Thesis Portfolio

Investigating Memory Concerns and Checking Strategies in the Older Population.

Miss Deborah Amy Elizabeth Green

Primary Supervisor: Dr Adrian Leddy

Secondary Supervisor: Dr Fergus Gracey

Doctorate in Clinical Psychology (ClinPsyD)

Faculty of Medicine and Health Sciences

University of East Anglia

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Abstract

Within an aging population the prevalence of dementia, a neurodegenerative condition affecting memory, has been increasing worldwide. This, in addition to, memory performance found to naturally decline with age, has led to increased awareness of the disease amongst the general population. Consequently, it is theorised that this may have generated a fear of developing dementia or 'dementia worry'. A systematic review was conducted to investigate the prevalence of dementia worry within the general population. Fifteen articles were included for review and a combined estimate from a subset of articles found 53.3% of the population reported 'dementia worry'. Furthermore, dementia worry was more prevalent in females, those closer in proximity to dementia, and with concerns about a perceived deterioration in memory. Those with concerns about memory performance may be more likely to utilise strategies to support memory difficulties, such as checking. Previous research, conducted with younger participants and individuals with obsessive-compulsive disorder, have consistently found that repeated checking can lead to increased memory doubt. However, this effect had not been fully explored within older populations. An empirical study found, following a repeated checking task, older participants reported significant deterioration in memory accuracy and memory confidence, with some deterioration in other aspects of meta-memory. These deficits were also indicated in a small sample of older adults with a diagnosis of dementia. Thus, repeated checking paradoxically causes increased memory errors and memory doubt for older participants both with and without cognitive impairments. Together, these papers indicate a possible relationship between dementia worry, memory doubt, and strategy use that may be exacerbating or maintaining these concerns. Clinicians should be aware of these

factors and ensure the most beneficial strategies are recommended. Further research is required to deepen our understanding of the consequences of dementia worry and further investigate the implications of memory strategies.

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Does Fear of Dementia Exist in the General Population? – A systematic review.

Miss Deborah A. E. Green*

Dr Adrian Leddy

Dr Fergus Gracey

Department of Clinical Psychology, Norwich Medical School, University of East Anglia,

Norwich, NR4 7TJ, UK.

*Corresponding author e-mail: d.green2@uea.ac.uk

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(See Appendix A for Author Guidelines)

Abstract

Dementia, a neurodegenerative disease, has been increasing in prevalence due to an ageing population and developments in medical care. With this increase, dementia has become a health priority across the world with campaigns to increase dementia awareness and knowledge in the general population. Poor knowledge and inaccurate stereotypes about dementia are thought to contribute to negative attitudes, stigma and a fear of developing dementia. The aim of this paper was to conduct a systematic review of the literature on the presence of 'dementia worry' or fear of developing dementia in the general population. Following a comprehensive search, 15 peer-reviewed studies met the criteria for inclusion in the review. All studies were quality assessed. Six of these studies were cross-sectional studies across the general population, and nine recruited middle to old-age populations. Several methods of measuring dementia worry were utilised. All studies documented the presence of dementia worry, and although high variation was found, a combined estimate of 53.3% of participants reported dementia worry across studies. The findings of several potential correlates of dementia worry including age, sex, ethnicity and proximity to dementia were also explored. These showed mixed results, with most evidence indicating that female gender, those closer in proximity to dementia, and those with memory concerns, were associated with greater fear of developing dementia. Further research is needed to enable a more cohesive understanding of the concept and its consequences. However, these findings may support healthcare professionals and dementia campaigns target key populations to help to reduce 'dementia worry'.

Keywords: Dementia, Memory, Dementia worry, Fear of dementia, Systematic Review.

Introduction

Dementia has become a health priority across the world with a focus on raising awareness of the disease, its risk factors for prevention, and to reduce stigma within the general population and healthcare staff (World Health Organisation; WHO, 2012). Additionally, further research to build upon the evidence base and support dementia strategies has been recommended (WHO, 2012). Dementia is classified as a neurodegenerative disease which affects several cognitive functions, including progressive deteriorations in memory, language, executive function, attention, visuospatial function, orientation, praxis and daily living skills (WHO, 1992). Recent prevalence studies estimate that 46.8 million people have a diagnosis of dementia worldwide, with this number thought to rise to 74.7 million by 2030 (Alzheimer's Disease International; ADI, 2015). These estimated rates are higher than those proposed by ADI in 2009, with a new case of dementia now estimated to be found worldwide every 3.2 seconds (ADI, 2015).

Risk factors for Dementia

Due to the predicted rise in prevalence of dementia, and the current lack of a cure for the condition, multiple studies have explored the risk and protective factors linked to dementia. The biggest risk factors for developing dementia have repeatedly been identified as age, family history of dementia, and genetic vulnerabilities (Baumgart et al., 2015). Of these, age is known as the highest risk factor with incidence rates of Alzheimer's disease rising from 2.4 per 1000 people in those aged 65–69 years to 70.2 per 1000 people in those aged 90 and over (Van der Flier & Scheltens, 2005). However, as these factors are pre-determined and essentially fixed, more recent research has explored possible modifiable and fluid

risk factors that could aid in the prevention of developing dementia. Evidence suggests that lifestyle factors such as increased physical activity, healthy diet, and reduced smoking, along with higher levels of education and cognitive training may be beneficial in reducing cognitive decline and risk of developing dementia (Baumgart et al., 2015). In line with the WHO report (2012), one objective of the U.K. National Dementia Strategy (Department of Health; DoH, 2009) was to increase professional and public awareness of these risk factors through the development of NICE guidance (2015) and public health campaigns including "what's good for your heart is good for your head" promotions (DoH, 2009). Despite these campaigns, however, there continues to be a lack of understanding and common misconceptions held about dementia amongst the general population (Cations, Radisic, Crotty & Laver, 2018).

