it difficult to understand the true directionality of relationships between variables. This limitation is discussed in Chapter 4 (section 4.5.2).

Second, the factors explored in this Chapter are not definitive. While all the factors identified in the systematic review and secondary data analysis were included, the model's variance suggests the presence of unobserved variables that could influence DRA which were not captured in this study.

Third, while the sample was relatively large and diverse, the findings are still not wholly representative of adolescents across all of England despite efforts to include different school types and various socio-demographics. Despite a greater number of participants identifying as non-White British, the findings still did not offer a clear understanding of whether each ethnicity and religion specifically influences DRA. This is particularly since there are nuances between religions and ethnic groups in caring attitudes for example (Regan, 2014). However, these variables also may be less relevant in younger or second and third generation young people compared to older generations (Johl et al., 2016) that researchers may need to consider.

Fourth, there were methodological limitations. Measures such as the BSDS, and AQ-8-C, displayed poor reliability (Cronbach's alpha of below 0.60), affecting their internal consistency. Additionally, some variables displayed skewed distributions, potentially introducing bias, though the large sample size helps mitigate this impact. Participant fatigue, evidenced in the boredom effects in the survey where there was

missing data largely towards the end of the questionnaire, could affect response reliability. To mitigate this, IER and MI were used to handle missing data. Last, the low reliability of the AQ-8-C led to the removal of some of its items, which may limit the comprehensiveness and interpretability of the DRA latent variable in the SEM. This reduction affected the variance representation and reduced the explanatory power of the attribution model in explaining DRA.

5.6 Conclusion

This is the first study to explore factors associated with DRA outcomes in a diverse sample of adolescents across England. The study highlights several mechanisms that influence DRA. Modifiable factors such as level of contact, ageism, and empathy were the strongest factors in the model. The findings indicated that modifiable factors of DRA are more influential compared to demographic factors in adolescents, although being older and being male were found to be associated with negative DRA through mainly mediatory mechanisms. Importantly, the findings highlight that empathy and contact are potentially critical targets for anti-stigma initiatives. Interventions that stimulate empathetic responses, may be one of the most effective route to improving dementia attitudes. The findings also confirm that adolescents have had more indirect contact with dementia (via TV and film) than directly. Descriptively, these contact experiences were contextualised as generally positive or negative quantitatively for the first time, with direct experiences of dementia generally described as positive. Lastly, this is the first study to explore dementia knowledge in adolescents from multiple regions of England. The study demonstrated that adolescents answered just under half the knowledge items correctly (48%) and many held misconceptions about dementia.

Overall, this thesis builds on prior works to build consensus on the factors determining DRA to help inform effective evidence-based dementia anti-stigma initiatives. The findings help guide stakeholders in the advocacy for wider education in the national curriculum. Moreover, greater understanding on the frequency and quality of contact with dementia in young people will be important future work to inform policy and support for young people. Lastly, British adolescents believe that dementia is

generally negatively represented in the media. This has implications in future advocacy work to ensure accurate representations of dementia.

Chapter 6: An exploratory cross-sectional sub-study on the relationship between implicit and explicit dementia-related attitudes

This Chapter consists of an exploratory sub-study on the relationship between implicit and explicit DRA in adolescents.

6.1 Aims, objectives, and hypotheses

This novel cross-sectional sub-study aimed to explore the relationship between implicit (IAT d-scores) and explicit DRA (Brief A-ADS and AQ-8-C). A secondary aim was to explore the relationship between implicit attitudes and other variables commonly associated with DRA explicit measures (ageism and social desirability).

The main objective of this Chapter was to:

1. Conduct exploratory regressions between measures of explicit and implicit DRA.

Secondary objectives included:

1. Controlling for demographic variables (age, ethnicity, religion, and sex) using partial correlations to ensure that the relationship between explicit and implicit attitudes are more likely to be due to the construct rather than demographic characteristics.
2. Examine demographic differences in IAT d-scores using t-tests.

While this sub-study is exploratory, there are five main hypotheses informed by the literature outlined in Chapter 1, section 1.3.

1. There will be no association between the explicit and implicit measures. This null hypothesis is based on the theory that explicit measures capture cognitive beliefs (Rudman, 2004) and influenced by social desirability (Phipps et al., 2019), while implicit measures assess unconscious, affective (emotional) biases that do not align with consciously endorsed attitudes (Rudman, 2004;

Phipps et al., 2019). The lack of association would reflect the different processes underlying the two attitude types (Rudman, 2004).

2. Implicit bias toward dementia will be detected in adolescents, and if so, it will reflect the affective (emotional) component of the Attribution Model, as emotional responses are known to shape implicit attitudes from a young age (DeCoster et al., 2006; Vezzali et al., 2023). However, if implicit bias is not detected, this will likely be due to insufficient associative learning about dementia in the adolescent sample, as adolescents may have limited direct exposure to dementia (see Chapter 1, section 1.3 and Chapter 5, section 5.5.1).

3. There will be significant associations between the explicit measures. Given the relationships detected in the prior Chapter (5), it is expected that the RAS and AQ-8-C will both have a significant, negative association with the Brief A-ADS. It is expected that there will be a significant, positive association between the Brief A-ADS and the BSDS. These associations reflect the likely interrelated dimensions of cognitive beliefs and social influences that these measures share.

4. There will be no significant demographic differences in IAT scores. This is based on a previous literature review on attitudes towards individuals with disabilities that suggests that demographic factors often do not significantly predict IAT scores, with several studies generally reporting no significant differences across several demographics (Wilson & Scior, 2014).

5. It is expected that there will be a positive association between females and higher scores of DRA compared to males, reflecting females having more positive DRA. This is in line with findings from Chapter 4 (section 4.5.1) and other studies (Farina et al., 2020a). Females are also expected to positively correlate with BSDS. Females are expected to display more social desirability bias compared to males (Camerini & Schulz, 2018), which may help explain why females score higher positive DRA scores.

6.2 Methods

6.2.1 Study design

This sub-study is a cross-sectional proof-of-concept experimental and quantitative survey design. The experimental paradigm selected was a reaction time computer task which measures implicit attitudes towards dementia. Participants were selected opportunistically and completed the IAT alongside an explicit measure of DRA via questionnaires. Adolescents aged 11-18 years old from secondary schools and sixth-forms across England completed a series of questionnaires relating to topics concerning DRA, and demographic information. A sub-group of these adolescents was selected opportunistically based on time allowance by gatekeepers to take part in the IAT component of this study. An amendment was submitted to the ethics committee to change the IAT from a longitudinal design to a cross-sectional design. This was due to having an insufficient number of participants. There were not enough schools who were able to facilitate the IAT alongside the questionnaire face to face due to time constraints in the school day. The IAT data was collected concurrently with the novel study from Chapter 5 and ran until March 2024.

The implicit attitude task (IAT) is a concurrent classification task where participants categorise pairs of stimuli into an equal set of categories. Response time (reaction time) is faster when matching the pairing categories if participants have pre-existing associations that interfere with the task. The IAT scores demonstrate the interference effect from these pre-existing associations (Greenwald et al., 2003).

6.2.2 Study setting and sample

The study setting and sample information is reported in Chapter 5. In total five schools consented to taking part in both the IAT and questionnaires. However, one school due to unforeseen circumstances entailing sudden short staffing meant they could not rearrange the date to take part. Another school completed the IAT face to face but did not have time to complete the questionnaire. The schools were provided with alternative dates and times until the March 2024 closing date to complete the questionnaire but this was not completed by the school. As a result, three schools took part in both the implicit and explicit data collection (see Table 36). In total, 130

adolescents aged 13-18 years old were recruited. Out of the 130 participants, three participants did not consent to processing of their data or taking part in the study. Eight participants had unique identifiers that were unable to be matched. Of the remaining 119 participants, 61 participants had a 100% questionnaire completion rate.

For the IAT, participants were selected opportunistically by the school gatekeeper based on the logistics of the school day. A quota of 192 participants in total was necessary to detect a significant association between implicit and explicit measures (effect size of r =0.02, p = 0.05, power set at 0.80). As the study was not sufficiently powered to interpret significant p values, the effect size and confidence intervals are used to interpret the data. Recruitment for the IAT was between February 2023 until March 2024.

Table 36 - School and participant characteristics for the IAT sub-study

School	Region	Regional deprivation	School characteristic	Age range of recruited participants	N recruited
1	Bedfordshire	LSOA in the 20% least deprived neighbourhoods in the country	Secondary Academy converter school, mixed gender, non-selective	13-16	32
2	Bedfordshire	LSOA in the 30% most deprived neighbourhoods in the country	Public School - Independent School, Single gender (boys)	16-18	15
3	Bedfordshire	LSOA in the 30% least deprived neighbourhoods in the country	Sixth form college, mixed gender	16-18	75
4	London	LSOA in the 40% least deprived neighbourhoods in the country	Secondary community school, mixed gender, non-selective	13-15	8

N.b. regional deprivation characterised by LSOA data (Ministry of Housing Communities and Local Government, 2019). The age range reflects the ages of the participants recruited from each school, and the N recruited represents the number of participants recruited for the study from each school.

6.2.3 Public Patient Involvement (PPI) and pilot testing

The LEAP and young people advisory group were consulted on the use and purpose of the IAT. The feedback given by the group was that the 'computer task' or 'implicit association test' sounded too much like being examined. Therefore, 'implicit association test' on the participant information sheets was changed to 'a word association task' instead. The IAT was piloted by the young people group where the IAT took no longer than 3.5 minutes to complete with a one-minute long explanation of the task. There were no word comprehension issues or concerns with what was required from the task noted.

6.2.4 Ethical approval

The sub-study was approved (ER/BSMS9PCH/1) and (ER/BSMS9PCH/2) by the Brighton and Sussex Medical School Research Governance and Ethics Committee (see Appendix D). School headteachers and other senior school staff were consulted for their expertise in conducting such a study within a school context.

6.2.5 Study procedure

The study procedure is the same as the information reported in Chapter 5. The questionnaire link (or paper copy) was disseminated to participants a week in advance of data collection. The school gatekeepers identified which year groups and classes were appropriate to participate, as well as providing EH with dates and times that were most convenient for their school to complete the study. Four schools consented to IAT data collection. A risk assessment for schools was completed for in-person data collection.

The questionnaire study procedure, consent, and withdrawal procedure are the same as those outlined in Chapter 5. For the IAT, participants were selected by the gatekeeper. EH explained to participants the IAT instructions which were also on screen. The implicit attitude measure is a single target implicit association test (Greenwald et al., 1998), a widely-used cognitive-behavioural paradigm measuring the strength of implicit associations between concepts in people's minds relying on latency measures in a simple sorting task. The IAT was run on the electronic software

Inquisit 6 lab. The IAT in total took 3.5 minutes for participants to complete. The researcher and an allocated gatekeeper sat by the classroom door in case participants had any questions. Participants sorted the negative and positive words while recording their reaction time. The IAT consisted of attributes of positive and negative words and a single target (see Table 37). Participants were asked to categorise attributes (see Figure 13) and a target (Dementia and Alzheimer's Disease) into predetermined categories via pressing keys. Participants needed to press the left key (E) of a keyboard if an item (an attribute) belonged to the category presented on the left (e.g., Dementia OR positive attributes such as 'competent') and pressed the right key (I) if the word (e.g., Alzheimer's disease) belongs to the category presented on the right (negative attributes such as 'incompetent'). These pairings were reversed for a second test. The order of the pairings was counterbalanced by group number. If participants made an error, a red 'X' appeared. Participants could press the space bar to move onto the next item following an error. Participants were instructed to go as fast as they could while making as few errors as possible. See Figure 13 for the sequence of the IAT.

The strength of an association between the concepts were measured by the standardised mean difference score of the 'hypothesis-inconsistent' pairings and 'hypothesis-consistent' pairings (D-score). The higher the D-score, the stronger the association is between the 'hypothesis-consistent' pairings (positive D-scores = 'Dementia-Positive' than 'Dementia-negative'). Negative D-scores represent a stronger association between the 'hypothesis-inconsistent' pairings (negative D-scores = 'dementia-negative' than 'dementia-positive'). The Inquisit lab calculated the D-scores using a scoring algorithm script (Greenwald et al., 2003). Once the questionnaire and IAT were completed, participants were presented with a debrief form and were entered into a prize draw to win vouchers (value of £20).

6.2.6 Data management

The data management for this sub-study is the same as the data management procedures described in Chapter 5 (section 5.3.6).

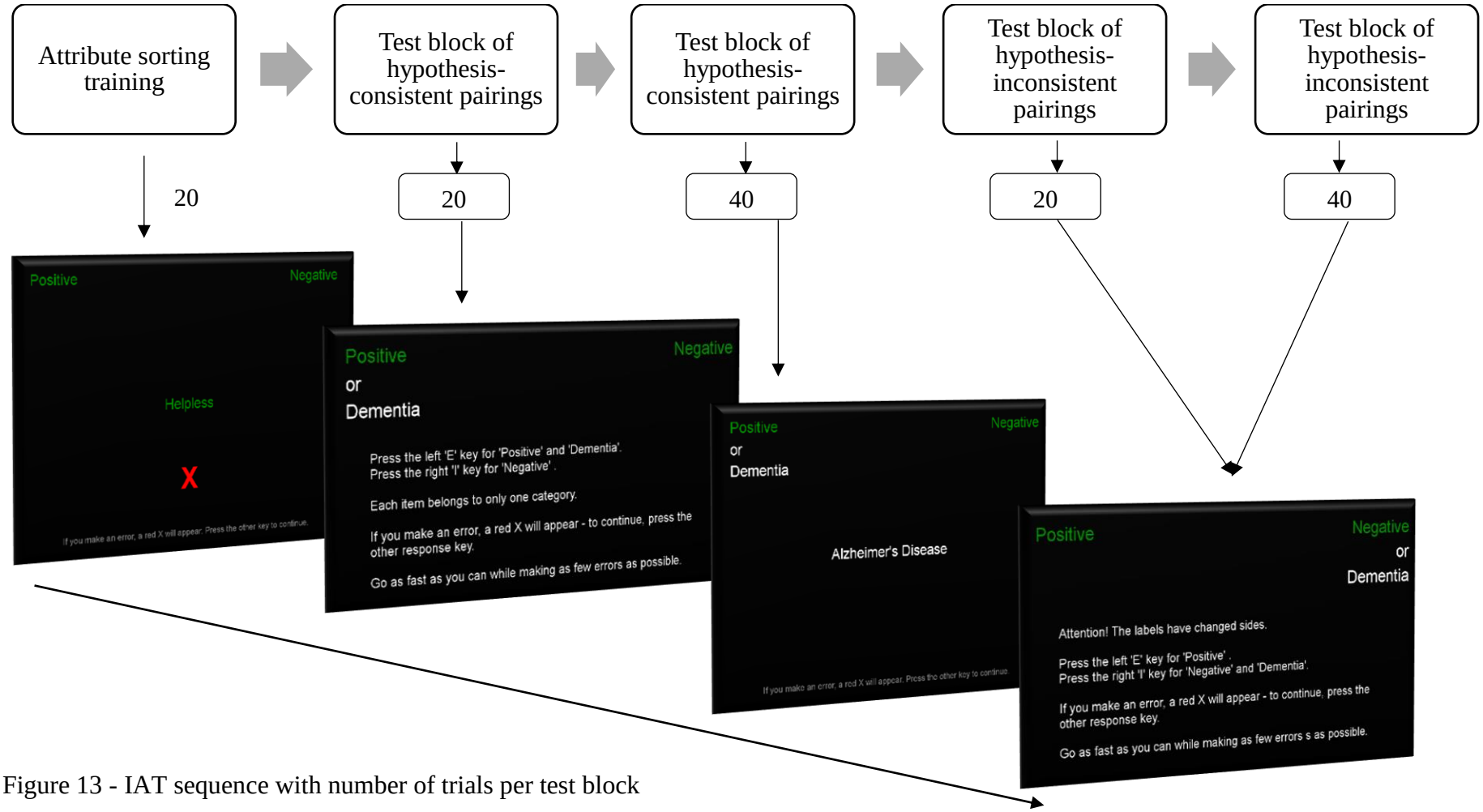

Figure 13 - IAT sequence with number of trials per test block

Figure 13 presents the screen for each key stage that participants see during the task. Participants first complete 20 trials of the training round where they sort positive and negative attributes into the respective positive or negative categories. Participants then complete 20 trials of hypothesis-consistent pairings (target is sorted into the positive category) followed by 40 trials of the same task. Participants then complete 20 trials of hypothesis-inconsistent pairings (target is sorted into the negative category) followed by 40 trials of the same task. Half the participants start with inconsistent pairings.

Table 37 - IAT item attributes for positive attributes, negative attributes and target items

	Attribute A label = Positive
Attribute A items	Competent Trustworthy Independent Knowledgeable Capable Reliable Inspirational Experienced
	Attribute B label = Negative
Attribute B items	Incompetent Untrustworthy Helpless Challenging Incapable Hopeless Unreliable Burdensome
	Target A label = Dementia
Target A items	Alzheimer's Disease Dementia

6.2.7 Variables

The measures consisted of demographic variables, DRA measures, social desirability, and the D-score of the IAT. Demographic variables were treated as categorical and were dichotomised (sex, ethnicity, and religion) except age, which was treated as continuous. This is consistent with the rationale from the prior chapters.

Questionnaires

Demographic variables: Age, sex, ethnicity, and religion.

A single item relating to 'whether participants have heard of the word dementia or Alzheimer's disease before

Relational ageism scale (RAS) (ageism) - The RAS (Gendron, et al., 2020) is a validated 16-item questionnaire consisting of three subscales, of which the 'collective affinity for older people' was used for this study.

Brief version of the Adolescent Attitudes Towards Dementia Scale (Brief A-ADS) - the Brief A-ADS is a validated measure consisting of 13 items (Farina et al., 2022) from the 23-item A-ADS (Griffiths et al., 2018).

Attribution questionnaire children's version (AQ-8-C) - the AQ-8-C is a shorter modified children's version of the attribution questionnaire of public stigma towards mental illness (Corrigan et al., 2003) designed for 10-18-year olds (Watson et al., 2004).

The Brief Social Desirability Children's scale (BSDS) – the BSDS is a four-item scale of social desirability (Haghighat, 2007).

For more details about these variables and measures, please refer to Chapter 5, section 5.3.7.

Implicit variables

An existing single target IAT was adopted from the Millisecond IAT library (Millisecond Software, 2022) and was modified to make the stimuli relevant to dementia by adjusting the words of the IAT coding syntax. The IAT (Greenwald et al., 1998) is a widely adopted experimental paradigm that detects the strength of automatic implicit attitude between a given concept and stimuli. The IAT captures a latency measure in a sorting task. The strength of an association between the concepts and stimuli is measured by a standardised mean difference score (d-score) (Greenwald et al., 2003). A positive d-score supports a stronger association between Dementia–positive than Dementia–negative while a negative d-score supports a stronger Dementia–negative than a Dementia–positive. See Table 38.

The IAT consisted of attributes of positive and negative words and a single target (i.e., Dementia and Alzheimer's Disease). Participants sort the negative and positive words whilst recording reaction time. The number of targets and attributes selected (one target with two attributes consisting of eight items) is sufficient to maintain the reliability and robustness of the test. Evidence suggests that a valid IAT can be produced in as few as two items to represent each concept and that the psychometric properties are not altered as a result of the measure (Nosek, Greenwald, & Banaji, 2005).

An ageism IAT was chosen to be adapted for this sub-study for several theoretical and empirical reasons. Since there is a lack of studies examining IAT towards dementia, especially in younger demographics, this approach builds on a more robust body of literature, while extending its applicability to the context of DRA in adolescents. Using IAT research based on a similar stigmatised group, where IAT is more extensively used and piloted in younger demographics provides greater validity to the choice of theoretical frameworks and attributes used.

Ageism attitude tests (e.g., Babcock, MaloneBeach, Hannighofer, & Woodworth-Hou, 2016) are particularly appropriate to use due to overlapping stereotypes between ageing and dementia (Low & Purwaningrum, 2020). The Motivation and Opportunity as Determinants model (MODE) is a commonly used framework for research using implicit attitude measures (Fazio, 1990). Applying this model would suggest that if associations are strong enough, evaluations may be activated automatically when an individual comes across a relevant attitudinal target (Fazio, 1990). Since the IAT entails the use of categories to sort positive and negative attributes (Cooley & Payne, 2017), categorisation should facilitate the activation of associated stereotypes of dementia. The spreading activation theory of memory (ACT-R) (Anderson, 1983 cited in Mace & Keller, 2024) can be used to make sense of the use of ageism as a framework for the IAT in this context. When there is a lack of personal experience (i.e., direct contact) of dementia in adolescents, but have had exposure to negative stereotypes of ageing, their implicit DRA may be influenced by related topics such as ageing or older people. Activation of the 'mental drawers' relating to similar topics to dementia in the context of the IAT, may help uncover implicit biases adolescents hold.

The positive and negative attributes chosen for the IAT in this sub-study reflect the common stereotypes associated in both dementia and ageing as reported in the Global ageism report (WHO, 2021a), the ADI report (2019), and already piloted ageism implicit tests such as the IRAP (Cullen et al., 2009). The positive attributes are close antonym words of the negative attitudes. As having dementia is not commonly associated with positive stereotypes, the ageism report and the study by Cullen and colleagues were used to ensure the positive attributes also reflected common positive stereotypes of ageing. These included “reliable, experienced, knowledgeable, and hard-working” (WHO, 2021a), and “productive” (Cullen et al., 2009).

Table 38 - IAT D-score interpretation (Greenwald et al., 2003)

D-score	Interpretation
D-score <= -0.65 =>	"a strong" preference for hypothesis non-conforming pairings
D-score < -0.35 =>	"a moderate" preference for hypothesis non-conforming pairings
D-score < -0.15 =>	"a slight" preference for hypothesis non-conforming pairings
-0.15 <= D-score <= 0.15	"little to no" preference
D-score > 0.15 =>	"a slight" preference for hypothesis-conforming pairings
D-score > 0.35 =>	“a moderate" preference for hypothesis-conforming pairings
D-score >= 0.65 =>	“a strong" preference for hypothesis-conforming pairings

6.2.8 Data analysis

SPSS (version 29) (IBM, New York, USA) was used to analyse the data. A statistician was consulted on the planned data analysis. Firstly, non-consents were removed from the analysis as well as participants who had not heard of either Alzheimer’s disease or dementia before. D-scores from the raw summary Inquisit 6 files were extracted from each participant and matched to the same participant’s questionnaire items in SPSS (version 29).