Attitudes Towards Dementia

Multiple studies have investigated the general population's knowledge, attitudes, and beliefs about Alzheimer's disease and dementia. A systematic review conducted on the general population's knowledge of dementia across fourteen countries, found knowledge to be poor or very limited (Cahill, Pierce, Werner, Darley, & Bobersky, 2015). Although some studies found awareness of dementia symptoms to be moderate; knowledge of risk factors, treatment, and causes were still poor (Cahill et al., 2015). There was an indication that younger participants had more knowledge of dementia, which may show that the awareness campaigns are effective with some cohorts. However, knowledge was reportedly still quite poor in older participants (Cahill et al., 2015).

Furthermore, a lack of knowledge about dementia is thought to contribute to the development of negative attitudes or stigma towards those with a diagnosis of dementia (WHO, 2012). Some of the negative beliefs and misconceptions reported to be held about dementia by older adults include believing nothing can help to improve quality of life or treat those with dementia, and that dementia means losing independence, control, identity, and dignity (Corner & Bond, 2004). A survey of the Australian public did report some positive beliefs amongst respondents including 46.1% of people believing those with dementia can engage in a variety of activities, 38.6% seeing their company as enjoyable and over a third (37.7%) seeing them as a source of wisdom (Phillipson, Magee, Jones & Skladzien, 2012). However, this study also found some participants felt they would be unable to have a meaningful conversation (50.8%) or would avoid spending time with a person diagnosed with dementia (11.7%), and if diagnosed themselves would feel ashamed (60%), anxious (76%) or depressed (70%) (Phillipson et al., 2012).

One of the other main misconceptions about dementia is that it is a normal or inevitable consequence of getting older (Glynn, Shelley, & Lawlor, 2017). This is supplemented by a lack of understanding about the differences between normal age-related memory decline and clinically severe difficulties indicative of a dementia (Cahill et al., 2015). Those who hold the view of dementia being an inevitable part of ageing or have difficulties differentiating normal memory loss from severe memory decline are subsequently less likely to seek medical support and advice (WHO, 2012). Conversely, increases in dementia awareness could lead to an over-recognition of symptoms and therefore, raise concerns that any memory lapse may be suggestive of developing a dementia (Devlin, MacAskill & Stead, 2007). High proportions of people concerned about memory deficits, or subjective memory

impairments, have been reported within the general population (Iliffe & Pealing, 2010). Some studies have found a relationship between those reporting subjective memory concerns and subsequent development of dementia (Rönnlund, Sundström, Adolfsson & Nilsson, 2015). However, a systematic review showed many older adults who expressed memory concerns did not have objective cognitive deficits on neuropsychological testing (Mendonça, Alves & Bugalho, 2015).

It has therefore been considered that difficulty in understanding and recognising the symptoms and causes of dementia, in addition to stigma and negative attitudes towards the disease, may be attributable to, or lead to, a fear of developing dementia (WHO, 2012).

Fear of Dementia

The concept of a fear of developing dementia or 'dementia worry' has been defined in several ways across the literature. Cutler and Hodgson (1996) firstly described the notion of "anticipatory dementia" where individuals may become concerned that age-related memory changes are in fact early warning signs of dementia. Other researchers have utilised a health belief framework where fear about developing dementia is understood within a construct of assessing an individual's perceived threat, susceptibility and severity of dementia (Shi, Sun, Liu, & Marsiglia, 2018). Conversely, a health anxiety model has also been used to conceptualise 'dementia worry'. Thus, knowledge or experience of a disorder (e.g. information or family history of dementia) and perception of personal risk are experienced in combination with ruminative thoughts about developing the disease and misattributions of normal signs (e.g. memory lapses) as indicators of the illness, causing increased anxiety and help-seeking (Warwick & Salkovskis, 1990).

A recent conceptual review which aimed to collaborate these views, defined 'dementia worry' as an emotional reaction, combining both affective and cognitive components, to developing all types of dementia (Kessler, Bowen, Baer, Froelich, & Wahl, 2012). Kessler et al. (2012) concluded that this definition of 'dementia worry' is conceptually distinct from thoughts about perceived risk of developing dementia, dementia knowledge, beliefs about dementia, and concerns about memory performance (subjective memory concerns). This last distinction was made as those who have concerns about their memory may not necessarily associate those concerns specifically with the development of a dementia. In addition, those who believe themselves to have a good memory may still have concerns about developing the disease (Kessler et al., 2012).