Unlike other chapters, due to the insufficient sample size, potential IERs were not removed from the analysis. This is a limitation to consider, and is explained in the discussion section of this Chapter.

Questionnaires were summed in line with guidelines (reported in Chapter 5, sections 5.3.7 and 5.3.8), and descriptive statistics were obtained. Missing cases for variables were checked. Less than 2% missing cases were detected for the Brief A-ADS, RAS and BSDS (n = <5 cases). The AQ-8-C had 39.1% (n = 45) missing cases. As a result, the data underwent multiple imputations to replace missing data and retain the integrity of the sample size since there was a relatively high proportion of missingness. Ten imputation iterations were chosen since this provides a balance between efficiency and imputation quality for datasets with moderate to high missingness (de Goji et al., 2013; Von Hipel, 2020). Following imputation, skewness and kurtosis were checked. There was a slight to moderate skewness and kurtosis exhibited pre and post-imputation across the Brief A-ADS, RAS, BSDS, and AQ-8-C. As these were not extreme values, they did not undergo transformations. As a result, a non-parametric test was used. The Spearman's rho bivariate correlation was selected due to its robustness, and its assessment for strength of the monotonic relationship between variables, which may be more appropriate for relationship between variables that are not strictly linear. The Spearman's Rho was used to test for associations between the implicit and explicit measures. An adjustment for bias with 95% CI was selected due to using non-normal data.

An independent samples t-test was performed to determine whether there was a significant difference between the means of two independent groups. The IAT d-score mean was compared between different demographic groups. For this, the demographic groups were dichotomised. For variables such as ethnicity and religion, the group with the most participants were categorised versus all other groups within that category (sex: female = 1, male = 2; religion: Muslim = 1, all other religions = 0; ethnicity: South Asian = 1, All other ethnic groups = 0; age: 13-16 years old = 1, 17-18 years old = 0; whether have heard of the terms Alzheimer's disease or dementia before: both terms = 1, one term = 0). 95% CI were obtained with t-tests and the effect size was reported using Cohen's d since the assumption of equal variances was obtained via Levene's test (Nordstokke & Zumbo, 2007).

6.3 Results

A total of 130 adolescents aged 13-18 years olds were recruited. Three participants (2.3%) had never heard of either ‘dementia’ or ‘Alzheimer’s disease’ before. As such, these individuals were removed from the analysis. Following data cleaning procedures (including removal of non-consenting participants), 115 adolescents remained in the analysis. On average, participants were 16.4 years old (SD = 1.2). Demographic features of the participants included the sample being predominantly Male (64.3%, n= 74), South Asian (47.8%, n = 55), and Muslim (52.2%, n = 60). The mean d-score of the 115 participants was .00, indicating ‘little to no preference’ overall for negative or positive bias towards dementia. See Table 39 for descriptive statistics.

Table 39 - Chapter 6 Demographics and Descriptive statistics

	Demographics	Valid %	M ± SD	N
Schools				**3**
	School 1	20.9%		24
	School 2	12.1%		14
	School 3	67%		77
Sex				**115**
	Female	35.7%		41
	Male	64.3%		74
Age			16.40 ± 1.2	**115**
	13	2.6%		3
	14	7.0%		8
	15	8.7%		10
	16	26.1%		30
	17	40.9%		47
	18	14.8%		17
Ethnicity				**115**
	White	20%		23
	Black	16.5%		19
	South Asian	47.8%		55
	East Asian	3.5%		4
	Mixed ethnic background	7%		8
	Other	5.2%		6
Religion				**115**
	No religion	17.4%		20
	Christian	22.6%		26
	Hindu	1.7%		2
	Muslim	52.2%		60
	Sikh	3.5%		4
	Did not want to answer	2.6%		3

Continued. Table 39 - Chapter 6 Demographics and Descriptive statistics

Whether participants have heard of Dementia, Alzheimer's Disease or both terms				**115**
	Dementia only	17.4%		20
	Alzheimer's Disease only	3.5%		4
	Heard of both terms	79.1%		91
Variables	Brief A-ADS total score		49.48 ± 6.89	115
	AQ-8-C total score		25.75 ± 6.70	115
	RAS total score		10.25 ± 2.76	115
	BSDS total score		3.04 ± 0.97	115
	BSDS dichotomised (low social-desirable responding) (score of 0 – 2)	23.5%		27
	BSDS dichotomised (high social-desirable responding) (score of above 2)	76.5%		88
	IAT d-score		0.00 ± 0.31	115

6.3.1 The relationship between explicit and implicit measures

A bivariate Spearman's Rho correlation revealed weak associations between explicit and implicit measures; AQ-8-C and IAT d-score (r_s = -.08, 95% CI = -.27 – .11), RAS and IAT d-score (r_s = .04, 95% CI = -.15 – .22), BSDS and IAT d-score (r_s = -.03, 95% CI = -.21 – .16), and Brief A-ADS and IAT d-score (r_s = .14, 95% CI = -.05 – .32). See Table 40. .

Table 40 - Bivariate Spearman's Rho correlation for the association between IAT d-scores and explicit measures

	Spearman's Rho bivariate correlation (n = 115)		
Variables	**r_s**	***p***	**CI [95%]**
IAT d-score and Brief A-ADS	.14	.13	-.05 – .32
IAT d-score and AQ-8-C	-.08	.37	-.27 – .11
IAT d-score and RAS	.04	.70	-.15 – .22
IAT d-score and BSDS	-.03	.78	-.21 – .16
AQ-8-C and Brief A-ADS	-.33	<.001***	-.49 – -.15
AQ-8-C and RAS	.14	.13	-.05 – .32
AQ-8-C and BSDS	-.11	.24	-.29 – .08
Brief A-ADS and RAS	-.56	<.001***	-.68 – -.42
Brief A-ADS and BSDS	.27	.00**	.09 – .44
RAS and BSDS	-.24	.01*	-.41 – -.06

Variables: IAT d-score; Brief AADS - Brief Adolescent attitudes towards dementia scale; AQ-8-C – Attribution questionnaire 8 items for children; RAS – relational ageism scale; BSDS – Brief Social desirability Children's Scale. Two-tailed statistical significance (*p*): * = *p* < 0.05; ** = *p* < 0.01; * *p* = < 0.001. r_s = Spearman's Rho coefficient; CI 95% = confidence interval 95% (lower – upper bound).**

6.3.2 Comparing the means of explicit measures, and IAT d-scores across socio-demographic variables

The independent samples t-tests indicated no statistically significant difference in IAT d-score between any socio-demographic groups ('little to no preference'). See Table 41 and 42.

When comparing the means of the explicit measures across the socio-demographic groups, only sex and religion were statistically significant. The independent samples t-test indicated that females had better attitudes (Brief A-ADS) and fewer stigmatising attitudes (AQ-8-C) compared to males. Both demonstrate moderate effects. Females had significantly higher scores of social desirability compared to males ($p<.001$, $d = .67$). The only other statistically significant difference was religion, with Muslim participants having fewer stigmatising attitudes (AQ-8-C) compared to other religions, ($p= .03$, $d= .42$). See Table 42.

Table 41 - IAT d-score means by socio-demographic group

Category	Group	N	IAT d-score Mean ± SD
Sex	Female (0)	41	.00 ± .30
	Male (1)	71	.01 ± .32
Religion	All other religions (0)	55	.05 ± .34
	Muslim (1)	60	.03 ± .28
Ethnicity	All other ethnic groups (0)	60	.00 ± .33
	South Asian (1)	55	.01 ± .30
Age	17-18-years old (0)	64	-.02 ± .28
	13-16-years old (1)	51	.03 ± .34
Heard of Dementia/Alzheimer's Disease	One term (0)	24	-.03 ± .29
	Both terms (1)	91	.01 ± .32

Table 42 - Comparing the means of the implicit and explicit measures across socio-demographic variable

		Independent samples t-test (n = 115), *df* = 113				Independent samples effect size (Cohen's d)		
Socio-demographics	**Variables**	**t**	**MD**	***p***	**95% CI**	**Standardised**	**Point Estimate**	**95% CI**
Age (0 = 17-18 years old)	IAT d-score	.88	.05	.38	-.06 – .17	.31	.17	-.20 – .53
	Brief A-ADS	.00	.01	1.00	-2.57 – 2.58	6.92	.00	-.37 – .37
	AQ-8-C	-1.35	-1.69	.18	-4.17 – .80	6.68	-.25	-.62 – .12
	RAS	1.04	.54	.30	-.49 – 1.57	2.76	.20	-.17 – .56
	BSDS	-1.35	-.24	.18	-.60 – .11	.96	-.25	-.62 – .12
Sex (0 = Female)	IAT d-score	-.13	-.01	.90	-.13 – .11	.31	-.03	-.41 – .36
	Brief A-ADS	2.53	3.31	.01*	.72 – 5.91	6.73	.49	.11 – .88
	AQ-8-C	-2.39	-3.06	.02*	-5.59 – -.53	6.57	-.47	-.85 – -.08
	RAS	-.88	-.47	.38	-1.54 – .60	2.77	-.17	-.55 – .21
	BSDS	3.42	.62	<.001***	.26 – .97	.93	.67	.27 – 1.06
Ethnicity (0 = All other ethnic groups)	IAT d-score	.06	.00	.95	-.11 – .12	.31	.01	-.36 – .38
	Brief A-ADS	.25	.32	.80	-2.23 – 2.88	6.91	.05	-.32 – .41
	AQ-8-C	.86	1.08	.39	-1.40 – 3.56	6.71	.16	-.21 – .53
	RAS	-.47	-.24	.64	-1.27 – .78	2.77	-.09	-.45 – .28
	BSDS	1.68	.30	.10	-.05 – .66	.96	.31	-.06 – .68

Continued. Table 42 - Comparing the means of the implicit and explicit measures across socio-demographic variable

Religion (0 = All other religions)	IAT d-score	1.36	-.08	.18	-.19 – .04	.31	-.25	-.62 – .12
	Brief A-ADS	-.48	-.62	.63	-3.17 – 1.94	6.91	-.09	-.46 – .28
	AQ-8-C	2.25	2.77	.03*	.33 – 5.20	6.59	.42	.05 – .79
	RAS	-1.51	-.78	.13	-1.79 – .24	2.75	-.28	-.65 – .09
	BSDS	.79	.14	.43	-.22 – .50	.97	.15	-.22 – .51
Heard of dementia/ Alzheimer's disease (0 = only heard of one term)	IAT d-score	.56	.04	.58	-.10 – .18	.31	.13	-.32 – .58
	Brief A-ADS	1.51	2.37	.13	-.74 – 5.49	6.85	.35	-.11 – .80
	AQ-8-C	-.61	-.94	.54	-4.00 – 2.12	6.72	-.14	-.59 – .31
	RAS	.34	.22	.73	-1.04 – 1.48	2.78	.08	-.37 – .53
	BSDS ǂ	-.33	-.09	.74	-.62 – .44	.97	-.09	-.54 – .36

Variables: IAT d-score; Brief A-ADS - Brief Adolescent attitudes towards dementia scale; AQ-8-C – Attribution questionnaire 8 items for children; RAS – relational ageism scale; BSDS – Brief Social desirability Children's Scale. t = independent samples t-test; df = degrees of freedom; MD = mean difference; *p* = two-tailed statistical significance: * = *p* < 0.05; ** = *p* < 0.01; * *p* = < 0.001; CI 95% = confidence interval 95% (lower – upper bound). The reference group in each socio-demographic variable is listed. Equal variances are assumed. ǂ = equal variance not assumed, *p*<.05 (Welch's t-test).**

6.3.3 Social desirability bias

On average, the IAT d-scores were higher in the low social desirability group (m = .09, SD. = .28) than in the high social desirability group (m = -.02, SD. = .32), though this did not reach statistical significance (t (113) = -1.75, *p* = .08, 95% CI [-.25 – .02], *d* =-.38).

Comparatively, there was a statistically significant difference between social desirability groups on the Brief A-ADS (t (113) = 3.14, p = .00, 95% CI [1.65 – 7.29], *d*= .67), with the high social desirability group having better DRA. A similar effect was observed for the RAS outcome (t (113) = 2.21, p = .03, 95% CI [-2.44 – -.13], *d*= -.47), with high social desirability being associated with holding more ageist beliefs. There was no statistically significant difference between the two groups in their AQ-8-C scores. See Table 43.

Table 43 - Comparing the mean difference between adolescents' low and high social desirability against implicit and explicit measures

		Independent samples t-test (n = 115), *df* = 113				Independent samples effect size (Cohen's d)		
Grouping variable	**Variables**	**t**	**MD**	***p***	**95% CI**	**Standardised**	**Point Estimate**	**95% CI**
BSDS (high social desirability)	IAT d-score	-1.75	-.12	.08	-.25 – .02	.31	-.38	-.80 – .05
	Brief A-ADS	3.14	4.47	.00**	1.65 – 7.29	6.63	.67	.24 – 1.10
	AQ-8-C	-1.16	-1.67	.25	-4.52 – -1.18	6.69	-.25	-.67 – .17
	RAS	2.21	-1.29	.03*	-2.44 – -.13	2.72	-.47	-.90 – -.05

Variables: IAT d-score; Brief A-ADS - Brief Adolescent attitudes towards dementia scale; AQ-8-C – Attribution questionnaire 8 items for children; RAS – relational ageism scale; BSDS – Brief Social desirability Children's Scale. The BSDS dichotomy denotes 1 = low social desirability and 0 = high social desirability. t = independent samples t-test; df = degrees of freedom; MD = mean difference; *p* = two-tailed statistical significance: * = *p* < 0.05; ** = *p* < 0.01; * *p* = < 0.001; CI 95% = confidence interval 95% (lower – upper bound). Equal variance assumed.**

6.4 Discussion

In this novel cross-sectional sub-study, the potential value of using implicit measures of DRA in adolescents was explored. See Table 44 for a summary of findings.

Table 44 - Summary of findings

Outcome of interest	Finding	Implications
Implicit attitudes in adolescents	No significant bias towards dementia in the IAT d-scores.	Aligns with the theory that early experiences may need to be emotional to influence implicit attitudes (Greenwald & Banaji, 1995; Rudman, 2004; Wilson et al., 2000).
The relationship between explicit and implicit measures	There was no relationship between explicit and implicit measures	Lack of correlation aligns with existing literature (Nosek, 2007; Phipps et al., 2019). Exploratory IAT could be a foundation for improving the tools used to measure implicit DRA. Refining the IAT could provide more accurate assessment of the relationship between explicit and implicit DRA.
Implicit attitudes across socio-demographic variables	Little to no preference for implicit bias towards or against dementia in any socio-demographic group.	Interventions aimed at reducing implicit bias can focus on psychological processes rather than tailored to socio-demographics, simplifying the intervention's implementation.
Social desirability bias	Explicit measures correlated with BSDS. There was no significant relationship between BSDS and the IAT (implicit attitudes).	Implications for the attitude measurement literature -influence of social desirability on explicit attitude measures. Highlights a discrepancy between what explicit and implicit measures might be capturing. Thus, future work will need to consider what constructs their explicit and implicit measures are capturing.

6.4.1. Implicit attitudes in adolescents

There was not a significant bias towards dementia in the IAT d-scores, indicating that the adolescents did not hold strong implicit bias towards dementia. This is similar to other related studies where implicit bias was not found in the IRAP trials towards older adults (Cullen et al., 2009). Similarly, in another study, there was little to no correlation between IRAP and dementia attitude trial types (Kane et al., 2020). In the broader IAT discrimination literature, a meta-analysis looking at various discrimination outcomes also found that overall, IAT effects were close to zero (Carlsson & Agerström, 2016).

6.4.2 The relationship between explicit and implicit measures

There was a weak positive relationship between the IAT and the Brief A-ADS. This may suggest a small agreement between implicit and explicit dementia attitudes, where these attitudes are relatively moderate to each other. This weak correlation aligns with existing literature that reports low correlations between explicit and implicit attitude measures (Nosek, 2007; Phipps et al., 2019). Methodologically, the IAT may have had some limitations with its sensitivity, which may have inhibited the relationship with explicit measures. For example, this IAT uses dementia and ageism stereotypes as attributes, which may not be as deeply ingrained or relevant as other social biases to adolescents (e.g., racial bias) (Johnson, 2020). As implicit attitudes are thought to be more stable than explicit attitudes due to their relationship with early associative learning (Vezzali et al., 2023), the developmental variability of adolescents may make the IAT not sensitive enough to detect implicit DRA.

In support of the early associative learning position, three notable early studies have investigated whether development events influence implicit attitudes more than recent events. In one study, attitude objects (such as smoking and body size) was explored. The findings revealed that developmental events could distinctively predict implicit attitudes while explicit attitudes predicted more recent events (Rudman et al., 2007). The findings suggest that early experiences may need to be emotional to influence implicit attitudes (Greenwald & Banaji, 1995; Rudman, 2004; Wilson et al., 2000). From this position, different representations can be activated in different situations,

leading to the inconsistency observed between implicit and explicit measures. Different types of attitude measures may be suited to predict one type of discriminatory behaviour instead of the other (Heider & Skowronski, 2007). This highlights that it is important to consider the type of association being assessed when interpreting data obtained from implicit measures (Gawronski, 2019). However, many of the prior studies examine political, race, and other 'mainstream' social issues in the IAT literature (e.g., see Charlesworth & Banaji, 2022) that make it challenging to apply to the context of dementia fully.

Regarding the translational relevance of these findings, this exploratory IAT could be a valuable foundation for improving the tools used to measure implicit DRA. Refining the IAT, or comparing the IAT with other implicit tasks such as the IRAP, could provide a more accurate assessment of the relationship between explicit and implicit DRA. It may also be able to capture implicit biases towards dementia more accurately in adolescents. In doing so, longitudinal studies in the future could help identify stages in adolescent's development where an anti-stigma intervention could be effective. This would be based on the persistence or change in implicit biases observed as adolescents grow older. This would help identify the types of interventions that could be most effective for reducing both explicit and implicit negative DRA.

6.4.3 Implicit attitudes across socio-demographic variables

The findings indicated that there was little to no preference for implicit bias towards or against dementia in any socio-demographic group. However, this is not necessarily universal across implicit bias research, with the strength and direction of the association typically context-dependent. In fields such as racial discrimination, implicit biases across socio-demographics in young people, including as young as six and ten years old have been demonstrated (Baron & Banaji, 2006; Williams & Steele, 2019). The findings in the context of the thesis may imply that implicit biases towards dementia are shaped by factors not strongly tied to socio-demographic variables. This is a plausible hypothesis given that this thesis highlights empirically that modifiable factors of DRA are more influential than socio-demographic variables (Hassan et al., 2023a).

Overall, the IAT is a context-sensitive test. Adolescents' likely limited direct familiarity with dementia could have contributed to the lack of detectable implicit bias across socio-demographic groups. Future work could track changes in implicit attitudes over time across different demographic groups to understand the cultural and social factors underpinning attitude development. Future work will need to recruit more diverse samples by including more regions of England, for example. In doing so, it could be possible to confirm that socio-demographic factors are less critical in implicit attitudes. This would allow researchers to focus more on the cognitive and affective mechanisms underlying implicit attitudes. As a result, a more generalised understanding of implicit attitudes could be achieved. Second, interventions aimed at reducing implicit bias can focus on psychological processes rather than tailored approaches based on socio-demographic features, simplifying the intervention's implementation. Last, it would allow future work to focus on new experimental designs and refine theoretical models of formation and change of implicit attitudes that emphasise non-socio-demographic influences (e.g., more situational factors and societal norms) (Shepherd, 2011).

6.4.4 Social desirability bias

The findings address a methodological gap in the literature by implementing a measure of social desirability alongside explicit and implicit attitude measures in adolescents. This is due to the challenges reported in accurately capturing self-reported attitudes (Van de Mortel, 2008). This was the case in this sub-study, with a high percentage of the participants displaying high social desirability bias (74.8%). Explicit measures (Brief A-ADS and RAS) and the BSDS significantly correlated. Notably, if young people have formed minimal cognitive, affective, and behavioural impressions on a social category due to lack of experience with it, they are more likely to select responses on explicit measures that they believe are what is socially expected of them by the researcher or their peers (McKeague, O'Driscoll, Hennessy, & Heary, 2015).

The findings also indicated that there was no significant relationship between BSDS and the IAT. The lack of a relationship between the BSDS and IAT is expected. Implicit measures such as the IAT are thought to be less susceptible to social desirability bias due to the IAT relying on automatic associations (Nosek, 2007). This

is supported by the dual process model, where deliberate processes involving reflective and controlled thought (self-report measures) are susceptible to social desirability, which is less relevant for implicit attitudes (Crano & Prislin, 2011).

There were also sex differences in social desirability that suggest that the analyses of sex differences on implicit and explicit measures should be made after controlling for social desirability scores. Males and females differ in the level of social desirability, with females in this study displaying a greater tendency to respond socially desirable. This aligns with prior research (e.g., Camerini & Schulz, 2018) as hypothesised (see section 6.1). This may explain why females reported more positive attitudes than males, reflecting socially desirable responding in the explicit measures rather than females' true attitudes. Although the BSDS was included to assess participants tendencies towards socially desirable responding, the score was not controlled for before the analyses of sex differences on implicit and explicit measures. Thus, the observed group-level differences may reflect unadjusted data, potentially introducing bias into the interpretation of the findings. Thus, future work should consider controlling BSDS scores to disentangle sex differences.

These findings have implications for the attitude measurement literature, as they highlight the influence of social desirability on explicit attitude measures. This highlights the need to consider how people may respond to items that align with perceived norms rather than true attitudes. This expected finding of high social desirability correlating with more positive explicit attitudes but not significantly influencing implicit attitudes, highlights a discrepancy between what explicit and implicit measures might be capturing. This is an essential methodological consideration for future work. Future work will need to consider what constructs their explicit and implicit measures are capturing.

In line with the above, social desirability had moderate to large effects on explicit measures (Brief A-ADS and RAS). However, there was no association between social desirability and the AQ-8-C. A methodological explanation could be that the AQ-8-C was positioned at the end of the questionnaire and had more response options (one to nine) for each item. Therefore, response fatigue could have occurred, leading to

participants responding less thoughtfully, which may have weakened the social desirability effect (Arthur, Hagen, & George, 2021, p. 112). Shorter scales are more likely to prompt participants to remember their previous response and respond more consistently by presenting desirably (Kieruj & Moors, 2010). This perhaps could explain why there was not a significant association between the AQ-8-C and other measures (e.g., RAS).

The central research gap in understanding the relationship between implicit, explicit and social desirability measures being used in adolescents is the developmental trajectory of social desirability on attitudes across the adolescent age groups. Understanding this could help scholars understand where social desirability peaks during this crucial developmental stage of attitude formation so that age-appropriate strategies to target social desirability can be implemented. Longitudinal studies can also examine whether social desirability is consistent over time.

6.4.5 Strengths and limitations

Strengths

First, using implicit and explicit measures allows for a multifaceted exploration of DRA and associated variables, providing a nuanced snapshot of DRA not previously captured in adolescents. The study employed validated ageism, social desirability, and DRA measures, strengthening the validity of this study. The use of these validated measures alongside the IAT, meant that there were theoretical underpinnings to the hypotheses. Developmental frameworks were considered to better understand what potential affective mechanisms of implicit attitudes (Rudman et al., 2007) occur in adolescents DRA. As we build evidence in time, this may contribute to our understanding of how DRA forms from a young age, and contextualise the different explicit and implicit processes that take place at the early stages of DRA formation.

Second, the explicit measures used in this study have been validated and tested recently in the adolescent demographic in the prior chapters of this study. The measures were piloted by young people to ensure readability and accessibility. Measuring social desirability helps account for potential misrepresentations in self-

reported data and helps explain how different demographic groups may exhibit varying explicit attitudes and provide a broader representation of DRA.

Third, the implicit measure was based on an existing IAT utilising the ageism paradigm, which increases methodological rigour. Constructing a new dementia-based IAT without sufficient empirical evidence would have been challenging. This is because the number of trials and attributes can vary widely in the literature, and there are mixed results across IATs used in developmental research involving younger demographics such as children (Rae & Olson, 2018). The study by Rae and Olson used an existing paradigm to avoid variability in IAT structure and improve comparability with other findings, given the mixed results in reliability and predictive validity of IAT in developmental research. Additionally, children's implicit attitudes may be less elaborate than adults (Phipps et al., 2019), and a slower reaction time in younger demographics can affect response to stimuli decision tasks (Bucsuházy & Semela, 2017). This is pertinent because reaction time is a key feature in most implicit measures (Epifania, Anselmi, & Robusto, 2020).

Fourth, this study presents the stimuli in the IAT as words instead of images. Evidence suggests that using images can introduce biases related to other social categories, such as race or sex (Olson & Fazio, 2003). Variations in such attributes can affect the types of associations and emotional reactions towards category members (Hagiwara, Kashy, & Cesario, 2012). Word stimuli help mitigate these issues, reducing the likelihood of measurement error (Cooley & Payne, 2017).

Lastly, there was a strategic effort to recruit a more diverse population of adolescents by targeting regions with greater ethnic diversity, deprivation, school type, and age range. This enhances the generalisability of the findings across different demographic groups, providing a broader perspective on implicit research conducted in adolescents.

Limitations

First, the sample size was relatively small (n = 115), making it difficult to generalise the findings to the broader adolescent population. The insufficient sample size impacted the study's power to detect significant relationships, potentially reducing the

overall validity and reliability of the results. Confidence intervals were used to interpret the findings as a result. While there was no significant relationship between the implicit and explicit measures (which was expected), a lack of detection of implicit attitudes towards dementia may be due to the study being insufficiently powered rather than a lack of implicit bias in the participants. Future work will need to recruit larger samples to improve the detection of effects. The study does have a larger sample size in comparison to other recent DRA implicit studies in young British adults (18-25-year-olds) (n = 56) (Kane et al., 2020). There is generally a lack of DRA implicit studies (Kane et al., 2020), and implicit attitude studies in young people generally (Phipps et al., 2019). As the employment of implicit tests becomes more widely used alongside explicit measures in DRA studies, there will likely be a greater ability to test the IAT in more young people. Publishing an IAT test in young people protocol could help researchers optimise the number of IAT trials or consistently use the same tools to increase reliability in the findings across DRA IAT studies.

Second, while the sample exhibited greater ethnic and religious diversity, it does not necessarily represent the demographic makeup of England. For example, White British adolescents were underrepresented (64.3% of school-age young people in England identify as White British [ONS, England and Wales Census, 2021] versus 20% in this study), and South Asian adolescents were overrepresented. Due to the limited sample size, weighting the data to account for these imbalances was not feasible particularly with dichotomised variables (i.e. even smaller sample size in groups), as this could lead to increased random errors or overrepresentation of certain groups (Bruch & Felderer, 2023) that make the findings less reliable.

Third, the data is cross-sectional, limiting the ability to make casual inferences and understand how variables influence each other over time. Although the intention was to conduct a quasi-longitudinal study, logistical constraints prevented this. A longitudinal approach would have provided more robust insights into temporal attitudes, addressing limitations in the DRA IAT literature regarding the lack of longitudinal testing (Kane et al., 2020).

Lastly, the presence of a researcher during data collection could have led to demand characteristics and higher social desirability bias among participants. This was likely given the high social desirability tendency observed in the sample (75%), compared to lower levels reported in the cross-sectional study reported in Chapter 5, which mostly took place remotely. To address this limitation in future work, conducting data collection remotely may help reduce the influence of the researcher's presence. One way to achieve this is by purchasing the Inquisit software licence covering remote data collection. However, this is costlier than an individual licence, which needs to be considered. Separately, the survey was anonymised, and participants were ensured confidentiality to reduce social desirability. However, with the presence of a classroom teacher and a researcher, it could have added pressure for the participants to respond desirably. Ideally, participants who exhibited social desirability could be removed from the analysis to retain the integrity and validity of the findings. However, due to the small sample size, this was not feasible. Recruitment of a larger sample size could account for exclusions without conceding statistical power (Ward & Meade, 2023).

6.5 Conclusions

This Chapter presents a novel, exploratory study on the relationship between implicit and explicit DRA. The findings contribute to the DRA literature by integrating explicit measures validated in adolescents and an implicit DRA (IAT) measure. The study underscores the importance of considering both measures when studying attitudes, particularly in adolescents, who are highly susceptible to social influences. The lack of a relationship between implicit and explicit DRA highlights three main implications for the DRA field. First, implicit attitudes may capture distinct components of attitudes (e.g., cognitive and affective processes). Integrating explicit and implicit measures is necessary to capture nuances in adolescents DRA quantitatively. Not least, social desirability was strongly related to DRA explicit measures, which IAT may help control. Second, there is a need for methodological adjustments. This includes the number of trials, and IAT validation to ensure the IAT can capture what it is setting out to capture. These would need to tailored for the age group of interest through piloting. Third, it would be useful for future work to observe the relationship of implicit and explicit IAT longitudinally across the adolescent stages of development

to pinpoint the underlying processes of attitudes, as well as the stability and temporality of attitudes in both explicit and implicit states. Overall, the application of capturing implicit DRA includes designing effective anti-stigma initiatives that better tackle the affective component of attitudes, given that this is associated with early attitude formation. Given the malleability of attitudes in adolescents, addressing implicit attitudes early may reduce the likelihood of developing negative biases towards dementia, and increase the likelihood of building positive experiences with people living with dementia.

Chapter 7 General discussion

The primary purpose of this thesis was to identify the potential determinants of DRA in young people, with an emphasis on identifying potentially modifiable factors for future anti-stigma initiatives. These factors were identified and presented across three main studies of this thesis. This includes the systematic review (Chapter 3), a secondary data analysis (Chapter 4) (Hassan et al., 2023a), and a novel cross-sectional study (Chapter 5). The purpose of this Chapter is to summarise the most pertinent findings from the thesis, outline the implications, identify the strengths and weaknesses of the thesis, discuss potential avenues for future research, and present the novel contribution to knowledge.

7.1 Results summary

An overview of each Chapter's aims, objectives, methods, and results are outlined below in Table 45.

Table 45 - An overview of each Chapter's aims, objectives, methods and key findings

Chapter 2	**Overview**
Aim	Identify what DRA outcome measures are used for the adolescent population.
Research question	What methods are used to measure DRA in adolescents?
Objectives	1. Conduct a scoping review to identify methodologies used to measure DRA in adolescents. 2. Identify which measures could be adopted or adapted in the subsequent empirical chapters of this thesis to measure DRA in adolescents. 3. Describe the psychometric properties of validated measures. 4. Identify the limitations of the measures currently used in DRA research in adolescents.
Methods	A scoping review using Arksey and O'Malley's framework and descriptive narrative synthesis.
Results and key takeaways	1. Fourteen studies were identified; with 13 unique measures. 2. The Brief A-ADS and KIDS were the most validated and psychometrically sound measures. 3. Construct validity – Brief A-ADS (single factor structure) while KIDS captures three. The measures reflect the construct *attitudes*. The KIDS adopted a tripartite framework of attitudes. Good convergent validity, indicating they measure similar constructs. Good concurrent validity. The two measures moderately correlated with each other. Both measures report content validity and good internal consistency. 4. No gold standard measure. Gaps in psychometric reporting and theoretical frameworks. No implicit measures used, limited number of questionnaires designed specifically for adolescents, and lack of definition for the construct attitude.
Chapter 3	**Overview**
Aim	Explore what evidence exists on factors associated with DRA in adolescents.
Research question	What factors are associated with DRA?
Objectives	1. Conduct a systematic literature review to identify factors associated with DRA in adolescents. 2. Investigate the strength of the association between identified factors with DRA in adolescents. 3. Identify the gaps in the current literature.
Methods	Systematic review using SPIDER; mixed methods appraisal tool; narrative synthesis.
Results and key takeaways	1. Across eight studies, seven factors were identified (age, ageism, empathy, ethnicity, gender, knowledge, level of contact). 2. Three factors were consistently associated with DRA (gender: three quantitative studies associated with DRA, one qualitative study not associated; knowledge: three quantitative studies associated with DRA; and contact: four studies associated with DRA, two quantitative, and two qualitative). Unclear associations between DRA and ageism, empathy, ethnicity, and age due to mixed findings or lack of studies. These require further investigation. 3. Main gaps in the literature include that empathy needs quantitative investigation as only qualitative association, unclear whether direct or indirect contact is more influential on DRA, studies had homogenous samples that make it difficult to generalise to other adolescents, and studies were judged as poor quality due to lack of reporting on methods (e.g., inclusion/exclusion criteria and lack of validated tools)

DRA: Dementia-related attitudes; Brief A-ADS: Brief adolescent attitudes towards dementia Scale; KIDS: Kids insight into dementia survey; SPIDER: Sample, phenomenon of interest, design, evaluation, and research type.

Continued. Table 45 - An overview of each Chapter's aims, objectives, methods and key findings

Chapter 4	**Overview**
Aim	Identify demographic groups more susceptible to negative DRA and associated modifiable factors.
Research question	What factors are associated with DRA in an adolescent cohort (<18 years) and how does modifiable factors (e.g., contact) or non-modifiable factors (e.g., age, sex, and ethnicity) influence these attitudes?
Objectives	1. Conduct a secondary analysis of existing cross-sectional data to explore factors associated with adolescent DRA. 2. Analyse the association between modifiable factors, non-modifiable factors and DRA using multiple regression. 3. Explore direct effects of non-modifiable and modifiable factors, and DRA using exploratory structural equation models to determine which factors are more influential on DRA. 4. Explore mediatory effects of non-modifiable and modifiable factors, and DRA using exploratory structural equation models to determine which factors are more influential on DRA.
Methods	Secondary data analysis of 432 participants aged 12-15 from secondary schools. Regressions and exploratory SEM. DRA outcomes: Brief A-ADS and KIDS. Behavioural intention: willingness to work with dementia, Predictor variables: age, gender, whether participants have heard of dementia, level of contact (direct and indirect subscales), empathy (affective, cognitive, and prosocial subscales).
Results and key takeaways	1. First study to explore the factors associated with DRA in adolescents using SEM. 2. Regressions: Increased prosocial empathy, high levels of direct contact, and being female were significantly associated with positive Brief A-ADS and KIDS (DRA) scores. 3. Direct effects in the SEM: gender and empathy on DRA. Empathy had a direct effect on contact. Attitudes had a direct effect on willingness to work with people with dementia. 4. Mediatory effects: Empathy was a key mediator in the SEM between contact and attitudes. Modifiable factors are more influential than non-modifiable factors in the model. Anti-stigma interventions using contact-based strategies should consider how to stimulate empathetic responses to shape DRA.

DRA: Dementia-related attitudes; Brief A-ADS: Brief adolescent attitudes towards dementia Scale; KIDS: Kids insight into dementia survey; SEM: Structural Equation Model.

Continued. Table 45 - An overview of each Chapter's aims, objectives, methods and key findings

Chapter 5	**Overview**
Aim B	Explore determinants of DRA in British adolescents.
Research question	What are the drivers and facilitators of DRA in British adolescents?
Objectives	1. Identify demographic groups more susceptible to stigmatising DRA through a novel cross-sectional study. 2. Analyse the association between modifiable factors, non-modifiable factors, and DRA using multiple regression. 3. Explore direct effects of non-modifiable and modifiable factors, and DRA using structural equation models to determine which factors are more influential on DRA. 4. Explore mediatory effects of non-modifiable and modifiable factors, and DRA using structural equation models to determine which factors are more influential on DRA.
Methods	Regressions, descriptive statistics, and SEM. Analysis included 1044 participants aged 11-18 from nine secondary schools across six regions of England. Participants completed questionnaires relating to DRA and demographic information. DRA outcomes: Brief A-ADS and AQ-8-C. Behavioural intention: willingness to work with dementia, Predictor variables: age, sex, whether participants have heard of dementia, level of contact (direct and indirect subscales), empathy (affective, cognitive, and prosocial subscales), level of knowledge, and ageism, ethnicity, religion.
Results and key takeaways	1. Age was the only demographic variable in the regression that was significantly associated with DRA outcomes. Older participants held more negative DRA than younger participants. 2. Modifiable factors influence DRA more than demographic factors in the regressions (higher levels of dementia knowledge, affective and prosocial empathy were associated with positive DRA while high levels of ageist beliefs were associated with negative DRA. 3. The largest direct effects in the SEM were contact, empathy, and ageism on DRA. 4. Empathy, contact, and ageism were the most influential mediators. Empathy and contact-based strategies are potential targets for anti-stigma initiatives. First study to explore several factors associated with DRA in diverse sample of adolescents using SEM.
Aim C	Determine the level of dementia knowledge in British adolescents.
Research question	What is the level of dementia knowledge among British adolescents?
Objectives	1. Obtain mean dementia knowledge in British adolescents by calculating the percentage of correct knowledge items. 2. Assess which items were answered most correctly using descriptive statistics and a one-sample binomial test. 3. Assess which knowledge items were answered correctly the least using descriptive statistics and a one-sample binomial test.
Methods	Survey assessing dementia knowledge across 1371 aged 11-18 years old. Exploratory descriptive statistics using cross-tabulation and one sample binominal test weighted estimates.
Results and key takeaways	1. Adolescents answered just under half the knowledge items correctly. Targeted education interventions may tackle misconceptions. 2. Most correctly answered item was *dementia was a disease of the brain*. 3. The least answered correctly was *dementia is a mental illness*. Young people hold common misconceptions about dementia.

DRA: Dementia-related attitudes; Brief A-ADS: Brief adolescent attitudes towards dementia Scale; SEM: Structural Equation Model; AQ-8-C: Attribution questionnaire-8-childrens version; IAT: Implicit attitudes test (mentioned in Chapter 6 overview).

Continued. Table 45 - An overview of each Chapter's aims, objectives, methods and key findings

Chapter 5	**Overview**
Aim D	Identify the various experiences of dementia in British adolescents.
Research question	Are different experiences of dementia generally positive or negative?
Objectives	1. Identify whether the quality of contact with dementia is generally positive or negative through a cross-sectional study. 2. Explore whether dementia experiences differ by contact type (direct or indirect) using cross-tabulations. 3. Obtain the percentage of participants who reported positive and negative experiences within each contact type.
Methods	Survey on quality and frequency of contact with dementia. Cross-tabulations and descriptive statistics. Included 1371 participants aged 11-18 from nine secondary schools across six regions of England (also for aim E).
Results and key takeaways	1. Direct contact experiences with dementia were generally positive, while indirect experiences were less positive. 2. A majority of adolescents who spent time with people with dementia felt it was generally a positive experience (90% of sample). Over half the participants felt that dementia was generally negatively portrayed in the media. 3. Strategies should focus on increasing direct, quality interactions between adolescents and people with dementia. Policy and advocacy work on media portrayal of dementia needed. First quantitative study to explore quality of contact with dementia.
Aim E	Identify the frequency of dementia contact in British adolescents.
Research question	Do British adolescents have more direct or indirect contact with dementia?
Objectives	1. Obtain a percentage across different levels of direct (e.g., family member) and indirect contact (e.g., media) with dementia. 2. Obtain the most frequent and least frequent type of contact using a one-sample binomial test.
Results and key takeaways	1. Adolescents had more indirect than direct contact with dementia. 2. A majority of participants had come across someone living with dementia. 3. The most frequent contact experience was watching a TV show or movie about dementia. The least frequently reported experience was looking after someone with dementia.
Chapter 6	**Overview**
Aim	Explore the relationship between implicit and explicit DRA.
Research question	What is the relationship between implicit and explicit DRA in adolescents?
Objectives	1. Conduct an exploratory cross-sectional, correlation study to examine relationship between implicit and explicit DRA measures. 2. Examine implicit DRA in adolescents using an implicit attitudes test. 3. Explore whether implicit attitudes vary across demographic variables using independent samples t-test to assess implicit d-scores. 4. Compare the mean difference between adolescents' low and high social desirability against implicit and explicit measures.
Methods	Relationship between explicit measures of DRA, ageism, social desirability, and implicit bias (IAT) using regressions. Independent samples t-test assessed implicit bias across different socio-demographic groups. N=132 adolescents aged 13-18 from three British schools.
Results and key takeaways	1. No significant evidence of implicit bias and no significant differences between implicit and explicit DRA. 2. No socio-demographic biases in IAT scores. 3. Females were associated with high social desirability compared to males. The IAT scores were higher in the low social desirability group. Social desirability scores correlated with explicit DRA measures. Explicit attitudes are a more reliable measure of DRA in young people presently. Social desirability should be controlled in future work.

7.2 Thesis applications to the DRA field

This section provides the thesis's overall practical and theoretical applications to the DRA field, education settings, and DRA policy.

Theoretical applications

The findings from this thesis contribute to the theoretical understanding of DRA in young people. The thesis integrates attitude formation frameworks, drawing on the ABC model, which understands attitudes developing from the lens of the affective, behavioural, and cognitive components (Breckler, 1984; Perry, Moorhouse, Jacobsen, Loveridge, & Macdonald, 2022). This also aligns with the Attribution Model of stigma developed with mental health in mind (Corrigan et al., 2003). The findings from the thesis demonstrate that young people's DRA are associated not just with knowledge and beliefs (cognitive components), but also with their emotions (affective components) and their interactions (behavioural components) with people living with dementia. This emphasises that DRA initiatives likely need to address all three elements to achieve meaningful attitude change (Eagly & Chaiken, 1993). The thesis also aligns with developmental and social theories, demonstrating that adolescent attitude formation is shaped by a complex interplay of factors (Krosnick & Alwin, 1989).

The findings from this thesis align with the impressionable year's hypothesis, with younger adolescents having more positive DRA compared to older adolescents. This may suggest that less positive attitudes among older adolescents reflects the transition towards the formation of more stable, persistent beliefs due to more life experiences. This highlights that younger adolescents are likely more malleable than older demographics. The findings help demonstrate the likely developmental shifts in attitudes that may occur at different stages of adolescence (Krosnick & Alwin, 1989). However, there are limitations in accounting for attitude stability or changes between younger and older adolescents since the thesis was unable to longitudinally examine attitude changes between the difference age groups.

Moreover, the findings from the thesis map onto Bronfenbrenner's (1977) ecological systems theory. Religion and ethnicity were not significant predictors of DRA which indicate that contextual factors (e.g., peers, school environment) may play a larger role in shaping adolescents DRA than cultural factors.

The thesis validates the contact hypothesis with both direct and indirect interactions with dementia influencing adolescents' DRA, as well as their experiences of dementia. Greater contact was related to less negative DRA and more positive empathy, supporting the empathy-altruism hypothesis where empathy reduces prejudice (Allport, 1954; Batson et al., 1991). The TPB also provided insight into how adolescents' DRA influence their behavioural intentions. Theoretically, attitudes and behaviour are strongly related via the affective and prosocial components of attitudes (Ajzen, 1991). Therefore, increasing opportunities for meaningful contact with people with dementia is essential for improving DRA. Integrating theoretical frameworks from this multifaceted lens gives a more comprehensive understanding of how several factors are inter-related. This builds a more complex picture of how DRA forms through numerous factors during a young person's development, which is important in the context of developing effective initiatives. This addresses the widely cited limitation in the DRA literature where there is a lack of reporting on the theoretical frameworks underpinning the measured constructs, and a lack of developmental consideration (Kane et al., 2020).

Practical applications

The practical applications of the findings from this thesis include providing actionable strategies to address DRA in young people. This aligns with England's policy aim 'Challenge on Dementia 2020' (Department of Health & Social Care, 2015; 2016). This includes the development of dementia awareness programmes, targeted interventions for various demographics, and public health policies aimed at improving DRA, which indirectly supports people living with dementia. Chapter 5 of this thesis highlighted that if we are to improve DRA in young people, contact as a strategy appears to be key. An example of contact-based interventions that demonstrate greater contact with dementia improved DRA includes 'Adopt a Care Home' initiative in 10-

year olds (Di Bona et al., 2019) and ‘An intergenerational reminiscence programme’ between youth (age 16) and older adults with dementia (Chung, 2009). The findings of this thesis also demonstrated that there are not only direct pathways to improve DRA, but there are also several indirect pathways through increased dementia knowledge and improved empathy. Since, contact, knowledge, and empathy directly and indirectly influenced DRA, interventions that utilise a combination of these elements (e.g., ‘Kids4Dementia Education program’, ‘Adopt a Care Home’ intergenerational initiative, and ‘DEALTS 2 programme’) (Baker et al., 2019; Di Bona et al., 2019; Heward et al., 2020, respectively) may be more effective for stigma reduction in young people.

Apart from potential age-related decline in DRA, it does not appear that there are specific demographics that have a better or worse DRA overall, despite the particularly mixed evidence on gender differences in DRA in the wider DRA literature. This indicates that there needs to be a universal approach to improve DRA, rather than prioritising specific groups.