Review Aim

Since the Kessler et al. (2012) conceptual review, many more studies have investigated the area of 'dementia worry'. To our knowledge no systematic review has yet been undertaken regarding the prevalence of dementia worry or fear of developing dementia. A systematic review would provide a more robust understanding of the prevalence of dementia worry and the characteristics of those more likely to have these concerns. Furthermore, it will support clinicians to identify potential dementia worry amongst their patients and aid campaigns, aimed to reduce stigma and increase understanding of dementia, to target appropriate populations. Therefore, this study aimed to systematically review the existing literature to assess the degree of fear of developing dementia in the general population, the measures used to assess degree of dementia worry, and whether a consensus can be drawn on specific characteristics that correlate with the presence of dementia worry. For the purpose of this review, "general population" will be

defined as any study which recruits a cross-section of the population who have not been pre-selected to target specific sample characteristics, with the exception of age.

Method

Search Strategy

Following basic scoping searches, seven databases (MEDLINE, CINAHL, PsychINFO, PsychArticles, Scopus, PubMed, Embase) were systematically searched for relevant literature. The search included literature dating from the databases inception until December 2018. Two strategies were used to identify eligible literature for the review. The first used a proximity search method to identify relevant terms within the abstract and title that were within four words of each other. Four words was found to be the optimum proximity for returning relevant studies. This search strategy was devised in collaboration with an information specialist and due to the subjective nature of the topic area, it was agreed that a proximity method would be more effective in extracting relevant literature compared to a standard diagnostic term search. The search terms were devised from reviewing key literature in the area to ensure all terminology used to investigate this topic were incorporated. Key search terms included (dementia OR cognitive impairment OR memory loss OR Alzheimer*) N4 (fear OR worry OR concern OR belief* OR attitude* OR perception* OR protective factors) and a separate search string of OR "Anticipatory dementia". Appropriate proximity searches were used depending on the platform of the database (e.g. ADJ4 for Embase). Secondly, reference lists of included studies were hand searched for additional relevant literature.

Inclusion and Exclusion Criteria

All literature returned using the search strategy was firstly screened via the title and abstract to assess its eligibility for inclusion in the review by the first author (DG). Articles were considered for inclusion if they were written in English, published in peer-reviewed journals and had quantitatively investigated 'dementia worry'. For this systematic review, the definition of 'dementia worry' was confined to exploring worry, fear or concerns about developing dementia, as used by Kessler et al. (2012).

Articles were excluded for the following reasons:

- Grey literature including dissertations, conference presentations, books, chapters and organisations/charity/government surveys were excluded due to the difficulty in ensuring a systematic and thorough search of this type of literature, and lower scientific validity of non-peer reviewed research.
- Papers that were systematic reviews or not original empirical research papers.
- Articles where investigation of dementia worry was not the primary aim or focus of the research. Articles where the focus of the study assessed dementia worry are likely to have been developed more rigorously and thoughtfully for examining this construct.
- Articles assessing perceived threat, subjective memory concerns and attitudes towards dementia were considered separate constructs. Therefore, articles where the definition of 'dementia worry' does not fit with the review's definition were excluded.
- Articles where the population examined focused on a specific cohort rather than a sample of the general population. Representative samples of a specific

age group (e.g. adults aged over 65 years), however, were included. This criterion was established to reduce the inclusion of articles which targeted populations where the level of dementia worry within the recruited sub-sample were predicted to be higher. These samples would therefore not be representative of the general population (e.g. geriatric and dementia healthcare workers).

- Articles included in the Kessler et al. (2012) paper were excluded as these have previously been summarised. However, due to this paper not being a systematic review, any relevant articles found in the current search which were not included in this paper were considered for inclusion.

Articles which were unclear regarding any of these issues during the initial screen were reviewed against these criteria using the full-text article. All articles identified were successfully collected. During the full-text screen, reasons for exclusion from the review were documented.

Data Extraction

All remaining papers that met the outlined criteria for inclusion in the review were collated into a database and relevant data extracted for analysis. Information extracted for each paper included study characteristics such as author, year of publication, study design, general focus of the study, and study location. Participant factors were extracted including type of participant recruited, number of participants, age, gender, and health status. Finally, relevant aspects of the study results were extracted which consisted of: how dementia worry was assessed, analysis method, level of dementia worry, and if the articles allowed any other relevant additional

outcomes such as data related to the correlates or demographic differences in dementia worry.

Quality Assessment

All articles included in the review were quality assessed using a tool developed by the authors based on pre-existing measures. The newly developed tool was based upon The Newcastle-Ottawa Quality Assessment Scale (NOS) for cohort studies (Wells et al., 2019) and the National Institute for Health (2014) Quality Assessment Tool for Observational Cohort and Cross-sectional Studies. The quality assessment tool evaluated: clarity of the research question, selection and representation of study populations, sample size, participation rate, measurement tool, comparability of groups, and analysis (see appendix B). The tool comprised of 10 items, with a possible total score of 12. Higher scores indicated a higher level of study quality with threshold scores for the measure adapted from those calculated by McPheeters et al. (2012). A total score on the adapted measure of ten or above was considered "good quality", between seven and nine equated to a "fair quality" study, between four and six points indicated "poor-fair quality" and a score of three of below was considered "poor quality". Quality assessment on all papers were undertaken by the first author (DG), with a subset of randomly selected articles (27%) assessed by the second author (AL) to ensure inter-rater reliability. Any disagreements in ratings were discussed and resolved collectively. No studies were excluded on their quality rating, but this was taken into consideration during interpretation of results.

Data Synthesis

Due to the nature of the papers included in the current review, the lack of homogeneity amongst research participants and assessment methods, it was deemed not appropriate for meta-analysis. Thus, a narrative synthesis approach was utilised. Guided by published frameworks for analysis (Centre for Reviews and Dissemination, 2009), the narrative synthesis process used in the current study involved constructing a clear summary of included studies and key characteristics, followed by detailed synthesis of study findings (grouped by population or key areas of investigation) to provide analysis of findings and assess relationships between and within groups. As described above the quality of studies and therefore the strength of the evidence was considered throughout. The protocol for this review was pre-registered on PROSPERO (CRD42019125631).

Results

Database and hand searches identified 9989 citations. Once duplicates were removed, 5865 citations were then screened for inclusion. The titles and abstracts were assessed for their eligibility for inclusion in the review, resulting in 135 remaining full-text papers to be assessed. See the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow chart below for the selection and screening process (Figure 1).

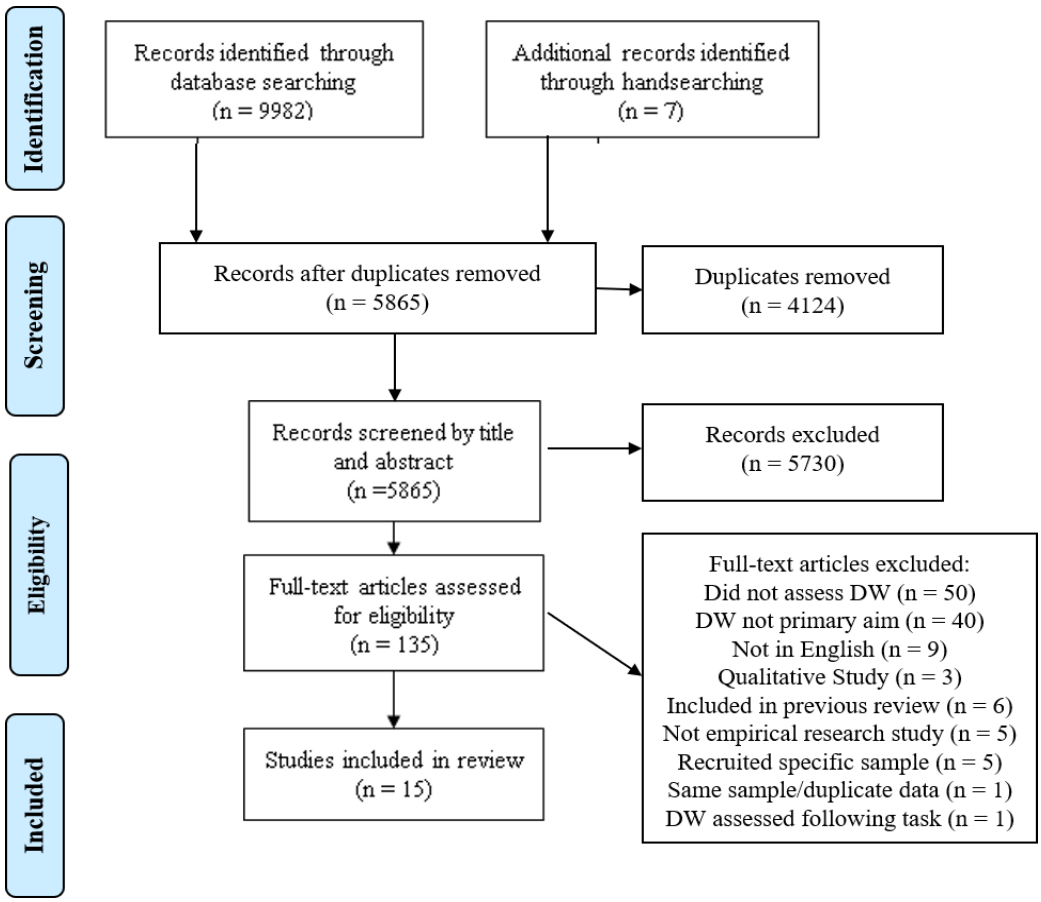

Figure 1. PRISMA flow chart for selection process of included studies.

After applying inclusion and exclusion criteria against the full-text articles, 120 were excluded; 50 citations were found not to assess dementia worry as defined in this review, 40 did assess dementia worry but this was deemed not to be the primary aim of the study, nine of the full-text articles were not written in English, five were not original empirical research studies and three were qualitative studies. In addition to this, six citations were included in the previous Kessler et al. (2012) review, five were found to recruit specific sample subsets, and one only assessed dementia worry following a priming task and therefore this was not deemed a true assessment of natural dementia worry in the population. Finally, one article was removed as two separate citations by the same authors were found to use the same

sample population. The article which reported a study aim more relevant to the review was kept for inclusion. Four related studies were found in the current search that were not included in the Kessler et al. (2012) paper, however, only one met criteria for inclusion in this review. This resulted in 15 papers that met eligibility criteria, totalling 17,438 participants. Information on the characteristics and results of included papers are detailed in Table 1.