Young people's level of dementia knowledge has scope for improvement, in line with prior research on British adolescents (Isaac et al., 2017). Given the misconceptions held by young people, insights gained from this thesis can inform the development of dementia awareness programmes. The findings impact public health policy, where policymakers can leverage these insights to advocate for the integration of dementia education in the school curriculum. This is in line with the national dementia strategy in England, which includes the goal for all primary and secondary schools to increase awareness and understanding of dementia (Department of Health and Social Care, 2015).

Notably, the findings highlighted that young people are coming into contact with dementia as well as providing some level of care. There is a real need to better support young people in caring for people living with dementia (Masterson-Algar et al., 2022; McNaney et al., 2017). With the increase in multigenerational living, more and more young people will likely form an essential part of the support system for people living with dementia. While there are efforts to recognise young people, who identify as

young carers (Masterson-Algar et al., 2023), there are likely young people across England going unsupported. This is particularly the case when being a ‘carer’ becomes overly formalised. Wider dissemination of support networks available for young people in their interactions with dementia may be helpful, as well as equipping young people with tools to support those with dementia. One such example is ‘iSupport for Young Carers’, an e-health intervention that supports the mental health, knowledge and skills of young dementia carers (Masterson-Algar et al., 2022).

The thesis identified that young people are generally unwilling to work with people with dementia in the future, though we can see some factors that might influence these behavioural intentions. Dementia care is a priority (NHS England, 2024; Department of Health and Social Care, 2015), yet we see that even among healthcare students, there is a low preference for working with older people and dementia (Fisher et al., 2022; Hebditch et al., 2020). This is concerning given the estimated workforce gap in the NHS by 2036 that may lead to the failure to meet the demands of people living longer with chronic conditions in England (NHS England, 2023). Understanding the factors influencing young people's attitudes towards working with people with dementia can help inform strategies that encourage young people to pursue careers in gerontology and ultimately contribute to the staffing of a skilled and empathetic workforce (Hebditch et al., 2020).

Methodological implications

In this thesis, it was noted that scholars have identified that there is a need to devise more rigorous study designs by adopting standardised DRA measures, diversifying participant samples, applying theoretical frameworks, and assessing attitudes through multiple means such as explicit and implicit measures (Kane et al., 2020). This thesis's empirical chapters overcome the DRA literature's main design limitations. The findings from the scoping review (Chapter 2, section 2.5) not only identified the number of measures that exist, but specifically reported the psychometric comprehensiveness of each tool by age group. This provides a distinction between the tools that are adequate for the use of DRA measurement in adolescents.

Theoretical frameworks underpinning these measures were identified. The study highlighted that the Brief A-ADS and KIDS had the most robust psychometric validity for DRA measurement in young people. Positionally, there is still scope for improvement in DRA measurement. The implications of using these higher-quality measures will increase the reliability of the findings in the future (Hendrick, Fischer, Tobi, & Frewer, 2013). A broader implication is that researchers adopting the measures with theoretical frameworks underpinning them provide a better understanding of the dimensions of attitude that are being captured. However, there is a cross-cultural relevancy limitation since the high-quality measures identified in the review are in English. Adopting these measures would require translation and ensuring the items are culturally relevant, sensitive, and validated in the language which they are translated into (del Rosario Basterra et al., 2011).

7.3 Future research: gaps and future work

This thesis has identified several avenues for future work, including research questions that have emerged that warrant further investigation. Methodological refinements are also needed to enhance future research when working with young people.

7.3.1 Future work

Shaping future interventions development and evaluation:

Findings from this thesis could inform how best to develop and evaluate future anti-stigma initiatives (e.g., contact-based interventions that elicit empathy). At present, we are aware of dementia awareness and anti-stigma initiatives that are either not theoretically underpinned, or robustly evaluated using standardised measures (e.g., Atkinson & Bray, 2013; Chow et al., 2018; Farina et al., 2020b). This will enable pertinent DRA outcomes to be robustly measured, and also ensure that potential mediators are captured too (e.g., changes in empathy). Demonstrating the benefits of the contact-empathy-based approach over conventional interventions could also justify the cost and time of running them with schools.

The findings from the thesis also has the potential to inform future policy. First, policy work could include guidance on effectively introducing dementia into the national school curricula (e.g., science, citizenship, health and social care) that integrates dementia knowledge with dementia contact. This can provide a structured approach to addressing dementia awareness (Department of Health and Social Care, 2015). At a broader level, the findings can be used to inform policy guidelines around the requirement to consult those with lived experience of dementia within the film and media industry. This is to ensure more accurate portrayals of dementia. This is based on the findings from Chapter 5 of this thesis that highlight that young people in general believe that dementia is represented negatively in the media.

Willingness to work with people with dementia specificity:

Since the item relating to willingness to work with people with dementia was nonspecific, with no guidance given on the type of careers, it is unclear what type of work young people are associating with dementia. Future research could carry out an experimental vignette survey (Atzmüller & Steiner, 2010) where young people are randomly given vignettes of doctors/nurses/carers. In some vignettes they are informed that they would be helping a person with dementia, in others, they are not. This could help disentangle whether it is the professions versus the population that young people have an issue with.

Longitudinal studies:

While this thesis provides a snapshot of the factors influencing adolescents' attitudes at a single point in time, longitudinal studies are necessary to understand how DRA change over time, which is a significant gap in the current adolescent DRA research. Longitudinal studies could give insight into how stable DRA are adolescents age. While this was the initial plan for this thesis, there were significant recruitment challenges. Future research should develop strategies to retain engagement with schools. A potential solution is to engage headteachers as PPI members to better understand how researchers and schools can facilitate this type of research in the school setting, and what factors incentivise schools to engage over time with research.

Use of mixed methods:

Qualitative methods are typically the preferred/most common approach in the DRA literature. Future work could incorporate qualitative research to provide a richer and more comprehensive approach beyond the quantitative findings, particularly as the quantitative data might be seen as reductionist (Choy, 2014). This is especially true when dichotomising the outcomes (Mehrad & Zangeneh, 2019; Pham, 2015). Mixed method approaches could help provide a more comprehensive picture of the topic (Creswell & Clark, 2017). For example, future work could quantify the association between dementia experiences, whilst also being able to delve deeper into the underlying stories through qualitative interviews. Triangulation is one method that allows for validating both data types (Hussein, 2009).

Expanding SEM:

While the SEM was able to explore the interactions between variables identified in the systematic review (Chapter 3), there are likely additional factors not covered in this thesis (e.g., urban versus rural living) (Burgener et al., 2015). This is because the factors did not explain all of the percentage variances in the models. Alongside building more complex models to account for additional variables, future work could use multi-group analysis to compare SEM's across different socio-demographic groups. This would provide insight into how these relationships between factors differ across these groups. However, there needs to be careful consideration of model complexity with practicality. If the aim is to practically improve DRA, we should be looking for the factors that have the strongest effect sizes. Similarly, simpler models have an advantage in terms of real-world applicability to settings realistically.

Dementia care in young people:

Over 25% of the participants reported that they have cared for someone with dementia before (Chapter 5, section 5.4.1). Future work could explore the amount of time (hours per week) a young person looks after someone with dementia, whether they currently live with someone with dementia, and the specific nature of their caregiving. Due to the exploratory nature of the analysis and focus specifically on DRA outcomes in this

thesis, this was not captured in the questionnaires. This leaves a gap in understanding the full extent of the young person's experience. Understanding this has important implications for advocating for support for young people and acknowledgement in future policy.

7.3.2 Considerations for methodological refinement

IAT:

Future work could refine and validate the IAT for adolescents and DRA research. Piloting and optimising adolescent trials would ensure their suitability and reliability for this demographic, which studies have yet to test extensively. Optimising the IAT's effectiveness would allow researchers to integrate its use alongside self-report measures more widely, contributing to a more comprehensive understanding of DRA.

Validation of tools:

The NILTS tool was not designed or validated for use in adolescents. This may impact the validity of the findings relating to the level of knowledge. This is despite the empirical support for the association between level of knowledge and DRA (Felc et al., 2021; Lo et al., 2020; Werner et al., 2017). To address this issue, exploring existing dementia knowledge tools is necessary. In the study by Isaac and colleagues, a knowledge questionnaire was used (Isaac et al., 2017), but this needed to be validated. A reflection on what types of knowledge is most pertinent to DRA in young people should be of particular focus.

Additionally, the quality of contact items has yet to be validated due to the lack of quantitative measurement in the literature. The items were inspired by input from the PPI group and young people panel, who identified that dementia representation in the media is a significant experience to capture despite the notable absence of measures to capture this. Future work could focus on validating and piloting these tools to build upon these initial findings. While the items relating to this was simply to contextualise the sample, future work could focus on the experience of dementia as a main outcome. Generally, the scoping review conducted in Chapter 2 identified the limited reporting

of psychometric properties across the measures. There is scope to improve the quality of measures used in DRA for young people.

Reducing boredom effects:

Boredom effects were detected in the data that contributed to missing data, potentially compromising data quality, albeit MI was used to handle missing data. The questionnaire length was deemed appropriate after piloting it with the young people panel. However, the panel were incentivised with Amazon vouchers, which may have skewed their interest in the questionnaire. Generally, shorter questionnaires result in better survey response rates (Rolstad, Adler, & Rydén, 2011). It is therefore important to consider whether current measures used with young people are appropriate in length. This is to mitigate factors such as boredom effects, participant fatigue (Ghafourifard, 2024), and the questionnaire being overly burdensome on the participant (Rolstad et al., 2011). An effort was made throughout the thesis to select validated shortened versions of questionnaires, such as the Brief A-ADS, BSDS, and shortened NILTS. However, notably, the EmQue-CA had 18 items. Chapters 4 and 5 identified the weak association between cognitive empathy and DRA. Future work could streamline the questionnaire by focusing on affective and prosocial intention related empathy, potentially omitting the cognitive empathy items.

7.4 Strengths and limitations

The strengths and limitations of each sub-study are presented in the respective Chapters. This section provides the strengths and limitations of the overall thesis, while considering the methodological components and design.

Strengths

This thesis has six main strengths.

Principally, this thesis is the first to explore associations between factors and DRA in young people within the SEM context. The SEM is a strength since past research has been limited to reporting an association with no indication of the mediatory

mechanisms behind the associations, which the SEM addresses. The findings add further context on how these factors may interact with each other, specific to this target age group. The findings are timely with the impending global publication by Alzheimer's Disease International, the World Alzheimer's Report on dementia attitudes (September 2024). The survey conducted for the report captures attitudes held by adults worldwide. Alongside their survey findings, the results of the studies conducted in this thesis are disseminated in this year's World Alzheimer's report, as a case study essay. The essay highlights the novel findings relating to British adolescents' experience and DRA, and the importance of this demographic being included in dementia awareness and advocacy.

Second, this thesis has several methodological strengths, notably robust quantitative methods which enhance the findings' generalisability. The structured approach of the thesis is a key strength, as it systematically builds on evidence identified across the DRA literature through a systematic review. This facilitated the replication of factors that already had good consensus on their association with DRA but also added evidence to the factors that had insufficient studies in the DRA literature to make conclusions on their association (e.g., ageism). Another example where the thesis built upon prior evidence is when Chapter 4 revealed that cognitive empathy was less influential than affective and prosocial empathy. Chapter 5 replicated this finding in a larger, more diverse cohort of young people, aligning with developmental frameworks. This increases confidence in the direction future work could move towards.

Third, exploring mechanisms and associations is grounded in theoretical and developmental justifications effectively addressing the methodological gap in the DRA literature, where there is a lack of theoretical underpinning and developmental consideration when measuring attitude constructs (Kane et al., 2020).

Fourth, the explicit DRA measures used in this thesis have been validated and tested recently in the adolescent demographic. The reliability of these measures was checked and reported in the analysis. The measures were also piloted by a sample of young people who deemed the readability and accessibility of the measure items as age-

appropriate. This directly utilises the recommendations from the findings of the scoping review conducted in Chapter 2, which was published (Hassan et al., 2023b). The measures in the review that did not use age-appropriate DRA measures had to change the wording of the questionnaire items to make them accessible, which may have consequences in accurately capturing the intended phenomenon.

Fifth, a strategic effort was made to recruit a more diverse population of adolescents by targeting regions with greater ethnic diversity, regional deprivation, school type, and age range. This addresses a population gap by making the thesis findings more generalisable across different demographic groups than prior research, providing a broader perspective on DRA in British adolescents than previously done.

Last, the primary outcomes of this thesis are not only guided by the evidence but also by those with lived experience of dementia and young people. PPI enhances research by bringing the perspective of those affected by the research so that the study is accessible and contributes research that benefits the population it impacts (Miah et al., 2019). Adopting an intergenerational PPI panel brings together diverse perspectives, which facilitates a richer understanding of how different age groups are affected by DRA. For example, the young people on the panel were able to offer insight into how young people may understand and engage with dementia and were methodologically helpful in checking for the readability and suitability of the questionnaire. At the same time, older members could share their experiences living and caring for someone with dementia. This ensured that the research questions, methods, and outcomes were relevant and beneficial across the age groups. The integration of those with lived experience, young people panel, and early discussions with school leaders on critical ethical considerations strengthen the validity of the thesis.

Limitations

This thesis has six main limitations.

First, the data is treated as cross-sectional. The main limitation of this is its difficulty in making causal inferences about the data and in truly identifying how variables influence each other (Spector, 2019). Findings should be interpreted with the view that

statistical associations do not necessarily equate to meaningful associations, albeit, the bias-corrected confidence intervals and bootstrapping procedures adopted are useful in bolstering accuracy of these associations (Penev & Raykov, 2010).

Second, this thesis captures a single snapshot in time. Generational differences in attitudes tend to reflect sociocultural changes and contexts that occur at particular periods (Donnelly et al., 2016). One study explored the extent to which there are differences in attitudes between different generations (Millennials 1980-1994; GenXers 1965-1979 and Baby Boomers 1946-1964) by analysing multiple large-scale surveys of various social attitudes. The findings revealed generational shifts in attitudes towards the self, community, work and materialistic lifestyle, with the millennial participants seen as more self-focused and individualistic. They displayed less community feeling and more social image than previous cohorts. Millennials were also less likely than previous cohorts to report empathetic concern or take others' perspectives (Twenge, 2014). Thus, while the findings are relevant to the current generation, their experiences of dementia may not necessarily reflect the experiences of the generation after them. Notably, the research was undertaken in the context of England. While this is already justified in Chapter 1 (section 1.9), caution is needed when generalising the findings globally. This is despite the broader global literature informing the factors explored in this study and the outcome measures adopted (as identified in the scoping and systematic reviews) (e.g., Australia – Baker et al., 2018a, Baker et al., 2018b; Baker et al., 2019).

Third, there are methodological limitations across the thesis;

Dichotomising outcomes oversimplifies data, although this was only utilised for certain outcomes. The implications are mentioned in the discussion section for each empirical Chapter where dichotomy has been used. However, it is worth noting that this binary approach fails to capture the complexity (Cost et al., 2022) of the DRA phenomenon across various demographic groups. It provides a story from one lens rather than the multifaceted nature of attitudes and individuality. Moreover, not all categories within a socio-demographic variable had sufficient sample size to provide a statistical comparison (e.g., ethnic groups).

There were issues with reliability in some of the tools used in this thesis. While most of the measures used in this thesis indicate good reliability, as evidenced by their Cronbach's alpha scores, the AQ-8-C, and BSDS were below the acceptable threshold (below 0.60). The lower reliability of these measures highlights potential issues with capturing the intended constructs consistently.

While the KIDS and AQ-8-C scales moderately correlated with the Brief A-ADS, indicating some overlap in the constructs they measure (cognitive, affective, and behavioural), it also demonstrates that they capture their distinct elements of DRA. In the context of SEM, where DRA needed to be represented as a latent construct, the differences across these measures, such as scale reliability, data normality, and conceptual focus, meant there were adjustments necessary to align the Brief A-ADS with the AQ-8-C, for example. This included shortening the AQ-8-C to improve reliability and overlap conceptually with the Brief A-ADS. Consequently, the Brief A-ADS accounted for a more significant proportion of variance in the latent DRA variable. This may skew the understanding of DRA towards the aspects the Brief A-ADS captures (i.e., behavioural items), which may overlook the nuances captured by the AQ-8-C (i.e., cognitive attitude items).

From a research methods perspective, the SEM method adopted for this thesis was the maximum likelihood (ML) model. The justification for this is outlined in Appendix L. Whilst the ML was deemed appropriate by the consulting statistician, it is worth recognising that ordinary least squares, or weighted least squares could have also been selected, and are popularly used for non-normal data (Shi & Maydeu-Olivares, 2020). However, there is no clear indication in the research methods literature on the superiority of a single method, with a diverse set of recommendations (Hair Jr, Matthews, Matthews, & Sarstedt, 2017).

Fourth, recruitment for the IAT was incredibly hampered by the lack of time for schools to facilitate in-person data collection. Having only one licence for the Inquisit software to run the IAT meant data collection could have been more efficient, with only ten participants' data possible to collect within the hour. Schools found this challenging to facilitate due to lack of time, staff capacity, and space, particularly as

'tutor time' is typically 30 minutes. In hindsight, securing a licence that allows for remote data collection could have broadened participant reach and mitigated the social desirability bias observed when explicit measures were conducted in person compared to remote data collection (Cormack & Hand, 2022; Ward & Mead, 2023).

Fifth, the thesis took a comprehensive approach to identifying the factors associated with DRA through systematically reviewing the literature, using secondary data, and using PPI. However, the regressions and SEM highlighted that the variables only accounted for a modest proportion of the models' variance. This indicates that other unobserved variables have yet to be captured, or explored in this thesis.

Finally, the thesis initially intended to fulfil thesis Chapter 5, Aim A (see Table 2) by carrying out a quasi-longitudinal study with a time point one that would address how DRA may form in the first place. Time point two would have aimed to assess whether DRA changes over time. This is due to Chapter 1 of the thesis (section 1.10) identifying that a significant limitation in the DRA literature is the need for longitudinal data. However, following time point one, it was evident that the schools needed more engagement to participate in point two. Every effort was made to identify schools and get expertise from school leaders and local councillors on understanding the logistics of running a study in the school setting, appropriate age groups, and whether the study would be interesting for schools to participate in. Despite the careful considerations given to the study's design with this preparation, several areas contributed to the failure of time point two:

First, there were ethical restrictions on the age of consent where participants under 13 years old required parental opt-in consent. Schools reported that opt-in consent was burdensome and lacked staff capacity to facilitate collecting consent from parents/guardians. This led to the schools choosing the older year groups, which was the most convenient way to facilitate the study. Consequently, by time point two, the 16-year-old participants had moved on to college, and the 14-15-year-olds were now going through their GCSE exams. This made it difficult for schools to continue participating in the study. Since participants were fully anonymous, they could not be followed up after finishing their GCSEs. A potential ethical solution is obtaining

consent from the parent/guardian. This could entail giving guardians an anonymous registration link to the study in the information sheet, allowing them to register their email address if they would be happy for the researchers to contact them with the questionnaire for their child to complete at time point two. While this would not guarantee parents voluntarily registering their email, it would be an ethical and straightforward way to increase the chance of retaining participants in a way that does not burden the school or the parent, given that they are choosing to opt-in.

Second, due to recruiting schools from varying levels of regional deprivation to ensure a more diverse sample, the low-resourced schools found it difficult to facilitate the research. Several barriers for these schools included high staff turnover, which led to difficulty in rearranging data collection due to the need for a point-of-contact staff member to facilitate the study. Importantly, low-resourced schools needed more computers to facilitate the study. Schools in this position could have opted for paper versions of the questionnaire, but a majority chose to allow the students to use their mobile phones for data collection at time point one. By time point two, the UK government had introduced guidelines for banning mobile phone use in schools (February 2024), with the schools prohibiting the use of mobile phones in line with the government "crackdown" (Department of Education, 2024). This made it difficult for schools to easily facilitate the study during class time in a way that was not disruptive to learning. Interestingly, schools from the most regionally deprived areas dropped out of the study compared to those in the least deprived areas, with the lengthy testing session of the IAT task needing to be more practical for these schools. Future work will need to importantly include school leaders in the PPI panel to not only understand what is feasible and how research barriers can be overcome in the school setting, but also to build relationships and interest in DRA with schools. This is mainly because other research projects are competing for interest with schools on topics that headteachers may feel align better with young people (e.g., research on young people's mental health).

Lastly, while participants were entered into a prize draw for £20 Amazon vouchers, the limited number of vouchers meant there was a low probability of winning (one winner in every thirteen participants). Increasing the number of incentives could have

increased participation. As an added incentive, certificates for the schools were created at the end of time-point one to recognise their participation in dementia research within their community.

Reflection on the challenges of ethical approval and recruitment

There were initial ethical challenges relating to the consent process. The ethics committee initially advocated for opt-in consent for all participants. EH highlighted that this could risk excluding participants where parents may not speak English or might not be actively engaged with the school. EH recognised these barriers from previous experiences such as engaging with parents when previously working at a secondary school, personal experience growing up in communities where English is not the first language, and growing up with a parent with little knowledge and understanding of the English language. To address this, EH had discussions with headteachers and local councillors to better understand the demographics of the school catchment areas, including the proportion of parents with limited English proficiency. Using these insights, EH was able to advocate for modification to the consent process so that opt-in consent was only required for participants under the age of 13. This helped mitigate potential exclusion of underrepresented groups and maximise the diversity of the sample, while adhering to ethical guidelines.

There were also school-specific differences in logistics and attitudes towards research. For example, state schools in general had significant time and resource constraints (e.g., lack of computers and staff) while the private schools had fewer logistical barriers (all students had their own learning iPad at school). There were also noticeable differences EH observed in the student's attitudes towards research participation during in-person data collection. In the state schools, students were more sceptical about getting involved in research and were not motivated to take part. The students in the private schools demonstrated greater enthusiasm and expressed research participation as an opportunity to enhance their CV and ask a researcher questions about science. From these experiences with the schools, EH has learnt about the importance of tailoring recruitment to address diverse needs of different schools and

the importance of understanding what meaningful engagement with participants looks like in different circumstances.

7.5 Thesis contributions

This thesis has three main contributions. It addresses population gaps, contributes new knowledge to the field by addressing limitations of existing studies in the DRA literature, and addresses methodological gaps and weaknesses of the DRA literature. The main contributions are listed below.