Study Quality

The majority of studies within the review were deemed to be of 'fair' quality (n = 11), with one study deemed to be 'poor to fair', scoring six points. Three studies were categorised as 'good' quality, all scoring ten on the assessment tool. These studies were clear about those who participated in the study and their methodology. The details of the quality assessment and rating of each study can be seen in Table 2. Inter-rater reliability of the quality scores for a randomised subset of four studies (27%) was calculated as excellent (Cohen's Kappa (*k*) = 0.83) with 90% agreement on all items.

Table 1. Study Characteristics of included studies within the Systematic Review.

Study	*Location*	*Target Population*	*Type of Study*	*Sample size*	*Age*	*Gender*	*Definition of Dementia Worry*	*Measure of Dementia Worry*	*Level of Dementia Worry*
Ayalon. (2013)	USA	Middle-age to older adults (50+)	Cross-sectional survey	2130	>75 years: n = 377 (31%)	Female: n = 709 (58%)	Worry about developing dementia	Single question (rated on five-point Likert Scale).	Strongly/Somewhat agree: n = 347 (28%)
Bowen, Kessler, & Segler. (2019)	Germany	Middle-age to older adults (40+)	Cross-sectional Questionnaire	219	M = 65.50 (11.34)	Female: 55.3%	Worry about developing dementia	Ten-item Scale assessing intensity, frequency, emotional tone, relevance of DW.	Not at all worried: 17.8% Hardly worried: 41.1% Somewhat worried: 37.9% Very worried: 3.2%
Cutler. (2015)	USA	Middle-age to older adults (50+)	Cross-sectional survey	1819	50-59: 34.4%, 60-69: 26.6%, 70-79: 25.5%, 80+: 13.5%.	Males: 43.8%. Females: 56.2%.	Worry about getting Alzheimer's.	Single question (rated on a five-point Likert Scale)	Strongly agree: 9.7% Somewhat agree: 20.5% Somewhat disagree: 21.6% Strongly disagree: 36.2%
Fresson, Dardenne, Geurten, & Meulemans. (2017)	Belgium	Older adults (59–70)	Questionnaire, Interventional study	72	M = 64.04 (2.87)	Female: n = 37 (51%)	Fear of Dementia	FADS	Pre-task: Group 1: M = 1.98 (.63) Group 2: M = 2.03 (.52)
Kinzer & Suhr. (2016)	USA	Older Adults (NS)	Cross-sectional questionnaire	100	(n = 89) M = 9.22 (8.50)	(n = 89) Female: n = 57 (64%)	Worry about developing dementia	Dementia Worry Scale	Men: M = 17.03 (6.55). Women: M =18.92 (7.61).

Laforce & McLean. (2005)	Canada	Two groups: 18-30, 55-90	Questionnaire Study	Younger: n = 127 Older: n = 118	Younger group: M = 19.6 (3.1). Older Group: M = 67.9 (7.9).	Younger group: Females n = 80 (63%) Males n = 47 (37%) Older group: Females n = 53 (44.9%) Males n = 65 (55.1%).	Fear of developing Alzheimer's disease.	Single question (rated on a five-point Likert Scale)	Younger group: M = 2.8 (1.3) Older group: M = 2.5 (1.4)
Norman et al. (2018)	USA	Older adults (NS)	Cross-sectional survey	202	M = 76.6 (6.8)	Female: (76%)	Concern about developing dementia	Single question (rated on a four-point Likert Scale)	Very concerned: n = 33 (16.2%) Somewhat: n = 66 (32.4%) Not very: n = 76 (37.3%) Not at all: n = 26 (12.8%) Not rated: n = 3 (1.5%)
Roberts & Maxfield. (2018)	USA	Older adults (60+)	Cross-sectional Questionnaire	83	M = 69.48 (6.45)	Females: n = 52 Males: n = 31	Fear of Dementia	FADS	M = 28.18 (14.73)
Scerri & Scerri. (2017)	Malta	Older adults (NS)	Questionnaire, Interventional study.	66 (pre-intervention)	M = 69.6 (6.33)	Females: n = 30 Males: n = 24	Fear of Dementia	FADS	M = 40.71 (14.75)
Arai, Kumamoto, Mizuno, & Arai. (2012)	Japan	General Population (20+)	Cross-sectional Survey	2115	20-39: n = 755, 40–64: n = 806, 65+: n = 600.	Female: n = 1149 Male: n = 1101	Concern about developing Dementia	Single Question (rated Yes or No)	Yes: n = 1335 (62.1%)

Cantegreil-Kallen & Pin. (2012)	France	General Population (18+)	Cross-sectional Survey	2013	18-34: NS 35-65: n = 1058 (50.09%), 65+: n = 424 (21.25%).	Female: n = 1045 (52.2%)	Fear of developing dementia	Single question (rating on a four-point Likert Scale)	Fear developing dementia: n = 1200 (59.97%)
Jang, Yoon, Park, Rhee, & Chiriboga. (2018)	USA	General Population (18+)	Cross-sectional Survey	2609	M = 42.8 (17.1)	Female: 55.2%	Concern about developing dementia	Single Question (rated on a four-point Likert Scale)	Somewhat/very much concerned: 17.7%
Tang et al. (2017)	USA	General Population (18+)	Cross-sectional Survey	4033	M = 46.5 (17.2)	Female: 51.8%	Worry about developing dementia	Single Question (rated on a five-point Likert Scale)	Very worried/worried: 12.8% Somewhat worried: 41.9% Not at all worried: 35.4%
Werner, Goldberg, Mandel, & Korczyn. (2013)	Israel	General Population (18+)	Cross-sectional Survey	632	M = 45	Female: 52.5%	Worry and Fear about developing Dementia	Two Question (rated on a five-point Likert Scale)	Worry: Female -53.2% Male - 33.3% Fear: Female – 56.1% Male – 46.6%
Zeng et al. (2015)	China	General Population (18+)	Cross-sectional Interview	2000	18-34: n = 699 (35%), 35-65: n = 1076 (53.8%), 65+: n = 225 (11.2%).	Female: n = 990 (49.5%)	Fear developing Dementia	Single question (rated on a five-point Likert Scale)	Fear of developing Dementia: n = 1531 (76.6%) Not at all concerned: n = 427 (21.4%)

Note: () = Standard Deviation or %, FADS = Fear of Alzheimer's Disease Scale, NS = Not specified, M = Mean score, n = Number of participants.

Table 2: Quality Assessment Ratings of Included Articles.

	Research Question (/1)	***Selection (/8)***							***Comparability (/2)***	***Outcome (/1)***		
Article	Research objective clearly stated	Was the study population clearly specified	Recruited from similar population or time-period	Representative of target population	Sample size	Participation rate >50%	Non-respondents compared	Measurement tool (**)	Study compares groups on main and additional factors (**)	Statistical test presented fully	**Total Score (/12)**	**Quality Category**
Ayalon. (2013)	-	*	*	*	*	*	-	*	**	*	9	Fair
Bowen et al. (2019)	*	*	-	*	*	*	-	*	**	*	9	Fair
Cutler. (2015)	*	*	*	*	*	-	-	*	**	*	9	Fair
Fresson, et al. (2017)	*	*	-	*	*	-	-	**	**	*	9	Fair
Kinzer & Suhr. (2016)	*	*	*	-	-	*	-	**	**	*	9	Fair
Laforce & McLean. (2005)	*	*	-	-	*	-	-	*	**	*	7	Fair
Norman et al. (2018)	*	*	-	-	-	-	-	*	**	*	6	Poor-Fair
Roberts & Maxfield. (2018)	*	*	*	*	-	-	-	**	**	*	9	Fair
Scerri & Scerri. (2017)	*	*	-	-	-	-	-	**	**	*	7	Fair
Arai et al. (2012)	*	*	*	*	*	*	-	*	**	*	10	Good

Cantegreil-Kallen & Pin. (2012)	*	*	*	*	*	-	-	*	**	*	9	Fair
Jang et al. (2018)	*	*	*	*	*	-	-	*	**	*	9	Fair
Tang et al. (2017)	*	*	*	*	*	*	-	*	**	*	10	Good
Werner et al. (2013)	*	*	*	*	*	*	-	*	**	*	10	Good
Zeng et al. (2015)	*	*	*	*	*	-	-	*	**	*	9	Fair

Note: (**) = Two stars available for this item, * = Item addressed, ** = Item fully addressed, - = Item unable to be established or not reported.

Study Characteristics

The studies included in the review represent a diverse range of countries. Although most studies were conducted in the United States of America (n = 7), the remaining studies were conducted in Europe (n = 4), Japan (n = 1), China (n = 1), Israel (n = 1) and Canada (n = 1) (see Table 1). Six studies recruited samples across the general population, whereas, eight studies focused their recruitment on older populations. One paper recruited two groups of participants to span both younger and older age ranges (Laforce & McLean, 2005). However, the age used as a cut-off for "older" participants varied between studies, ranging from 40 years and older (Bowen, Kessler & Segler, 2019), to those over 60 years of age (Roberts & Maxfield, 2018). Most of the studies utilised a cross-sectional questionnaire or survey design, however, two papers utilised an interventional study design (Fresson et al., 2017, Scerri & Scerri, 2017).

Measure of Dementia Worry

Several variations in the method of measuring dementia worry were found across studies. Four studies assessed the presence of worry towards the umbrella term of 'dementia' (Arai, et al., 2012; Zeng et al., 2015; Kinzer & Suhr, 2016; Bowen, Kessler & Segler, 2019), whereas, all other studies focused on measuring worry towards a single subtype of dementia, in this case Alzheimer's Disease. Two thirds (n = 10, 67%) of the studies utilised a single question approach in assessing dementia worry. One of these studies separated out worry and fear of developing dementia into two separate question items (Werner et al., 2013). Many of the studies, however, varied in the wording of the single item question and how it was measured. For example, Cutler (2015) asked to what degree participants agreed with

the statement "You worry about getting Alzheimer's someday" on a five-point Likert Scale (1 being strongly disagree, 5 being strongly agree), whereas, Norman et al. (2018) asked participants "How concerned are you about personally developing Alzheimer's disease?" using a four-point Likert Scale (1 being very concerned, 4 being not at all concerned). Arai, Kumamoto, Mizuno and Arai (2012) used a dichotomous single question approach where participants answered yes or no to the question "Are you concerned about developing dementia in the future?"