Identifying what DRA outcome measures exist and are used in adolescents and whether these are validated in adolescents:

The scoping review (Chapter 2) (Hassan et al., 2023b) is the first in the DRA literature to map out measures administered in adolescents, addressing a knowledge gap in the literature. The scoping review provides recommendations for researchers for future work using DRA measures specific to capturing DRA in adolescents. In doing so, some of the limitations of the current literature base are available for researchers to consider and work towards establishing a gold-standard measure for DRA in young people, including adolescents.

Synthesising the factors associated with DRA in adolescents and establishing their strength of association in the existing literature:

The systematic review (Chapter 3) is the first in the DRA literature to gather evidence on the factors associated with DRA specific to adolescents. This addresses a knowledge gap in the literature, where previous systematic reviews on public stigma focused on the general adult population, healthcare workers, and university students. No prior review existed in the DRA literature in the context of focusing on under-18-year-olds. Three factors were identified as strongly related to DRA in adolescents (gender, knowledge, and level of contact). The knowledge gained by conducting this study provides foundational knowledge for researchers to build upon in testing the strength of these associations in well-designed and heterogeneous cohorts to better

establish their usefulness as targets for dementia anti-stigma initiatives in young people.

Identifying factors associated with DRA in adolescents using secondary data analysis:

The secondary data analysis (Chapter 4) (Hassan et al., 2023a) addressed several knowledge gaps in the literature, such as which factors were most strongly associated with DRA, which socio-demographic groups are most susceptible to negative DRA, what mediatory relationships exist between these factors and DRA, and lastly, whether direct or indirect contact was more influential on DRA. This study was the first to address these gaps using SEM. By employing SEM, the study was able to delve beyond mere associations as previous research reports and contribute the knowledge of how these factors interact with each other so that researchers can begin understanding how attitudes may form in the first place in adolescents. This study advances the field by examining how these determinants mediate each other's effects, providing a deeper understanding of the pathways that lead to negative DRA development. By integrating socio-demographic variables, the model identified that modifiable factors are likely more critical targets, crucial to understanding and creating effective anti-stigma interventions based on evidence.

Further generation of new knowledge includes the fact that indirect contact was more influential than direct contact with dementia in adolescents. Understanding how resources and time could be directed toward anti-stigma initiatives was important to optimise future initiatives.

Validated measures:

The thesis addresses a methodological limitation in the existing literature, mainly using validated measures designed for children and adolescents. Given that the systematic review conducted in Chapter 3 identified studies that were not of high quality due to their methodological weaknesses overall (e.g., MMAT scoring), by using validated instruments, the thesis has greater accuracy in its findings. The

adoption of theoretical frameworks underpinning the findings and associations sets a standard for adolescent DRA research.

Addressing the population gap:

The DRA literature has in general, been limited to homogenous samples (see Chapter 3, section 3.4.1 - ethnicity), which makes it difficult to generalise to the rest of England. The thesis has contributed to the understanding of DRA in the largest and most diverse population of adolescents in England, with six regions of England participating in the research. Level of regional deprivation, which was descriptively reported in Chapter 5, meant that there was greater inclusion of adolescents than prior studies conducted in England. The thesis has not only provided a more representative understanding of young people's DRA, but also provides a new opportunity to understand the experience of dementia in these various demographic groups in future work.

Building the evidence base for factors with a lack of consensus on their association with DRA:

Due to the lack of literature on the factors determining DRA in young people, there needed to be more consensus on many of the factors associated with DRA. For example, empathy is an essential construct within the broader attitude and stigma literature. However, only one study explored empathy with DRA in young people (Baker et al., 2018a), while only one study was identified for the association between ageism and DRA (Werner et al., 2017). The thesis builds on these prior works, beginning to build consensus on these factors. The thesis goes one step further by providing novel context to these factors by identifying their relationship with other factors and how they serve as mediators, a new contribution to the literature.

Level of dementia knowledge in British adolescents:

Prior studies reporting the level of dementia knowledge in British adolescents were limited by their homogenous samples (Isaac et al., 2017), which made it difficult to generalise to the British adolescent population. This thesis (Chapter 5) establishes the

level of dementia knowledge in a larger, more diverse cohort of adolescents in England. The findings evidence widespread misconceptions about dementia, which is helpful in guiding stakeholders when advocating for wider dementia education in the national curriculum.

Contextualising the experiences of dementia in British adolescents:

While media is often assumed to have a role in adolescents' DRA and is thought to represent dementia negatively, this is often qualitatively reported. This study provides quantitative support to these findings by demonstrating that dementia is represented negatively through the perception of young people. This further provides scope to explore media influencing DRA in future work and advocacy implications in ensuring accurate representations of dementia.

The relationship between explicit and implicit DRA:

There was a minimal exploration of implicit measures used in DRA, and no prior empirical studies on implicit DRA in adolescents. A significant criticism of the assessment of DRA is the heavy reliance on explicit measures (Scerri & Scerri, 2013). The DRA literature recommended incorporating implicit measures and social desirability bias checks to address the social desirability bias vulnerability of explicit measures. The exploratory sub-study (Chapter 6) is the first study to use implicit measures of DRA in adolescents and explore how it is related to explicit measures.

British adolescents' willingness to work with dementia:

The mental illness literature demonstrates there is a relationship between attitudes, factors associated with negative attitudes, career preferences (Ioerger, Machia, & Turk, 2019; Lim et al., 2020; Poreddi, Thimmaiah, & Math, 2015). Yet, the literature that includes student populations mostly focuses on individuals aged 18 years and over. A measurement gap in the literature is that the primary outcome of these studies is usually the 'attitude' instead of treating the behavioural intention item as a primary outcome (Hebditch et al., 2022). Therefore, it is unclear what factors are associated with willingness to work with dementia in adolescents. The thesis findings from

Chapter 4 and Chapter 5 both address these gaps by adopting a behavioural intention item as a primary outcome variable, and exploring the factors associated with willingness to work with dementia in a population under the age of 18 years old. The novel contribution to the DRA field is that this is the first-time mediatory mechanisms influencing this behavioural intention and DRA is explored in the context of British adolescents. Notably, the findings build on the adult literature, demonstrating a continued trend that future healthcare workers show little interest in dementia-related careers, which has implications for workforce planning and education in the sector.

7.6 Conclusion

This thesis advances the DRA in young people literature by expanding the current knowledge in this field through the methods adopted in this thesis. For example, this thesis recruited the largest and most diverse sample of British adolescents to date, using SEM to simultaneously explore multiple factors association with DRA, which had not previously been done before in this literature, as well as adopting theoretical frameworks. The thesis also pushes the field forward by exploring empathy, which had not been previously employed as a quantitative outcome in the DRA young people literature. Yet, this thesis demonstrates its importance in relation to DRA. The thesis also identified that contact with dementia, may be one of the best ways to improve DRA in young people as it theoretically can stimulate empathy, and improve dementia knowledge.

This thesis identified that common misconceptions of dementia are held by young people that potentially feed into stigma. These misconceptions were in line with the general public's perceptions of dementia. The thesis also reaffirms the notion that young people have experiences of dementia and therefore they are directly impacted. More than a quarter of young people stated that they had looked after someone with dementia. Additionally, the majority of young people indicated that they would not be willing to work with people with dementia in the future, which has implications for the future training of the healthcare workforce. The insights gained from this thesis provide a foundation for developing anti-stigma interventions tailored to adolescents.

The thesis acknowledges potential determinants of DRA in young people that have not yet been captured in the DRA literature. Additional work must identify further factors to get a more comprehensive picture. Nevertheless, the findings from this thesis has implications for public health policy and education, particularly in creating a dementia-inclusive society. By targeting young people, we can foster early-stage, positive perceptions, and address misconceptions that may translate into long-term societal benefits that better support people living with dementia.

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Appendix A. Publications

Hassan, E., Hicks, B., Tabet, N., & Farina, N. (2023a). Factors associated with dementia attitudes in an adolescent cohort: structural equation modelling. *Alzheimer's & Dementia*, *19*, e073575. https://doi.org/10.1002/alz.073575 [Poster abstract for Alzheimer's Association International Conference, Amsterdam, 2023] [Chapter 4].

Hassan, E., Hicks, B., Tabet, N., & Farina, N. (2023b). Factors associated with dementia attitudes in an adolescent cohort: structural equation modelling. *Cogent psychology*, *10*(1), 2235125. https://doi.org/10.1080/23311908.2023.2235125 [Chapter 4].

Hassan, E., Hicks, B., Tabet, N., & Farina, N. (2023c). Measures Determining Dementia-Related Attitudes in Adolescents: A Scoping Review. *Journal of Intergenerational Relationships*, 1-21. https://doi.org/10.1080/15350770.2023.2229837 [Chapter 2]

Appendix B. Sex and Gender terminology

In this thesis, the terminology ‘sex’ was adopted due to the biological distinctions between males and females during this adolescent stage of puberty, physical and mental maturation and development. This includes empirical evidence that suggests that sex differences can have influence on the development and manifestation of empathy (Paz, Orlitsky, Roth-Hanania, Zahn-Waxler, & Davidov, 2021; Rochat, 2023). Empathy is a key factor explored in this thesis. However, it is important to acknowledge the distinction between ‘sex’ and ‘gender’ and to recognise that there are certain contexts in this thesis where ‘gender’ may be more appropriate. As a result, where a research study in the review chapters (Chapter 2 and 3) use ‘gender’ or where a variable is predetermined from the secondary data analysis (Chapter 4) (i.e., ‘gender’), then the term ‘gender’ is adopted. This approach ensures consistency within the terminology employed by other researchers to maintain clear interpretation of results from the broader academic discussion. It is worth also acknowledging that there are limitations to treating this variable dichotomously as it is does not capture the nuances of the experience of those who may not identity with the dichotomous categories.

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Appendix C. Ethics Approval ER/BSMS9PCH/1

brighton and sussex medical school

BSMS Research Governance Ethics Committee

Certificate of Approval	
Reference Number	ER/BSMS9PCH/1
Title Of Project	Young people's views of dementia.
Principal Investigator (PI):	Esra Hassan
Student	Esra Hassan
Collaborators	Dr Ben Hicks Dr Nicolas Farina Dr Sahdia Parveen Prof Naji Tabet
Date Of Approval	14-Nov-2022
Approval Expiry Date	14-Nov-2023
RGEC Chair	Caroline Brooks
Name of Authorised Signatory	Dr. Peter West-Oram
Date	14-Nov-2022

The Brighton and Sussex Medical School Research Governance and Ethics Committee (RGEC) has assessed your application and granted Ethical and Research Governance Approval to proceed with the above named project.

Approval is granted on the following basis:

Duration of Approval

Approval covers the period stated above. Research must commence within 12 months of the certificate start date; any delay beyond 12 months and this certificate of approval will lapse necessitating renewed review of the project.

Project Amendments

Any substantial changes or minor amendments to the project following issue of the certificate of approval should be submitted to the Research Governance and Ethics Committee for review and authorisation prior to implementation. Please submit your application for an amendment to the Committee (via rgec@bsms.ac.uk) using the Request for an Amendment Form.

Reporting Adverse and Unexpected Events

Any incidents occurring during the project's lifespan presenting ethical and safety implications must be reported immediately to the Chair of the Research Governance and Ethics Committee. In the event of an adverse (undesirable an unintended) and unexpected event occurring during the project, research must be stopped immediately and events reported to the Chair of the Research Governance and Ethics Committee within 24 hours of its occurrence.

Monitoring

The Medical School has a duty to ensure all its research is conducted in accordance with the University of Sussex's Code of Practice for Research and Research Governance and Ethical Review Framework. In order to ensure compliance auditing may be undertaken annually and /or periodic monitoring of a percentage of approved research studies. If your project is selected you will be given 4 weeks' notice to prepare all study documentation for inspection.

Notification of End of Study

Please notify the Research Governance and Ethics Committee once the study has completed. It is also your responsibility to inform the Committee in the event of early termination of the project or if the work is not completed.

Appendix D. Ethics Approval ER/BSMS9PCH/2

brighton and sussex medical school

BSMS Research Governance Ethics Committee

Certificate of Approval	
Reference Number	ER/BSMS9PCH/2
Title Of Project	Young people's views of dementia. (COPY)
Principal Investigator (PI):	Esra Hassan
Student	Esra Hassan
Collaborators	Dr Sahdia Parveen Prof Naji Tabet Dr Ben Hicks
Date Of Approval	16-Oct-2023
Approval Expiry Date	16-Oct-2024
RGEC Chair	Vacancy
Name of Authorised Signatory	Dr. Peter West-Oram
Date	16-Oct-2023

The Brighton and Sussex Medical School Research Governance and Ethics Committee (RGEC) has assessed your application and granted Ethical and Research Governance Approval to proceed with the above named project.

Approval is granted on the following basis:

Duration of Approval

Approval covers the period stated above. Research must commence within 12 months of the certificate start date; any delay beyond 12 months and this certificate of approval will lapse necessitating renewed review of the project.

Project Amendments

Any substantial changes or minor amendments to the project following issue of the certificate of approval should be submitted to the Research Governance and Ethics Committee for review and authorisation prior to implementation. Please submit your application for an amendment to the Committee (via rgec@bsms.ac.uk) using the Request for an Amendment Form.

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Appendix E. Scoping Review Protocol

Outcome measures used to determine dementia stigma and attitudes in young people: A Scoping Review Protocol

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Dr Nicolas Farina (NF), Brighton and Sussex Medical School, Centre for Dementia Studies

Abstract

Background: This article is a protocol for a scoping review that will be conducted on the outcome measures used to determine dementia stigma and attitudes in adolescents (10-18 years old). To develop evidence-based anti-stigma programmes for adolescents, underlying factors that drive negative dementia stigma and related domains in adolescents need to be captured. However, it is unclear what measures currently exist to measure dementia stigma and related domains in adolescents and if any measures have been validated. The prospective scoping review will aim to provide a map of the literature for researchers on what current measures exist for this purpose, whether any are validated and what limitations and gaps may need addressing when measuring dementia-stigma and related domains in adolescents.

Methods: This scoping review will adopt the Arksey and O'Malley (2005) scoping review framework and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) study flowchart for transparency on the reporting, selection and analysis of the literature. The following research question will be explored, 'what measures are used to determine dementia stigma and associated domains in adolescents?'. Systematic searches for peer-reviewed articles will be conducted in the following databases: PubMed, PsycInfo and Web of Science. Two independent reviewers will screen titles and abstracts before full texts are independently extracted by two reviewers.

Results: Results will be summarised, presenting the overall findings, key limitations and gaps to consider when using measures of dementia stigma and related domains in adolescents.

Keywords Dementia, stigma measures, attitudes measures, young people, scoping review

Introduction

Dementia has become a public health priority in national and international policy. It is estimated that approximately 55.2 million people are currently living with dementia worldwide (Kafadar et al. 2021), with this number projected to rise to 78 million by 2030 (World Health Organization, 2021).

With no current cure, a key priority is to improve the quality of life for people living with dementia which includes tackling dementia stigma (Prince et al. 2016). Whilst there have been efforts to accomplish this, people living with dementia continue to face stigmatisation. This has led to barriers to seeking timely diagnosis and treatment (Prince et al. 2016; Herrmann et al. 2018).

Measures that aim to capture dementia stigma and related domains are mainly purposed to assess the attitudes of people living with dementia, carers, healthcare practitioners, and increasingly, the general public (adults) (Herrmann et al. 2018). Attitudes held by adolescents towards dementia are less understood in comparison. The limited evidence that does exist suggests that some adolescents do hold negative attitudes and misconceptions about people living with dementia (Farina et al. 2020). However, measures used in other populations are unsuitable to capture dementia stigma and related domains in adolescents, as findings may not necessarily be generalisable to younger populations. There is also the question as to whether any measures that do exist in adolescent stigma and related domains are sufficient enough to identify factors that drive negative attitudes in adolescents, which will be important for researchers to consider in the future when creating tailored and effective anti-stigma interventions.

The World Health Organisation (WHO) defines adolescents as young people between the ages of 10-19 years old. The majority of adolescents fall under the age-based definition of ‘child’ which is a person under the age of 18 years old as adopted by the Convention on the Rights of the Child (WHO, 2024). This scoping review will focus on adolescents as defined by those that fall under WHO’s definition and the Convention of the Rights of the Child (10-18 years old). Adolescents are a valuable age group to target for anti-stigma and dementia awareness initiatives (WHO, 2020). Reasons for this include attitude change frameworks such as the ‘impressionable years

hypothesis' that suggests adolescents are highly prone to attitude change in adolescence through to early adulthood (Krosnick & Alwin, 1989). Schools are also useful for implementing widespread anti-stigma initiatives nationally and internationally (Di Bona et al. 2019).

Within the stigma and related domains literature, research adopts different measurement scales depending on the aspect of stigma that is being targeted which is hugely important as this leads to different outcomes and implications. Corrigan and Watson's (2002) stigma framework is the most widely adopted framework in assessing public behaviour attitudes towards dementia (Kim et al. 2019; Rüsch et al. 2005). However, there is still a general lack of frameworks used in dementia stigma research (Werner et al. 2020) and it is currently unknown how many measures for adolescents exist where a public stigma framework underpins the measure (Rüsch et al. 2005) within this literature. Moreover, the dual process model (Pryor et al., 2004) suggests people have implicit and explicit negative responses to stigmatised conditions. It is therefore important to understand whether current measures used in adolescents integrate any implicit measures alongside explicit measures when assessing stigma that increases the validity and reliability of the measure to address social desirability that can occur in measuring attitudes (Silke et al., 2017).

Rationale

The purpose of this scoping review is to provide an overview of the evidence within the literature to address an exploratory research question, in this case, what measures are used to measure dementia stigma and associated domains in adolescents. Scoping reviews are deemed useful in identifying available evidence, and knowledge gaps and an ideal tool to establish the scope of the literature, the volume of studies on measures and scales that exist by systematically searching, selecting and synthesising the existing body of literature (Colguhoun et al. 2014). Identifying already validated and psychometrically sound measures and which can be further tested in larger samples of adolescent populations will be useful in striving towards greater generalisability within the adolescent population (Parveen et al. 2020).

Since societal views change over time, validated measures created formerly may not be relevant or sufficient enough to capture attitudes of adolescents today. Therefore,

measures evaluating attitudes in recent contexts are necessary. It is therefore important to determine what newly established measures exist and whether these may need further validation. With no current agreement on what the 'gold standard' measure (Harper et al. 2019) in adolescents is, further psychometric refinement and testing will be able to better capture current adolescent attitudes (Read et al. 2021) This is important as measures not specifically developed 'from the ground up' could influence adolescents' responses (Isaac et al. 2017). Providing transparency and scope to further develop and validate measures will contribute to striving for a gold standard measure that can be used.

Objectives

The main objective for this projected scoping review is to identify and map literature on the outcome measures used to measure dementia stigma and related domains in adolescents. The results of the scoping review are anticipated to inform researchers what current measures exist in this literature and provide recommendations based on identified gaps on future research in the consideration of adopting, adapting or creating validated measures and summarise the key frameworks adopted if any, in the adolescent stigma measures.

Aims

The aim of this scoping review is to identify the types of questionnaires used to measure dementia attitudes in adolescents. Through a comprehensive literature search using scoping review methodology, the aim is to; 1) identify which scales could be adopted or adapted in a subsequent longitudinal survey looking into dementia attitudes in young people; 2) determine the psychometric properties of validated measures and 3) identify limitations of the types of measures currently used in dementia attitude research, providing scope for future researchers to consider.

Methods

The protocol adopted for this scoping review is the Arksey and O'Malley's (2005) scoping review framework (Arksey and O'Malley, 2005) due to its transparency, rigorousness and the ability to replicate the search strategy which further increases the reliability of the review (Munn et al. 2018). The framework entails 1) identifying the research question, 2) identifying relevant studies, 3) study selection (inclusion and

exclusion criteria is applied), 4) charting the data and 5) collating, summarising and reporting the results (synthesis). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram (Moher et al. 2010; Page & Moher, 2017) and PRISMA-ScR guidelines (PRISMA extension for scoping reviews) (Tricco et al. 2018) will be adopted for transparency on the reporting, selection and analysis of this literature.

1. Identifying the research question

The scoping review framework entails identifying a research question that covers a broad topic but narrow enough to provide specific knowledge within an area in the existing topic. The research question provides guidance and clarity on what inclusion and exclusion criteria can be applied to ensure the studies extracted answer the questions and fulfil the objectives and aims of the scoping review (Arksey & O'Malley, 2005). Therefore, within the dementia attitudes literature, 'what measures are used to determine dementia stigma and associated domains in adolescents?' has been agreed by EH and NF to fulfil the scoping review's objectives and purpose. The term 'dementia stigma and associated domains' is used to refer to key terms that fall under the concept of public stigma. This includes attitudes, perceptions, discrimination, stereotypes and beliefs.

2. Identifying relevant studies

Information sources

Studies will be identified through systematically searching through sensitive electronic databases which include Web of Science, PubMed and PsycInfo. The databases will be searched with no limitations set for the time period in which the articles were published. This is to allow for all relevant literature to be included.

Alternative databases to identify grey literature such as conference abstracts and theses, will not be used for this scoping review as only peer-reviewed studies were eligible. This is to exclude any potential measures of poor quality.

A 'snowballing' (Pham et al., 2014) method will be adopted to further identify relevant studies of measures through checking reference lists from the primary articles and

reviews as well as citation searches (‘cited by’) and related articles from the eligible articles identified for the scoping review.

Search Strategy

Search strategies have already been drafted and further developed by EH. EH consulted with NF on the synonyms of the search terms included. Boolean operators, ‘AND’; ‘OR’ were used to search for relevant articles in the databases: Web of Science, PubMed and PsycInfo. No exclusion terms (e.g. ‘NOT’ operator) in the search strategies were embedded in case studies had an age range of students that also included under the age of 18-year olds amongst older cohorts. A combination of MeSH terms, synonyms, variations of the spelling for search words and text words were used to curate the search string. The key search terms included those associated with ‘dementia’, ‘stigma’, and ‘adolescents’. All search strategies, date of searches and exact Boolean strings were saved for replicability and ability to update the searches as needed. All searches were performed using the terms in English.

Individuals with dementia may face different types of stigma and perceptions dependent on what subtype of dementia they may have. For example, young onset dementia does not fit the ‘traditional’ stereotypes adopted by society and adolescents towards people with dementia such as the view that people with dementia are ‘old’ and ‘unproductive members of society’ (Prince et al. 2016) which are typically attributed to more commonly thought of dementias such as Alzheimer’s disease. Therefore, this scoping review will focus on the subtypes of dementia that fall under the dementia umbrella term that experience stigma and the associated domains in line with the mental illness and ‘old age’ stigma literature to capture the dementia public stigma associated with adolescents. Hence, the choice of search terms included in the search strategy have been created to reflect this rationale.