Five studies (33%) used validated measures, with three (Fresson et al., 2017; Scerri & Scerri, 2017; Roberts & Maxfield, 2018) using the Fear of Alzheimer's Disease Scale (FADS; French, Floyd, Wilkins, & Osato, 2012), a 30-item self-report measure which covers three domains: general fear of dementia, physiological symptoms, and attitudes; and one (Kinzer & Suhr, 2016) using the Dementia Worry Scale (DWS; Suhr & Isgrigg, 2011) a 15-item self-report measure which assesses cognitive factors including the presence and controllability of dementia worries. Finally, one of the studies (Bowen et al., 2019) used their own ten-item questionnaire to measure dementia worry, which had been developed in a previous study (Kessler, Südhof & Frölich, 2014). The measure was based on items from existing measures of dementia worry and other health questionnaires, and although was reported to have high internal consistency (Cronbach's $\alpha = 0.92$), the authors also stated that the validity of the measure required further evaluation (Kessler et al., 2014). The psychometric properties of the measure were not revisited in the Bowen et al. (2019) study.

Prevalence of Dementia Worry

All studies evidenced the presence of dementia worry; however, the proportion of participants reporting dementia worry differed. Across the studies, five papers allowed for the data to be combined to ascertain an estimate of the prevalence of dementia worry (Cantegreil-Kallen & Pin, 2012; Arai et al., 2012; Ayalon, 2013; Zeng et al., 2015; Norman et al., 2018). Total numbers of participants who indicated that they were "strongly" or "somewhat" worried, feared, or concerned about developing dementia were calculated. These were deemed to indicate dementia worry, whereas, those who rated "not very" or "not at all" worried, fearful, or concerned were classed as not reporting dementia worry. This grouping has been used for analysis previously within the literature (Jang et al., 2018). These five studies provided a combined total sample of 8460 participants, aged 18 and over, of which 4512 reported dementia worry. This equates to 53.33% of the participants, 95% CI [52.3%, 54.3%]. However, the variation in measurement scales used within these studies (e.g. yes/no, four or five-point scales) should be taken into consideration during interpretation.

General population studies.

Out of the six studies which investigated dementia worry within the general population, three studies showed a high percentage of their participants reporting worry about developing dementia (Arai et al., 2012; Cantegreil-Kallen & Pin, 2012; Zeng et al., 2015). For example, in a large cross-sectional survey of the general population in China (n = 2000), it was found that 76.6% were concerned about developing dementia (Zeng et al., 2015). Around 60% of participants reported dementia worry in the other two studies. In contrast, one study which recruited an

Asian American population (n = 2609), reported the opposite result, with only 17.7% indicating that they were concerned about developing the disease (Jang et al., 2018). However, this study sample contained more younger participants (18-39 years = 48.3%) compared to the Chinese study (18-35 = 35%), and both varied in their assessment of dementia worry, which may contribute to these differences. The final two studies within this category, showed similar results to the estimated prevalence calculated above, with similar levels of participants reporting dementia worry to those who did not (Werner et al., 2013; Tang et al., 2017). For example, a cross-sectional survey which used random sampling to assess the general population in Israel (n = 632) found just over half of their female participants reporting to be worried (53.2%) or fearful of (56.1%) developing dementia (Werner et al., 2013). Although, within this study just under half of the males reported a fear of developing dementia (46.6%), but a significantly smaller proportion (33.3%) reported worry (Werner et al., 2013).

Older population studies.

It is harder to determine the extent of dementia worry from the nine studies which recruited middle-age to older adult participants due to the variation in report methods. Of the four studies that reported percentages for the degree of worry amongst their sample, three showed a higher proportion of participants were not concerned or worried about developing dementia (Ayalon, 2013; Cutler 2015; Bowen et al., 2019). For example, in Cutler's (2015) cross-sectional survey (n = 1819), 57.8% of participants indicated that they strongly or somewhat disagreed with the statement "You worry about getting Alzheimer's someday". Similarly, only 28% indicated worrying about developing dementia in Ayalon's (2013) study (n = 2130). Conversely, Norman et al. (2018), showed more even levels of reported dementia

worry within their cross-sectional survey, with 48.6% reporting dementia worry, in comparison to 50.1% who reported no concerns.

Four studies investigating older adults used validated measures of the DWS and the FADS (Kinzer & Suhr, 2016; Fresson et al., 2017; Scerri & Scerri, 2017; Roberts & Maxfield, 2018). The FADS items are rated on a five-point Likert scale (0 = never to 4 = always), resulting in a total score ranging between 0 and 120 (French et al., 2012). Kinzer and Suhr (2016) only used 12 items from the DWS with statements rated on a five-point Likert Scale (1 = not at all typical of me 5 = very typical), resulting in a total score ranging between 12 and 60. Higher scores indicated more worry. Scerri and Scerri (2017) reported a mean score of 40.71 (SD 14.75) on the FADS, which the authors state indicate that participants were concerned about developing dementia. Kinzer and Suhr (2016) found a mean score on the DWS across participants of 17.03 (SD 6.55) for males and 18.92 (SD 7.61) for females, which would suggest participants scored more than one on some items. However, to the current author's knowledge there are no defined cut-off scores for either measure.