Table 1 – PubMed Search Strategy. Search component, date of search and the result of the number of articles founded by the database.

	Search component	Search strategy
1	Dementia	((“Dementia”[Title/Abstract] OR “Alzheimer*”[Title/Abstract])
2	Adolescents	(“adolescent*”[Title/Abstract] OR “teen*”[Title/Abstract] OR “young people”[Title/Abstract] OR “child*”[Title/Abstract] OR “student*”[Title/Abstract] OR “college student*”[Title/Abstract])
3	Stigma	(“Stigma”[Title/Abstract] OR “perception”[Title/Abstract] OR “attitude*”[Title/Abstract] OR “discrimination”[Title/Abstract] OR “social distance”[Title/Abstract] OR “prejudice”[Title/Abstract]))
		1 AND 2 AND 3
Date of search and results	03/11/2021	332 Results

Table 2 – Web of Science Search Strategy. Search component, date of search and the result of the number of articles founded by the database.

	Search component	Search strategy
1	Dementia	(((AB=((dementia OR Alzheimer*)))
2	Adolescents	AB=((adolescent* OR teen* OR "young people" OR child* OR "college students")))
3	Stigma	AB=((attitudes OR stigma OR perception OR prejudice OR discrimination OR stereotypes OR "social distance")))
		1 AND 2 AND 3
Date of search and results	03/11/2021 183 results	

Table 3 – PsycInfo Search Strategy. Search component, date of search and the result of the number of articles founded by the database

	Search component	Search strategy
1	Dementia	ab((dementia OR Alzheimer*))
2	Adolescents	ab((adolescent* OR teen* OR "young people" OR child* OR "college students"))
3	Stigma	ab((attitudes OR stigma OR perception OR prejudice OR discrimination OR stereotypes OR "social distance"))
		1 AND 2 AND 3
Date of search and results	03/11/2021	477 results

Study records

All articles retrieved from each database will be downloaded onto the reference manager Zotero for manual and automated de-duplicate entries. Studies will be included in the review if they are in the English language. Only English language papers will be included as there is not an available team of multi-lingual speakers to translate non-English papers and secondly, there is no concern for which language the tool has been developed in or used, although, the language the tool has been developed and used in will be noted.

3. Study selection

At the screening stage, EH alongside a second reviewer, NF, will independently examine the titles and abstracts from each of the databases using the exclusion and inclusion criteria on the Rayyan platform (Ouzzani et al., 2016). Any records in which there are inconsistencies and disagreements will be brought through to the full-text review stage. Full texts will then be screened by EH and NF independently, recording reasons for exclusion (see Table 4). If there are disagreements between the reviewers, NF and EH will discuss to reach a decision. Full texts that are eligible will undergo

citation screening through snowballing to identify any further articles not identified in the databases.

3.1 Eligibility – Inclusion criteria

The following inclusion criteria will be applied; a) English language paper; b) adolescents (as defined as secondary school age, 10-18 years old); c) measures for dementia-related stigma/attitudes; d) quantitative outcome and e) peer-reviewed articles.

3.2 Eligibility – Exclusion criteria

The following exclusion criteria will be applied; a) population target is above the age of 18 years old; b) undergraduates and university students; c) qualitative measures; d) specialist professions (medical or healthcare professionals); e) measures on self-stigma or stigma by association; f) knowledge scales and g) grey literature.

For eligible studies, Y (yes) should be applied from the inclusion criteria list whilst a Y (yes) response in the exclusion criteria would mean excluding the study.

Table 4 – Eligibility checklist table reviewers will use to determine whether articles are to be included or excluded

Inclusion criteria	Y/N	Exclusion criteria	Y/N
English language paper		Only measures knowledge as an outcome	
Population includes adolescents (10-18 years old)		Only use qualitative research methods	
Outcome measures dementia-related stigma or associated domain		Only measures self-stigma outcome	
Quantitative outcome		Population is exclusively composed of university students	
Peer reviewed			

The scoping review will adopt a PRISMA study flow chart to exhibit the transparency of the scoping review process.

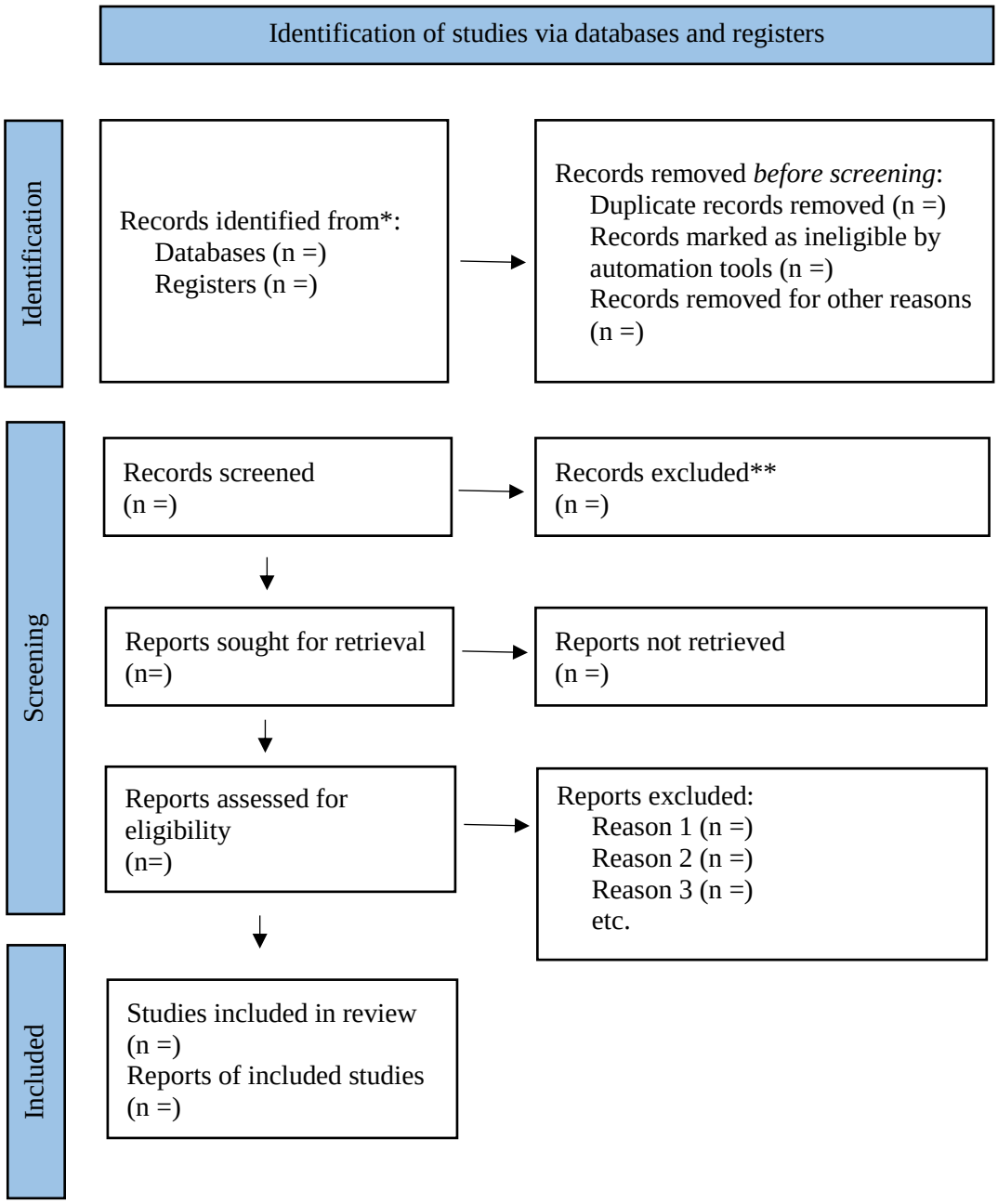

Figure 1 - PRISMA study flow chart for scoping review (Adapted from Page et al., 2021)

The PRISMA recommendations will therefore be followed in the presenting of the identification, screening, eligibility and included studies process (Moher et al. 2010) as Figure 1 demonstrates.

4. Data charting and extraction

Full texts that are identified as appropriate to include following the exclusion and inclusion criteria, will undergo full text extraction. Data charting will be performed by EH using excel to create a charting form. The data that will be extracted include descriptive information regarding the methodology, type of measure and outcomes. Psychometric properties of outcomes will be extracted if reported. See Table 5 for a summary of the data that will be extracted.

Table 5 – Extracted characteristics and the description of each characteristic for each study

Characteristic	Description	
Author (et al.)		
Year of Publication		
Name of measure		
Study design		
Sampling method		
Country		
Target population		
Sample size		
Inclusion and exclusion criteria		
Mode of data collection (face to face, online)		
Validated or unvalidated measure	**Psychometric properties of validated measures in each study**	
	Validated (Y/N)	
	Pilot data (Y/N)	
	Theoretical framework (state if any)	
	Inter-rater reliability	
	Construct validity	
	Content validity	
	Criterion validity	
	Retest reliability	
	Cronbach alpha	
Language of measure, how many other languages adapted the measure and location of these		
Is the measure adapted from another measure? If yes, what is this measure		
Outcomes of the measure		
Main strengths		
Main limitations		
Response rate (%)		

The studies that are identified as validated measures will undergo charting for psychometric properties. The validity and reliability details will be stated.

4.1 Risk of Bias

A risk of bias assessment was outside the scope of this review. This is in line with the scoping review framework as proposed by Arksey and O'Malley (2005).

5. Data synthesis and results

Descriptive data of the studies will be reported in tables and summarised narratively. If there are sufficient outcome measures identified, the narrative will be split into key themes based on key characteristics of the outcome measures.

Discussion

This will provide a summary of the overall findings, key limitations and gaps to consider when using these measures, and based on the evidence, which measures may be particularly useful in measuring dementia attitudes in young people.

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Appendix F. Scoping Review Updated (10/06/2024)

Due to the scoping review being performed in 2021, the scoping review search was updated using the search strategy from Appendix E. All of the alert searches that were set up during the main search that might meet the original criteria were checked. This was conducted by EH, who screened each possible relevant article based on title and abstract. This was to identify any new measures that would be relevant to the literature since conducting the review.

The measures identified in 2021 from this scoping review was integral to the decisions made in the thesis to conduct the studies. The measures were adopted with the knowledge at the time that the measures selected were the most robust and psychometrically sound. This updated search is to acknowledge that the scoping review is outdated.

The search included published articles between November 2021 and June 2024. There were 37 studies published between the set dates. Three studies met the title and abstract inclusion (Hassan et al., 2023; Liao et al., 2022; Wu et al., 2022). However, upon full-text screening, the participant mean age in the study by Wu et al. (2022) was 18.52 (15 to 30-year-olds). This therefore led to the exclusion of the study as this was above the age range for inclusion (10-18). Thus, two studies in total met the inclusion criteria (Hassan, Hicks, Tabet, & Farina, 2023; Liao et al., 2022). One of the studies is published in this thesis:

Hassan, E., Hicks, B., Tabet, N., & Farina, N. (2023). Factors associated with dementia attitudes in an adolescent cohort: structural equation modelling. *Cogent psychology*, *10*(1), 2235125.

Appendix Table F – Studies that met the inclusion (not including Hassan et al. 2023)

Author	Year	Outcome Measure	Measure and psychometric properties	Participants
Liao et al.	2022	The Dementia Attitudes Scale (DAS) was developed by O'Connor & McFadden (2010). Liao et al. (2022) – DAS translated into Chinese. DAS – validated not in the target population (undergraduate students) (O'Connor & McFadden, 2010).	The DAS has 20 items. Each item is rated using a seven-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). Higher scores indicate better attitudes toward dementia. DAS has two dimensions: 1) dementia knowledge 2) social comfort. Reliability reported: Cronbach's alpha reported by O'Connor &	Total of 200 adolescents aged 12–18 years old (mean = 13.73 to 15.62 years-old) were recruited from nine schools in northern Taiwan. 95% of participants were female.

			McFadden (2010): 0.83 to 0.85. Liao et al., (2022): Cronbach's alpha for the total score: 0.85 – 0.87. Cronbach's alpha for social comfort: 0.77. Dementia knowledge: 0.82 – 0.86. No other psychometric properties were reported in the study.	

In conclusion, the updated review included two new studies. No additional unique measure was identified. The DAS, which was not validated in adolescents originally was identified in the scoping review conducted in 2021. Since the measure itself is a Chinese version that has not been used in British adolescents, these findings did not change the direction of the literature with the Brief A-ADS and KIDS still the most psychometrically robust tools used in British adolescents presently. Caution should be applied to these findings due to the lack of formal scoping review procedures.

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Appendix G. Systematic Review Protocol

Hassan, E., Tabet, N., & Farina, N. (2021). Factors associated with dementia-related stigma and associated domains in adolescents: A Systematic Review Protocol. **Protocols.io.** https://www.protocols.io/view/factors-associated-with-dementia-related-stigma-an-b2hjqb4n.html

Appendix H. Systematic Review Final Search Strategy

PsycInfo (ProQuest) – 685 results (02/06/2023)

ab(Dement* OR Alzheimer*) AND ab(adolescent* OR teen* OR “young people” OR child* OR student*) AND ab(Stigma OR perception OR attitude* OR discrimination OR “social distance” OR prejudice)

Web of science – 388 results (02/06/2023)

((AB=(Dement* OR Alzheimer*)) AND AB=(adolescent* OR teen* OR “young people” OR child* OR student*)) AND AB=(Stigma OR perception OR attitude* OR discrimination OR “social distance” OR prejudice)

PubMed – 355 results (02/06/2023)

((Dement*[Title/Abstract] OR Alzheimer*[Title/Abstract]) AND (adolescent*[Title/Abstract] OR teen*[Title/Abstract] OR “young people”[Title/Abstract] OR child*[Title/Abstract] OR student*[Title/Abstract])) AND (Stigma[Title/Abstract] OR perception[Title/Abstract] OR attitude*[Title/Abstract] OR discrimination[Title/Abstract] OR “social distance”[Title/Abstract] OR prejudice[Title/Abstract])

SCOPUS – 542 results (02/06/2023)

(ABS (dement* OR Alzheimer*) AND ABS (adolescent* OR teen* OR “young people” OR child* OR student*) AND ABS (stigma OR perception OR attitude* OR discrimination OR “social distance” OR prejudice))

OADT – 178 results (02/06/23)

All fields(Dement* OR Alzheimer*) AND All fields(adolescent* OR teen* OR child* OR student* OR “young people”) AND All fields(stigma OR prejudice OR attitude* OR “social distance” OR perception)

Appendix I. Systematic Review Master MMAT matrix

Mixed Methods Appraisal Tool Evaluation of the articles included in the systematic review

SCREENING QUESTIONS				
First author	Year	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	Comments
Baker	2018a	Yes	Yes	Research aim to develop and validate a new self-report tool to measure children's tripartite attitudes towards people with dementia reflected in collected data through psychometric properties of KIDS
Baker	2018b	Yes	Yes	What children in the community know, feel or behave around people with dementia reflected in themes identified through patterns of responses and coded in cognition, affect and behaviour
Farina	2020a	Yes	Yes	Adolescents perceptions and experiences were clearly reported into sections in the study.
Felc & Flec	2021	Yes	Yes	Research objective relates to knowledge. Attitudes section of the results presents the results but no rationale to this, results are presented for attitudes.
Fox	2020	Yes	Yes	Analyses such as ANOVA and post hoc test appropriately chosen to answer research question

Fuh	2005	Yes	Yes	Demographic factors and attitudes through association and comparison tests (chi-squared) answers research question
Lo	2020	Yes	Yes	Statistical analysis on knowledge, attitude and preventive practice of dementia care answers aim of paper to investigate these in the proposed population
Werner	2017	Yes	Yes	Correlations support hypotheses proposed

1. QUALITATIVE STUDIES							
First Author	Year	1.1. Is the qualitative approach appropriate to answer the research question?	1.2. Are the qualitative data collection methods adequate to address the research question?	1.3. Are the findings adequately derived from the data?	1.4. Is the interpretation of results sufficiently substantiated by data?	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	Comments
Baker	2018a	Yes	Yes	Yes	Yes	Yes	1.1 Gives rationale for why conducting qualitative inquiry. 1.2 Sampling and techniques interviews and focus groups used are clearly stated and adequate for the research question. 1.3 inductive and deductive, coded and has criteria. 1.4 provides quotes as evidence for theme and in accordance

							to evidence tripartite framework. 1.5 Clearly links data, what analysis used and descriptive interpretation.
Felc & Felc	2021	Can't tell	No	Can't tell	Can't tell	No	1.1 Does not state qualitative descriptive aspect in research question. Qualitatively asks about attitudes but research question is about knowledge. 1.2 data collection is adequate but is not relevant to research question as one is not state. 1.3 answers categorised and narrative method stated but decisions on how to categorise was not given. 1.4 Quotes not provided to justify categories but percentages are derived from the data. 1.5 There is no link or mention made of the qual and quant aspect. Overall confusion to whether this was a qualitative or quantitative paper. Not strong enough as a mixed study.

4. QUANTITATIVE DESCRIPTIVE STUDIES							
Author	Year	4.1. Is the sampling strategy relevant to address the research question?	4.2. Is the sample representative of the target population?	4.3. Are the measurements appropriate?	4.4. Is the risk of nonresponse bias low?	4.5. Is the statistical analysis appropriate to answer the research question?	Comments
Baker	2018b	Yes	Yes	Yes	Can't tell	Yes	4.1 Justification provided for how participants were sampled and was adequate (sampling adequacy was done). 4.2 KIDS intended for children – target population. Sample appropriate and stated. 4.3 Measures are appropriate – validation and piloting. 4.4 No reporting of nonresponse bias. 4.5 Statistical analysis appropriate – provides rationale for statistical tests required for validity and reliability of KIDS.
Farina	2020a	Can't tell	Yes	Yes	Yes	Yes	4.1 Sample appropriate to target population but does not give justification for sample frame or how schools were selected. 4.2 Appropriate to target population – details inclusion/exclusion criteria. 4.3

							validated measures used, variables clearly defined. 4.4 no evidence of nonresponse bias. 4.5 gives clear justification for choice of statistical analysis
Felc & Felc	2021	Yes	Can't tell	No	Can't tell	Yes	4.1 Details sampling method and rationale for this and sampling procedure outlined. 4.2 describes target population and the sample but no inclusion/exclusion criteria given and There was no clear indication whether students that responded within the schools were bias. 4.3 There is a lack of transparency on the measure, it was adapted, but not said how. No new psychometrics reported. 4.4 5.2% completed the survey inappropriately. Only valid answers were considered. 4.5 statistical analysis clearly stated and its justification for its use provided.

Fox	2020	Can't tell	Can't tell	Can't tell	Can't tell	Yes	4.1 sampling procedure stated "class teachers selected participants" but does not state how schools were selected and if this was random. 4.2 Different academic ability meant representative sample of the class, but no inclusion/exclusion criteria given or reasons of those who opted out. 4.3 rationale for measurement choice e.g. Likert scales, measures adopted and adapted appropriately to target audience but can't tell if measures were validated and no psychometric properties. 4.4 not reported. No evidence of nonresponse bias. 4.5 statistical tests justified and rationale given – appropriate.
Fuh	2005	Yes	Can't tell	No	Can't tell	Yes	4.1 gives geographic considerations for the random sampling. 4.2 attempts to achieve more representative sample by geographic locations considered and representative of target population but exclusion and inclusion criteria not stated. 4.3

							does not give details of origins of questionnaire, no psychometric properties but does measure what is intended. 4.4 “high response rate”, no evidence of nonresponse bias. 4.5 Explains what statistical test is being used for which outcome and appropriate to them study aim – relationship/association.
Lo	2020	Yes	Can’t tell	Yes	Can’t tell	Yes	4.1 random selection 4.2 no exclusion/inclusion criteria but does consider form levels but does not state why non-participants. 4.3 survey validated and relevant. 4.4 no evidence on nonresponse bias. 4.5 answers aim of the study.
Werner	2017	Can’t tell	Can’t tell	Yes	Can’t tell	Yes	4.1 Does not state how the sample was selected. 4.2 gives rationale for participant choice (Arab and Jewish) – target population matches but no exclusion/inclusion or reason for non-partaking 4.3 measures appropriate and validated e.g. “Cronbach’s alpha”. 4.4 no evidence of nonresponse bias. 4.5

							statistical tests stated and justified, answers research aims.

Appendix J. Systematic Review Updated (10/06/2024)

The search for the systematic review in Chapter 3 was last updated in 2023. The search was updated using the search strategy as seen in Appendix H to identity any new literature that would be relevant. This consisted of checking all of the alert searches that were set up during the main search that might meet the original criteria. This was conducted by EH, who screened each possible relevant article based on title and abstract.

The search included articles published between 02/06/2023 and 10/06/2024. A total of 38 titles and abstracts were screened. There were no studies that met the criteria for inclusion except the article published in this thesis:

Hassan, E., Hicks, B., Tabet, N., & Farina, N. (2023). Factors associated with dementia attitudes in an adolescent cohort: structural equation modelling. *Cogent psychology*, *10*(1), 2235125.

As a result, there are no new results that change the current evidence in a new direction. However, caution is needed in interpreting these results due to the lack of formal systematic procedures.

Appendix K. Coding Syntax for measures

Brief A-ADS

```
RECODE AADS2.T1 AADS13.T1 (1=5) (2=4) (3=3) (4=2) (5=1) INTO AADS2r AADS13r.
EXECUTE.
COMPUTE AADS13TOTAL=SUM.13(AADS1.T1, AADS2r, AADS3.T1, AADS4.T1, AADS5.T1, AADS6.T1, AADS7.T1, AADS8.T1, AADS9.T1, AADS10.T1, AADS11.T1, AADS12.T1, AADS13r).
EXECUTE.
```

KIDS

```
RECODE KIDS8.T1 KIDS9.T1 KIDS10.T1 KIDS11.T1 KIDS3.T1 KIDS5.T1 (1=5) (2=4) (3=3) (4=2) (5=1) INTO
   KIDS8.T1.R KIDS9.T1.R KIDS10.T1.R KIDS11.T1.R KIDS3.T1.R KIDS5.T1.R.
EXECUTE.
COMPUTE Stigma.KIDS=SUM.6(KIDS8.T1.R, KIDS9.T1.R, KIDS10.T1.R, KIDS11.T1.R, KIDS3.T1.R, KIDS5.T1.R).
EXECUTE.
COMPUTE Person.KIDS=SUM.5(KIDS1.T1, KIDS7.T1, KIDS2.T1, KIDS6.T1, KIDS12.T1).
EXECUTE.
COMPUTE Know.KIDS=SUM.3(KIDS13.T1, KIDS4.T1, KIDS14.T1).
EXECUTE.
COMPUTE KIDSTOTAL=Stigma.KIDS + Person.KIDS + Know.KIDS.
EXECUTE.
```

AQ-8-C

No reverse scoring. 8 items – pity, dangerousness, fear, blame, segregation, anger, help and avoidance. Total scores range between 8 and 72. Increasing scores = higher level of stigma. Assign labels to variables for each AQ.

Blame – AQ4
Anger – AQ6
Pity – AQ1
Help – AQ7
Dangerousness – AQ2
Fear – AQ3
Avoidance – AQ8
Segregation – AQ5

Willingness to work with people with dementia

No reverse scoring. 1 – strongly disagree, 2 – disagree, 3 – neither agree nor disagree, 4 – agree, 5 – strongly agree.

ALOCD

Higher scores indicate more contact with people with dementia. Subscales (indirect and direct contact).

(direct) 1 I have come across people living with dementia
(direct) 2 I have spent time with people living with dementia

(direct) 3 I have spent time with a family friend who is living with dementia
(direct) 4 I have spent time with a family member living with dementia
5 (direct) I have looked after someone living with dementia
6 (indirect) I have watched TV shows or movies in which a character has dementia

7 (indirect) I have come across adverts (e.g., billboards, leaflets) about dementia in my community
8 (indirect) I have come across people living with dementia on social media (e.g., Twitter, Facebook)
9 (indirect) I have searched for information on dementia on the internet
10 (indirect) I have spoken to family or friends about dementia

Continuum total score: COMPUTE ALOCD=SUM.10(ALOCD1, ALOCD2, ALOCD3, ALOCD4, ALOCD5, ALOCD6, ALOCD7, ALOCD8, ALOCD9, ALOCD10).

For dichotomous:
COMPUTE DirectContact=SUM.5(ALOCD1, ALOCD2, ALOCD3, ALOCD4, ALOCD5).
EXECUTE.
COMPUTE InDirectContact=SUM.5(ALOCD6, ALOCD7, ALOCD8, ALOCD9, ALOCD10).
EXECUTE.

EmQue-CA
An 18-item general measure of adolescent empathy, which captures 'affective empathy', 'cognitive empathy', and 'intention to comfort'. Each item has a 3-point Likert response format, where participants rate items "Not True", "Sometimes True" and "Often True". Totals were scored according to online syntax [31], in which higher scores reflect higher levels of empathy.
Contagion
Compute epcon=mean(ep1, ep4, ep7, ep10, ep13, ep16)
Attention
Compute epatt=mean(ep3, ep6, ep9, ep15, ep18, ep20, ep12)
Prosocial
Compute eppro=mean(ep2, ep5, ep8, ep11, ep14, ep17)

NILTS (dementia knowledge)
Dementia is a disease of the brain **TRUE**
Dementia is a mental illness **FALSE**
Dementia is part of the normal process of ageing **FALSE**
Dementia is another term for Alzheimer's disease **FALSE**
People who eat healthily and exercise are less likely to get dementia **TRUE**
There are many different kinds of dementia **TRUE**
Dementia can be cured **FALSE**

The relational ageism scale (factor 2: collective sub-scale)
COMPUTE Ageism=SUM.5(1,2,3,4,5)
Higher scores indicate higher levels of ageism.

Experience of dementia (can be summed and individual) categorical (positive, negative)

1 When I have spent time with people with dementia my experience has been…
2 My experience of looking after someone living with dementia is…
3 When I have come across dementia on social media, the person is represented…
4 When I have heard family or friends talk about dementia it is…
5 In tv or film I feel that the person with dementia was represented as…
Generally positive 1
Generally negative 0

Brief social desirability Children's scale

Those who score more than two socially desirable answers can indicate participants who have a high tendency towards social desirability. Yes and no category. SUM then if function greater 2. High tendency and low tendency – dichotomise

"The BSDS is a four-item scale of social desirability developed for its brevity and practicality. The BSDS is the most commonly used social desirability scale across psychology and other disciplines. Items include "Would you smile at people every time you meet them?" and "Do you always practice what you preach?" Item 4: "Would you ever lie to people?" is reversed scored. Items are answered with "yes" or "no" with a score of 1 allocated to "yes" and 0 for "no." The total scores are summed. The cut-off score can be set from anything > 1 (more than one socially desirable answer) to > 2 (more than two socially desirable answers) to exclude people with a high tendency towards social desirability".

Appendix L. Chapter 4 Detailed SEM Methodology

Exploratory Model Development

In this study, an exploratory model was constructed to determine model fit using a non-recursive path analysis via SEM with the maximum likelihood estimation (CB-SEM) (Grønneberg & Foldnes, 2018). This method was chosen to explore mediation effects between factors, using the Iteration Five raw SPSS data file.

Data Handling and Complexity

At this stage of the analysis, there was no missing data as the dataset had undergone multiple imputations during phase I. The model was moderately complex due to the sample size and number of variables. However, the statistical power was sufficient to detect meaningful relationships within the model, considering the moderate effect sizes.

Parcelling and Variables

To manage the model's complexity, scales connected with latent variables were parcelled using the total scores per participant rather than individual scale items, which follows recommendations to reduce observed variables while still capturing the essence of each construct (e.g., Wang, Zhang, Maxwell, & Bergeman, 2019; Willet, Singer & Martin, 1998). Parcelling can also improve the distribution of observed variables, making the SEM assumptions more reasonable (Bollen, 1989). The variables gender and willingness to work with people with dementia were indicated by single categorical items.

Regression weights were set to one for certain parcel variables, and additional weights were constrained as necessary to achieve model fit. Both standardised and unstandardised coefficients were obtained. However, as standardising coefficients can be misleading when distribution varies between variables, unstandardised coefficients with standard errors (s.e.) and bias-corrected 95% confidence intervals (CI) are reported (Wang et al., 2019; Willet et al., 1998). Error terms were added for all variables, except gender, to account for potential measurement errors. Decisions on which error terms covaried were guided by modification indices from AMOS, considering both the highest values and theoretical justifications, in line with the literature (Bollen, 1989).

Bootstrapping and Model Fit

Given that the data was not normally distributed, a bootstrapping procedure was applied (Nevitt & Hancock, 2001). This involved drawing independent samples and calculating target statistics to estimate standard errors. Bootstrapping is particularly effective under non-normal data conditions (Fitrianto & Cing, 2014). With a sample size of 432 and 10,000 bootstrap samples, this ensured an effective estimation. Bias-corrected confidence intervals (BsCI) were obtained using CB-SEM with maximum likelihood estimation (Cheung & Lu, 2008). CB-SEM was chosen over percentile CI

methods for its ability to provide more accurate estimates in CB-SEM contexts (Efron, 1987).

CB-SEM vs. PLS-SEM

The decision to use CB-SEM with maximum likelihood estimation was informed by several factors. CB-SEM is known for its robustness against violations of normality, especially in cases where sample sizes are sufficiently large (Olsson, Foss, Troye, & Howell, 2000). This approach also allows for the generation of global fit statistics, which are crucial for model validation. In contrast, partial least squares (PLS) methods, while useful for smaller samples and exploratory research, were deemed less suitable for this study due to their tendency to produce biased estimates under certain conditions (Dolce & Lauro, 2015; Sarstedt, Hair, Ringle, Thiele, & Gudergan, 2016). Additionally, the focus on theory testing and the need for a comprehensive model fit statistic made CB-SEM the preferred method over PLS-SEM, which is often criticised for its lack of emphasis on overall model fit (Rigdon, 2012).

Bollen-Stine Bootstrap

The Bollen-Stine bootstrap was used to obtain a goodness-of-fit statistic (at 10,000 bootstrap samples) to provide the model fit (Corrêa Ferraz, Maydeu-Olivares, & Shi, 2022). The Bollen-Stine can correct for standard error and fit statistical bias that may occur in SEM due to non-normal data (Bollen-Stine, 1992). The method takes the empirical sample of size and randomly draws repeated samples with a replacement of the same size (Becker, Meiring, & Van der Westhuizen, 2019). A *p-value* of above 0.05 indicates a good fit (Corrêa Ferraz et al., 2022; Walker & Smith, 2017). Evidence suggests that poor practice in SEM occurs when the outcome of the model $\chi 2$ test is not considered in addition to the individual parameters (Kline, 2018). Indexes are used as indicators of the exploratory model fit including $\chi 2$ *p* value. The User-defined estimand function was utilised to create specific indirect effects and indirect serial effects by adding paths to the parameters.

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Appendix M. Chapter 4 Univariate regression findings

Univariate linear regressions (enter method) were used to assess which variables (age, gender, direct contact, indirect contact, affective empathy, cognitive empathy, prosocial intention empathy, ethnicity, and whether participants have heard of dementia or Alzheimer's disease before) were associated with DRA.

Brief A-ADS

The univariate linear regression models revealed that higher Brief A-ADS scores were significantly associated with increased empathy (prosocial, $p < 0.001$; affective, $p < 0.001$ and cognitive, $p = 0.002$), higher levels of indirect contact ($p < 0.001$), higher levels of direct contact ($p < 0.001$) and being female ($p < 0.001$). The following variables did not significantly predict the Brief A-ADS attitude scores; age ($p = .26$), ethnicity ($p = .73$) and whether participants had heard of dementia or Alzheimer's disease ($p = .85$).

KIDS

The univariate linear regressions revealed that higher KIDS scores were significantly associated with increased empathy (prosocial, $p < 0.001$ and affective empathy, $p = .003$), higher levels of direct contact ($p < 0.001$), higher levels of indirect contact ($p < 0.001$), being female ($p < 0.001$), and have heard of Alzheimer's and dementia before ($p = .005$). The following variables did not significantly predict the KIDS attitude scores; age ($p = .68$), cognitive empathy ($p = .07$) and ethnicity ($p = .23$).

Willingness to work with people with dementia

The univariate logistic regression revealed that increased empathy (prosocial, $p = .001$ and affective, $p = .02$), direct contact ($p < 0.001$) and indirect contact ($p < 0.001$) were all associated with increased willingness to work with people with dementia. Males were 41% less willing to work with people with dementia compared to females ($p = .007$). No other variable was significantly associated with willingness to work with people with dementia ($p > 0.05$). Table Appendix M.I presents the outcomes of univariate logistic regressions.

Appendix M. Table Appendix M.I – Univariate linear regressions for the outcome variables Brief A-ADS and KIDS

	Univariate linear regression (n = 430)					
	Brief A-ADS			KIDS		
	β	B	CI [95%]	β	B	CI [95%]
Age	-0.06	-0.38	-1.04 – 0.28	-0.02	-0.15	-0.88 – 0.58
Gender: Male	-0.19***	-2.08	-3.10 – -1.06	-0.17***	-2.06	-3.19 – -0.93
Ethnicity: White British	-0.02	-0.21	-1.41 – 0.99	0.06	0.81	-0.51 – 2.13
Affective empathy	0.28***	0.55	0.37 – 0.73	0.15**	0.32	0.11 – 0.52
Cognitive empathy	0.13**	0.38	0.11 – 0.64	0.09	0.27	-0.02 – 0.56
Prosocial intention empathy	0.30***	0.74	0.51 – 0.96	0.19***	0.52	0.27 – 0.77
Direct contact	0.28***	0.27	0.18 – 0.35	0.43***	0.45	0.36 – 0.54
Indirect contact	0.32***	0.44	0.32 – 0.56	0.20***	0.30	0.16 – 0.44
Heard of dementia or Alzheimer's: Yes	-0.10	-.026	-2.90 – 2.39	0.13**	4.12	1.24 – 7.01

Outcome variable: Brief A-ADS and the KIDS. Statistical significance: * = $p < 0.05$; ** = $p < 0.01$; *** $p = < 0.001$. Dichotomous variables are coded as 0 versus 1. *B* = unstandardised beta coefficient, β = standardised beta coefficient; CI = confidence interval (lower – upper bound) [95%]

Appendix M. Table Appendix M.II – Univariate linear regression for the outcome variable Willingness to work with people living with dementia

Predictors	Univariate logistic regression (n=432)		
	B	**Odds ratio: Exp (B)**	**CI [95%]**
Affective empathy	0.09*	1.09	1.02 – 1.17
Cognitive empathy	0.06	1.06	0.96 – 1.17
Prosocial intention empathy	0.15**	1.17	1.07 – 1.28
Direct level of contact	0.08***	1.08	1.05 – 1.12
Indirect level of contact	0.12***	1.13	1.07 – 1.18
Gender: Male	-0.53**	0.59	0.40 – 0.87
Age	-0.15	0.86	0.67 – 1.10
Ethnicity: White British	0.14	1.15	0.74 – 1.79
Heard of dementia or Alzheimer's: Yes	0.02	1.02	0.39 – 2.69

Outcome variable: Willingness to work with people with dementia. Statistical significance: * = $p < 0.05$; ** = $p < 0.01$; *** $p = < 0.001$. Dichotomous variables are coded as 0 versus 1. B = unstandardised beta coefficient; Exp (B) = odds ratio; CI = confidence interval (lower – upper bound).

Appendix N. Chapter 5 SEM Direct and Mediatory Pathways Hypotheses

Appendix Table N – SEM Direct and Mediatory Pathways Hypothesis

Direct Effects (pathways)	Theoretical Frameworks	Hypotheses	Justification and Evidence
Contact > Empathy	Intergroup Contact Theory (Allport, 1954)	Higher contact increases empathy.	Contact reduces prejudice and increases empathy between groups (Chapter 4: Contact > Empathy; Hassan et al., 2023a)
Contact > Knowledge	Intergroup Contact Theory (Allport, 1954)	Increased contact improves dementia knowledge.	Contact with dementia led to increase in dementia knowledge (Kim et al., 2021)
Age > Knowledge	Social Cognitive theory (Bandura, 1986)	Older adolescents have higher dementia knowledge.	Cognitive abilities and experiences associated with increase with age. Older participants reported more dementia knowledge than younger participants (Wu et al., 2022)
Knowledge > Ageism	Social cognitive theory (Bandura, 1986); Attribution Theory (Weiner & Weiner, 1985)	More dementia knowledge reduces ageist attitudes.	High dementia knowledge leads to lower ageist attitudes (Donizzetti, 2019)
Empathy > Ageism	Empathy Altruism Hypothesis (Batson et al., 1991); Social Identity Theory (Tajfel et al., 1971)	Higher empathy correlates with lower ageism.	Empathy reduces prejudice against outgroup members and decreases ageist views. Higher empathy was associated with less ageism (Larsen et al., 2021)
Empathy > Attitudes	Empathy Altruism Hypothesis (Batson et al., 1991); Tripartite Model (Rosenberg et al., 1960)	Higher empathy leads to positive DRA.	Empathy leads to more positive attitudes (Batson et al., 1997). Chapter 3 (qualitative evidence) (Baker et al., 2018a) and Chapter 4 (quantitative evidence) (Hassan et al., 2023a)
Ageism > Attitudes	Intergroup Threat theory (Stephan & Stephan, 2013); Social Identity Theory (Tajfel et al., 1971)	Increased ageism correlates with negative attitudes towards older adults.	Ageism reflects perceived threats and ingroup favouritism, leading to negative outgroup attitudes (Werner et al., 2017)
Knowledge > Attitudes	Tripartite (Rosenberg et al., 1960); Attribution Model (Weiner & Weiner, 1985)	More knowledge leads to positive DRA.	Knowledge associated with DRA. Chapter 3 systematic review identified the association between knowledge and DRA (Felc et al., 2021; Lo et al., 2020; Werner et al., 2017).
Contact > Attitudes	Intergroup Contact Hypothesis (Allport, 1954); Tripartite Model (Rosenberg et al., 1960)	More contact results in positive DRA.	Contact reduces prejudice and influences attitudes (Allport, 1954). Evidence from Chapter 4 (Hassan et al., 2023a).

Age > Attitudes	Tripartite Model (Rosenberg et al., 1960)	Older adolescents are associated with negative DRA.	Life experiences - mature cognitive development and emotional experiences can mean as we age we have more preference for negative perceptions (Hess, 2006). Mixed findings on the relationship between age and DRA (Fuh et al., 2005; Fox, 2020; Lo et al., 2020).
Attitudes > Willingness to work with people with dementia	Reasoned action approach (RAA) (Fishbein & Ajzen, 1977); TPB (Ajzen, 1991); Tripartite model (Rosenberg et al., 1960)	Positive DRA increases willingness to work with people with dementia.	Attitudes shape intentions and behaviours (Ajzen, 2011), influencing career choices (Hebditch et al., 2020; 2022). Evidence of direct effect in Chapter 4.
Age > Willingness to work with people with dementia	TPB (Ajzen, 1991)	Older adolescents are less likely to be willing to work with dementia.	Studies with a wide age range support observed age differences in attitudes towards (Fox et al., 2010). Chapter 4 findings from SEM, a majority of participants expressed being unsure or unwilling to work with people with dementia.
Mediatory Effects (pathways)	**Theoretical Frameworks**	**Hypotheses**	**Justification and Evidence**
Contact > Empathy > Attitudes	Intergroup Contact hypothesis (Allport, 1954); Empathy Altruism Hypothesis (Batson et al., 1991); Tripartite model (Rosenberg et al., 1960); Attribution Model (Weiner & Weiner, 1985)	Empathy mediates the effect of contact on DRA.	Contact enhances empathy, which fosters positive DRA (Chapter 4 – Hassan et al., 2023a).
Empathy > Ageism > Attitudes	Empathy Altruism Hypothesis (Batson et al., 1991); Intergroup Threat Theory (Stephan & Stephan, 2013)	Higher empathy effect on positive DRA mediated by less ageist beliefs.	Empathy lowers prejudice and discrimination, reducing ageism and improving DRA (Nguyen & Li, 2020).
Empathy > Attitudes > Willingness to work with people with dementia	Empathy Altruism Hypothesis (Batson et al., 1991); Tripartite model (Rosenberg et al., 1960); TPB (Ajzen, 1991)	Positive DRA mediates the relationship between empathy and willingness to work with people with dementia.	Higher empathy leads to positive DRA. Attitudes predict behavioural intention (Ajzen, 1991; see evidence – Chapter 4, section 4.5.1).
Contact > Knowledge > Attitudes	Intergroup Contact Hypothesis (Allport, 1954); Tripartite Model (Rosenberg et al., 1960)	Dementia knowledge mediates the effect of contact on DRA.	Contact increases knowledge (Bacsu et al., 2022). Both increased contact Baker et al., 2018a, Baker et al., 2018b; Hassan et al., 2023a; Werner et al., 2017) and knowledge are associated with positive DRA (Lo et al., 2020; Werner et al., 2017).

Contact > Knowledge > Ageism > Attitudes	Intergroup Contact Hypothesis (Allport, 1954); Social cognitive theory (Bandura, 1986)	More dementia knowledge and reduced ageist beliefs mediate the relationship between contact and DRA.	Contact improves knowledge (Bacsu et al., 2022), reduces ageism (Marques et al., 2020) and fosters positive DRA (Baker et al., 2018a, Baker et al., 2018b; Werner et al., 2017).
Knowledge > Ageism > Attitudes	Attribution theory (Weiner & Weiner, 1985)	Less ageist beliefs mediate the effect of knowledge on DRA.	Knowledge decreases ageism (Rababa et al., 2020). Knowledge associated with DRA (Lo et al., 2020; Werner et al., 2017).
Contact > Attitudes > Willingness to work with people with dementia	Intergroup Contact hypothesis (Allport, 1954); TPB (Ajzen, 1991)	Positive DRA mediates the effect of contact on willingness to work with people with dementia.	Contact fosters positive attitudes, which increase willingness to work with dementia (evidenced in SEM findings from Chapter 4).
Age > Knowledge > Attitudes	Social Cognitive theory (Bandura, 1986)	Knowledge mediates the relationship between age and DRA.	Being older is associated with more dementia knowledge, and higher knowledge is associated with positive DRA (Wu et al., 2022). However, age has mixed results in the association with DRA (Fox, 2020; Lo et al., 2020; Fuh et al., 2005) (Chapter 3 systematic review).
Age > Knowledge > Ageism	Social cognitive theory (Bandura, 1986)	Dementia knowledge mediates the relationship between age and less ageist beliefs.	Age associated with dementia knowledge (Wu et al., 2022). Higher knowledge of older adults associated with less ageist beliefs (Rababa et al., 2021).
Ageism > Attitudes > Willingness to work with people with dementia	Intergroup Threat Theory (Stephan & Stephan, 2013); Social Identity Theory (Tajfel et al., 1971)	Positive DRA mediates the effect of reduced ageism on being more likely to express willingness to work with dementia.	Lower levels of ageism associated with nursing students' intentions to work in dementia care (McKenzie & Brown, 2014). Attitudes predict behavioural intention (Ajzen et al., 2018).
Sex > Empathy > Attitudes	Empathy Altruism Hypothesis (Batson et al., 1991); Tripartite Model (Rosenberg et al., 1960)	Empathy mediates the relationship between sex and DRA.	Females tend to have higher empathy (Van der Graaf et al., 2018) and more positive DRA (Farina et al., 2020a).

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N.B. All other references have been cited in the main thesis Chapters and therefore are located in the thesis' main reference list (Before Appendix A).

Appendix O. Participant Materials

PARTICIPANT INFORMATION SHEET

Young people's views of dementia.

We are inviting you to take part in a research study. Please take time to read the following information carefully and discuss it with others if you wish. Before you decide whether to take part, it is important for you to understand why the project is being done and what it will involve. Please ask your teacher or the researcher if there is anything that is unclear, or if you would like more information.

1. What is the purpose of the study?

Currently, we do not know much about what young people's views of dementia are and how this might change over time. We want to explore young people's views and understanding of dementia.

2. Why have I been invited to participate?

You are aged between 11 - 18 years old and go to secondary school. Your school has said they are happy for the research to be offered.

3. Do I have to take part?

It is up to you to decide whether or not to take part. Not participating will not affect your education in any way.

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

On a day and time set by your school, you will be asked to fill in a form that says you are happy to be involved in the research. On the day of the study, you will have an opportunity to ask the researcher in person any questions you may have before taking part. If you have been given this information sheet in advance, this means you have up to one week before the research begins to ask the teacher any questions.

We will ask you questions about your views and experiences of dementia. The questionnaire takes approximately 10minutes to complete. The statements and questions are mainly multiple choice. You may also then be asked to complete a short 3-minute word association computer activity related to the questionnaire. No one will know how you have answered, not even your parents or teachers.

5. What are the possible benefits of taking part?

The study may help us and other scientists to learn about young people's views about dementia. You will also be entered into a prize draw for each year you participate. You have the chance to win a £20 amazon voucher to thank you for participating in the research. There are 60 vouchers in total. Only one submission of the questionnaire per person is eligible for the prize draw.

6. Are there any possible disadvantages or risks to taking part?

The study will take 10 minutes of your time. For some young people with family members living with dementia, it might bring up sad feelings about dementia. At the end of the study you will be provided with access to the Alzheimer's Society web page that gives you further information and support related to dementia. You may also wish to discuss any concerns with a member of the wellbeing team from your school.

7. What will happen with the information I give you?

All information and data you share will be kept securely on University of Sussex computers to begin with but we will later share it online (UK Data Archive) so other scientists can use it. Your data will be stored for a minimum of 10 years. Any information we store will not directly be linked with you, so no one can know who you are. Your age and gender will be collected but identifiable information such as your name will not be collected. Scientists will use this information to write reports in scientific magazines and present findings at scientific conferences. Anything we report will not contain any personal information that would allow someone to know who you are.

8. What will happen if I don't want to carry on with the study?

You can stop participating in the study at any time, without giving a reason. If you change your mind after you have finished the questionnaire then you have around one month to withdraw. Please provide the teacher with your unique code, and they will get in contact with us and we will delete your data. You can also withdraw by going onto the following link **https://redcap.link/ypvodwithdraw** and entering your unique code. Please note down your unique code which you will create at the start of the questionnaire.

9. What should I do if I want to take part?

Please read the consent form carefully and tick the boxes to the statements you agree to.

10. What will happen to the results of the research study?

The results of the study will be included in a PhD thesis and written up for scientific magazines and conferences. The results will help researchers and policy makers identify useful dementia awareness strategies in the future. The lead researcher will provide your school a summary of the findings at the end of the study, who will be able to share them with you.

11. Who is organising and funding the research?

Esra Hassan, a PhD student at **Brighton and Sussex Medical School (BSMS)** is the lead researcher conducting this study. The Alzheimer's Society is funding this research [Grant number: 545].

12. Who has approved this study?

This research has been approved by the Brighton and Sussex Medical School Research Governance and Ethics Committee (RGEC) (ER-BSMS9PCH-1).

13. Who is responsible if something goes wrong?/What if there is a problem?

If you are worried about the research, or how it is being run then you should try and speak to your teacher. The teacher might be able to answer your questions or get in touch with someone who can.

14. Insurance

The Universities of Brighton and Sussex have insurance in place to cover their legal liabilities in respect of this study.

Thank you for taking the time to read this information sheet

brighton and sussex medical school

YOUNG PEOPLE'S VIEWS OF DEMENTIA QUESTIONNAIRE:

Version 2

Please read the information page carefully before completing this questionnaire. Once you have completed the questionnaire, please hand it in to your teacher.

Please DO NOT write your name on this questionnaire.

Consent Form (please put a tick in the box to indicate your answer)

	Yes	No
I understand that any information I provide is confidential, and that no information that I disclose will lead to the identification of any individual in the reports on the project, either by the researcher or by any other person.		
I have read the information sheet, had the opportunity to ask questions and I understand the purpose of the study, what the study involves, and possible risks involved.		
I consent to the processing of my data for the purposes of this research study. I understand that such information will be treated as confidential and handled in line with data protection laws.		
I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without it having an impact on my education or future studies.		
I agree to take part in the above-named research project.		
I consent for the information I provide to be used in further research, data analysis and by other researchers with ethical approval as long as any of my data I provide is anonymous so that I remain confidential.		

Please complete this box carefully, as it will help us match your responses later and your code to withdraw from the study.

What was your assigned gender at birth? *(tick one)*

Male ☐ *Female* ☐

What is your birthday month? *(tick one)*

January ☐
February ☐
March ☐
April ☐
May ☐
June ☐
July ☐
August ☐
September ☐
October ☐
November ☐
December ☐

Number of biological older brothers _____

Number of biological older sisters _____

The **second letter** of your **first name** (please write in CAPITAL) _____

The **first letter** of your **surname** (please write in CAPITAL) _____

How old are you? *Please circle your age*

11 12 13 14 15 16 17 18

What best describes your ethnicity? *Please tick one box*

White (White British, English, Scottish, Welsh, Northern Irish, Gypsy, Roma, any other white background)	
Black (Black, African, Caribbean, Black British)	
Asian - South Asian (British South Asian, Indian, Pakistani, Bangladeshi, any other south Asian background)	
Asian - East Asian (British East Asian, Chinese, any other east Asian background)	
Middle Eastern (Arab and any other middle eastern background)	
Mixed or multiple ethnic background (Black Caribbean and White, White and Black African, Asian and White.	
Black and Asian, any other mixed or multiple ethnic background)	
Other	
I do not want to answer	

If you have ticked the option 'other', please state your ethnicity here

What is your religion? *Please tick one box*

No religion	
Christian (including Church of England, Catholic, Protestant and all other Christian denominations)	
Buddhist	
Hindu	
Jewish	
Muslim	
Sikh	
Other religion	
I do not want to answer	

If you have ticked the option 'other religion', please state your religion here

Please continue to the next page

Many young people have not heard of the words <u>Alzheimer's disease</u> or <u>Dementia</u>. We would like to know whether you have <u>heard</u> of either of these words. Please tick ONE option below.

☐ I have NOT heard of either of these words. 0

☐ I have only heard of "Alzheimer's Disease" 1

☐ I have only heard of the word "Dementia" 2

☐ I have heard of both "Alzheimer's Disease" and "Dementia" 3

If you have selected that you have not heard of either Alzheimer's disease or dementia before, you do not need to continue with the questionnaire. We thank you for your time!

We are interested in what people think of dementia. Could you tell me whether you think the following statements are true or false?... (please circle one number for each statement)

	True	False	Don't know
Dementia is a disease of the brain	1	2	77
Dementia is a mental illness	1	2	77
Dementia is part of the normal process of ageing	1	2	77
Dementia is another term for Alzheimer's disease	1	2	77
People who eat healthily and exercise are less likely to get dementia	1	2	77
There are many different kinds of dementia	1	2	77
Dementia can be cured	1	2	77

We would like to know what you think about dementia or people with dementia. In the table on the next page is a list of statements. Please read each one and rate how much you agree with it by circling ONE choice only. Please rate ALL statements as honestly as you can, and not how you think you should respond. Your name is not on this questionnaire, and no one will know that it was you who filled it out.

Don’t spend too much time on each statement; just go with your first thought. There are no right or wrong answers.

Start on the next page…

We're interested in attitudes of young people towards dementia…. (please circle a number for each statement)

	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly Agree**
I would volunteer to spend time with people with dementia	1	2	3	4	5
I would be annoyed if my parents asked me to spend time with a family friend who has dementia rather than see my friends	1	2	3	4	5
I would donate my time or money to help people with dementia	1	2	3	4	5
If I saw someone with dementia struggling to do something, I would help them	1	2	3	4	5
It is rewarding to work with people who have dementia	1	2	3	4	5
People with dementia can be creative	1	2	3	4	5
I am comfortable holding hands with people with dementia	1	2	3	4	5
Every person with dementia has different needs	1	2	3	4	5
It is possible to enjoy spending time with people with dementia	1	2	3	4	5
I feel relaxed around people with dementia	1	2	3	4	5
I admire how people with dementia deal with things	1	2	3	4	5
We can do a lot now to improve the lives of people with dementia	1	2	3	4	5
I would feel uncomfortable being around people with dementia	1	2	3	4	5
In the future, I would be willing to work with people who have dementia	1	2	3	4	5

These statements are about your level of experience or contact with people living with dementia… (please circle a number for each statement)

	Never	Rarely	Occasionally	A moderate amount	A great deal
I have come across people living with dementia	1	2	3	4	5
I have spent time with people living with dementia	1	2	3	4	5
I have spent time with a family friend who is living with dementia	1	2	3	4	5
I have spent time with a family member living with dementia	1	2	3	4	5
I have looked after someone living with dementia	1	2	3	4	5
I have watched TV shows or movies in which a character has dementia	1	2	3	4	5
I have come across adverts (e.g., Billboards, leaflets) about dementia in my community	1	2	3	4	5
I have come across people living with dementia on social media (e.g., Twitter, Facebook)	1	2	3	4	5
I have searched for information on dementia on the internet	1	2	3	4	5
I have spoken to family or friends about dementia	1	2	3	4	5

Please only circle one number for each statement.

	I have not	Generally positive	Generally negative	Don't know
When I have spent time with people with dementia, my experience has been…	0	1	2	3
My experience of looking after someone living with dementia is…	0	1	2	3
When I have come across dementia on social media or the internet (e.g., twitter, Instagram, google search), I feel that the person with dementia was represented as…	0	1	2	3
When I have heard family or friends talk about people with dementia, it is…	0	1	2	3
In tv or films, I feel that the person with dementia was represented as…	0	1	2	3

Below you will find 18 short sentences. Every sentence is a statement about how you can react to other people's feelings. You can mark each sentence if this is often true, sometimes true or not true for you. Choose the answer that best fits you. You can only mark one answer. Please remember that there are no wrong or right answers.

	Not True	Sometimes True	Often True
If my mother is happy, I also feel happy.	0	1	2
I understand that a friend is ashamed when they have done something wrong.	0	1	2
If a friend is sad, I like to comfort them.	0	1	2
I feel awful when two people quarrel.	0	1	2
When a friend is angry, I tend to know why.	0	1	2
I would like to help when a friend gets angry.	0	1	2
If a friend is sad, I also feel sad.	0	1	2
I understand that a friend is proud when they have done something good.	0	1	2
If a friend has an argument, I try to help.	0	1	2
If a friend is laughing, I also laugh.	0	1	2
If a friend is sad, I understand mostly why.	0	1	2
I want everyone to feel good.	0	1	2
When a friend cries, I cry myself.	0	1	2
If a friend cries, I often understand what has happened.	0	1	2
If a friend is sad, I want to do something to make it better.	0	1	2
If someone in my family is sad, I feel really bad.	0	1	2
I enjoy giving a friend a gift.	0	1	2
When a friend is upset, I feel upset too.	0	1	2

Please continue to the next page

We're interested in young people's views towards older people…. (please circle a number for each statement)

	Strongly agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly Disagree**
I enjoy being around older people	1	2	3	4	5
I like to go visit older relatives	1	2	3	4	5
I enjoy talking with older people	1	2	3	4	5
I feel comfortable when I am around an older person	1	2	3	4	5
I enjoy doing things for older people	1	2	3	4	5

You are doing great.

Continue to the next page…

Charlie is an elderly friend of the family who will be moving into your home. Your parents explain that Charlie has dementia and was previously living in a care home. Please circle one number for each statement.

	None at all								Very much
I would feel pity for Charlie.	1	2	3	4	5	6	7	8	9
	None at all								Very much
How dangerous would you feel Charlie is?	1	2	3	4	5	6	7	8	9
	None at all								Very much
How scared of Charlie would you feel?	1	2	3	4	5	6	7	8	9
	Not at all								Yes, very much
I think Charlie is to blame for the dementia.	1	2	3	4	5	6	7	8	9
	None at all								Very much
I think Charlie should live in a special home for people with problems, not a home like mine.	1	2	3	4	5	6	7	8	9
	None at all								Very much
How angry would you feel at Charlie?	1	2	3	4	5	6	7	8	9
	Definitely would not help								Definitely would help
How likely is it that you would help Charlie with chores?	1	2	3	4	5	6	7	8	9
	None at all								Very much
I would try to stay away from Charlie at home**.**	1	2	3	4	5	6	7	8	9

This is the last page. Choose the answer that best fits you. You can only mark one answer for each question. Please remember that there are no wrong or right answers.

	Yes	No
Would you smile at people every time you meet them?	1	0
Do you always practice what you preach to people? (behave as you would have others behave)	1	0
If you say to people that you will do something, do you always keep your promise no matter how inconvenient it might be?	1	0
Would you usually lie to people?	1	0

Thank you for completing this questionnaire

DEBRIEF FORM

Thank you for taking part in this study that helps us get a better understanding of what young people's views and understanding of dementia are. Your time and contribution is appreciated. You will be entered into a prize draw to win a £20 amazon voucher. A member of staff at your school will let you know if you are a winner. If you have any questions about the study, you can ask a member of staff who can then get in contact with the research team to answer any questions you may have.

How to withdraw

You are still free to withdraw your consent, without giving a reason. You can ask to withdraw any of your data within one month of completing your questionnaire. Please let your school teacher know if you wish to withdraw your data. You can provide them with the unique code you created at the start of the questionnaire which consisted of:

- your sex (male or female)
- your birthday month
- number of biological older brothers
- number of biological older sisters
- second letter of your first name
- first letter of your surname

The member of staff can then get in contact with the research team to withdraw your data. Alternatively, you can also go onto the following link https://redcap.link/ypvodwithdraw and enter your unique code. We can then delete your data.

If you wish to seek further support and information about dementia, here are some resources you may find helpful:

https://www.alzheimers.org.uk/

https://www.alzheimersresearchuk.org/kids/dementia-explained/

https://www.alzheimers.org.uk/get-support/publications-factsheets/helpsheets-about-dementia

If you would like any more support, please contact your wellbeing team at your school.

Thank you for your time.

Appendix P. Chapter 5 School and participant characteristics

Appendix Table P - School and participant characteristics

School	Region	Index of Multiple Deprivation (2019)	School characteristics	Ages selected by the school to take part	Invited to take part by the school
1	Bedfordshire	Amongst the 20% least deprived neighbourhoods in the country.	Secondary, Academy converter. Non-selective, mixed gender.	13-16	900 invited, 0 parental opt outs, 574 participants took part, 453 valid questionnaires, 52 did not give their consent to take part, 69 did not fill out the consent, 323 questionnaires were not given out by the school due to lack of time.
2	Bedfordshire	Amongst the 20% most deprived neighbourhoods in the country.	Secondary, Academy sponsor led. Non-selective, mixed gender.	13-14	280 invited, no parental opt out, 221 valid questionnaires (59 did not consent)
3	Bedfordshire	Amongst the 20% most deprived neighbourhoods in the country.	Secondary, Academy converter. Non-selective, single gender.	13-16	No parental opt out, opportunistic recruitment, 43 valid questionnaires
4	East Sussex	Amongst 30% least deprived neighbourhoods in the country.	Secondary, Community School. Non-selective, Mixed gender.	13-14	299 invited, 1 parental opt out, 115 valid questionnaires

5	Hertfordshire	Amongst the 20% least deprived neighbourhoods in the country.	Secondary, Academy converter. Non-selective, single gender.	11-18	Opportunistic - No parental opt out, 94 valid questionnaires
6	Devon	Amongst the 20% most deprived neighbourhoods in the country.	Secondary, Academy converter. Non-selective, Mixed gender.	11-18	Opportunistic - No parental opt out, 146 valid questionnaires
7	East Sussex	Amongst the 10% least deprived neighbourhoods in the country.	Secondary, Community school. Non-selective, Mixed gender.	11-15	Age 14-15 (n = 237) Age 11-12 (n = 47 parental opt in) Age 12-13 (n = 187 parental opt in). 203 valid questionnaires
8	Leicestershire	Amongst the 30% most deprived neighbourhoods in the country.	Secondary, Academy converter. Non-selective, Mixed gender.	14-16	Opportunistic, 105 took part, 81 valid questionnaire
9	West Midlands	Amongst the 10% most deprived neighbourhoods in the country.	Secondary, Academy converter. Selective, singe gender.	13-16	Opportunistic , 16 valid questionnaires

Appendix Q. Chapter 5 SEM methodology

Parcelling

The parameters were set with a regression weight set to the value of one from one of the parcel variables to their associated latent variable with further regression weights added to parameters that needed constraining to obtain the model fit.

Error terms

The literature suggests that correlated error terms should be used conservatively with the wider measurement theory used to determine which error terms to correlate (Bollen, 1989). As a result, the following variables in the SEM were covaried; AQ-8-C covaried with NILTS due to the similar construct of 'understanding' in the measure items of the AQ-8-C "I think Charlie is to blame for dementia", and the NILTS, "People who eat healthily and exercise are less likely to get dementia". Willingness to work with people with dementia and prosocial empathy also conceptually overlap since prosocial motivation is the inclination to help and is empirically associated with behavioural intention (Godman, Nagatsu, & Salmela, 2014). A 'willingness' to engage in a behaviour indicates motivation. The RAS also includes items that conceptually share this motivated behaviour (e.g., "I enjoy doing things for older people"). The RAS and AQ-8-C construct also covary due to involving avoidance contact and avoidance behaviours associated with ageing-related conditions. An example item in RAS includes "I enjoy being around older people", and "I like to go visit older relatives" while the contact element translates as "I would try to stay away from Charlie" in the AQ-8-C. This is why ALOCD (contact) can also covary with AQ-8-C and the RAS. Lastly, there is an overlap in the affective domain of empathy and AQ-8-C where the item in the AQ-8-C "how scared of Charlie would you feel", taps into the emotional construct of empathy and stigma.

CBM vs PLS

ML estimation was selected for its robustness in theory testing, particularly suitable for this study's focus on untested SEM involving variables like ageism and knowledge. This method was preferred over PLS-SEM, which is more appropriate for exploratory studies with smaller sample sizes (Dolce & Lauro, 2015). The decision to use CB-SEM was also supported by evidence that it better handles non-normal data conditions, especially with sufficient sample sizes, enhancing the reliability of model parameters (Sarstedt, Hair, Ringle, Thiele, & Gudergan, 2016).

References

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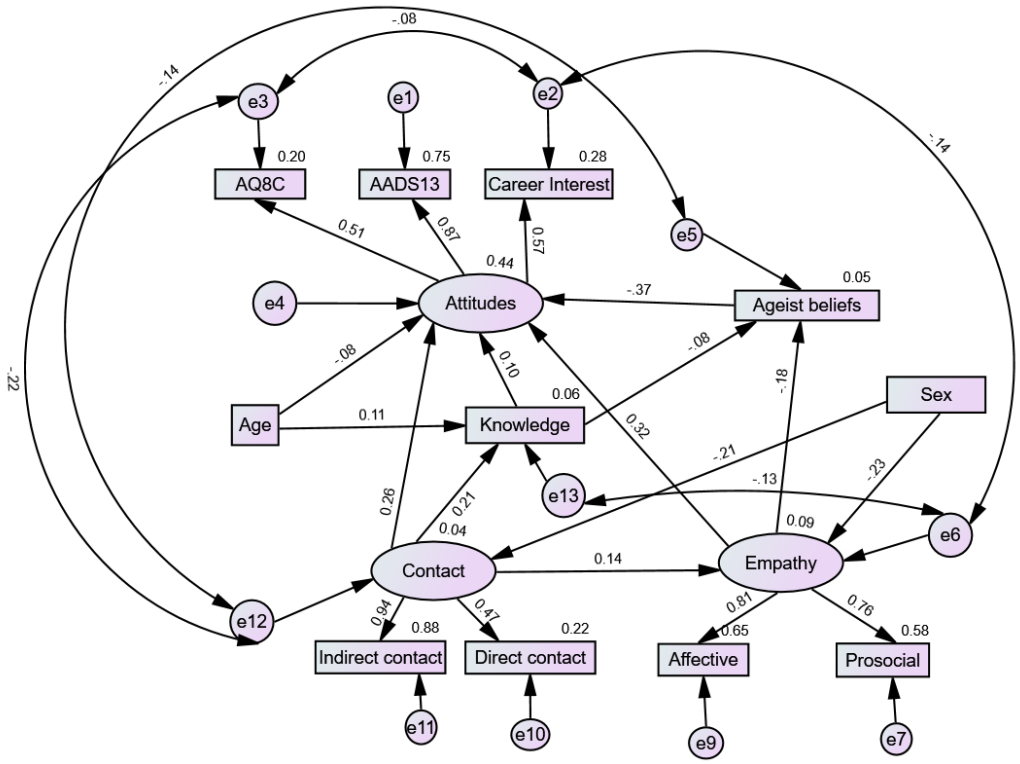
Appendix R. Chapter 5 SEM Exploratory Model Building II with the variable sex



Appendix Figure R – SEM exploratory model building II (standardised coefficients).

This SEM explored the direct and mediatory effects involving sex in the model. The findings revealed a direct, significant negative relationship between sex and empathy, and sex and level of contact with dementia. Sex had a direct effect on levels of empathy, with males being associated with having lower levels of empathy than females (β = -.23, *p* = .00, 95%CIs -.29 to -.16). Males also had lower levels of contact with dementia (β = -.21, *p* = .00, 95%CIs -.27 to -.14). All indirect pathways were significant where the variable sex was involved. The largest effect was a significant negative relationship between sex and attitudes via the mediator empathy, where males were associated with having less positive DRA via having lower levels of empathy than females (β = -.51, *p* = .00, 95%CIs -.79 to -.32). See Appendix Table R for all the indirect pathway results. Note. 'CareerInterest' represents willingness to work with people with dementia.

Appendix Table R – Mediation effects in the model

Parameters	β	Lower CI [95%]	Upper CI [95%]
Sex > empathy > attitudes	-.51**	-.79	-.32
Sex > empathy > attitudes > Willingness to work with people with dementia	-.04**	-.06	-.03
Sex > contact > attitudes	-.37**	-.60	-.22
Sex > contact > attitudes > Willingness to work with people with dementia	-.03**	-.05	-.02
Sex > contact > knowledge	-.02**	-.03	-.01
Sex > contact > knowledge > attitudes	-.03**	-.06	-.01
Sex > contact > knowledge > attitudes > Willingness to work with people with dementia	-.00**	-.01	-.00

Note. β = standardised regression coefficient estimate. Two-tailed statistical significance: * = p < 0.05; ** = p < 0.01; *** p = < 0.001. CI = bias corrected [95%] confidence interval (lower and upper bound). If 0 falls between the lower and upper bound, the indirect effect is not statistically significant. Estimates with (-) = negative relationship.