Fresson et al. (2017) also used the FADS measure, reporting mean scores as 1.98 (SD 0.63) and 2.03 (SD 0.52) for each sample group. However, the paper does not state how these figures were calculated, as it is unlikely to represent a mean total score, and therefore reliable information on the degree of dementia worry cannot be derived. Furthermore, one study (Laforce & McLean, 2005) presented mean response scores from the five-point Likert scale of the single item question posed to participants (scoring 2.8 (SD 1.3) and 2.5 (SD 1.4). The authors report that higher scores indicate more fear but do not establish the responses along the scale, and thus it is again difficult to derive a meaningful conclusion from these results.

Correlates of Dementia Worry

Further to assessing the prevalence of dementia worry amongst the general population, several of these studies also explored the sociodemographic characteristics which may correlate with the presence of dementia worry. The most common factors investigated in the included studies were age (n = 11) gender (n =11), proximity to dementia (n = 9) and ethnicity (n = 3).

Age.

Across the included studies dementia worry was reported to be present in all age groups, indicating that dementia worry is experienced across the lifespan. However, ten studies explored further whether there was an association between age and level of dementia worry, with varying results.

Five of these studies showed that within older age groups there was increased concerns of developing dementia compared to younger participants (Cantegreil-Kallen & Pin, 2012; Arai et al., 2012; Tang et al., 2017; Jang et al., 2018; Bowen et al., 2019). Furthermore, some found significantly greater dementia worry was reported in the middle age groups (40 – 59 years) or older groups (60+) when compared to those aged between 18 and 39 (Jang et al., 2018; Tang et al., 2017, Cantegreil-Kallen & Pin, 2012). However, although similarly finding higher rates of dementia worry reported in participants aged 50-59 years, Cutler (2015) found that dementia worry significantly decreased with increasing age. Laforce & McLean (2005) however, found younger participants rated higher levels of fear in comparison to older participants. Furthermore, several studies (n = 3) reported to find no relationship between age and level of dementia worry (Zeng et al., 2015; Scerri & Scerri, 2017; Norman et al., 2018).

Using regression analyses to investigate which factors were most predictive of dementia worry, Werner et al. (2013) found that age was the only predictor of worry in females, but this factor did not reach significance in the male participants. In addition, one study assessed whether the same variables were predictive of dementia worry across different age groups (Cantegreil-Kallen & Pin, 2012). The authors reported that within the 18-35 age group, higher levels of dementia worry were found in those with higher incomes and in dementia caregivers. Within the 35-65 age group, higher dementia worry was associated with being female, lower education, higher income, poor self-perceived health and again dementia caregivers. No significant predictor variables were found within those aged 65 and over within the multivariate analysis (Cantegreil-Kallen & Pin, 2012).

Gender.

Eleven of the included studies assessed the association between dementia worry and gender, with nine (81%) finding significantly higher levels of dementia worry or concern reported by female participants in comparison to males (Arai et al., 2012; Cantegreil-Kallen & Pin, 2012; Werner et al., 2013; Zeng et al., 2015; Cutler, 2015; Fresson et al., 2017; Tang et al., 2017; Jang et al., 2018; Bowen et al., 2019). However, Cutler (2015) found this effect became non-significant when other variables were controlled within bivariate analysis but was significant with multivariate analysis. The final two studies (Kinzer & Suhr, 2016; Norman et al., 2018) did not find a significant difference in reported fear of dementia between males and females.

Proximity to dementia.

Several studies assessed whether proximity to dementia (caregiver, relative or knowing someone with a dementia) was related to level of dementia worry. Eight (72%) out of the eleven studies that explored this factor found that those who were related, closer to, or knew someone with dementia were more likely to fear developing dementia and score higher on this measure than those who have no prior experience of dementia (Arai et al., 2012; Cantegreil-Kallen & Pin, 2012; Zeng et al., 2015; Cutler, 2015; Kinzer & Suhr, 2016; Tang et al., 2017; Norman et al., 2018; Jang et al., 2018). The remaining three studies found no correlation between fear of developing dementia and those in closer proximity to dementia (Bowen et al., 2019; Scerri & Scerri, 2017; Laforce & McLean, 2005). However, two of these studies were within the lower scoring quality studies included in the review.

Tang et al. (2017) investigated this more specifically looking at the difference between caregivers of any condition and non-caregivers. They found more dementia worry overall in caregivers of any condition compared to non-caregivers. Although, as would be expected, the level of dementia worry was significantly higher in caregivers of people with a diagnosis of dementia compared to caregivers of other conditions (Tang et al., 2017). Further to this, Cutler (2015) also found that those who were aware that having a relative with Alzheimer's disease increases the chance of personally developing dementia also reported significant increases in dementia worry.

Ethnicity.

As previously mentioned, the studies included in this review span a wide range of countries, although most would be considered as "developed" economic

countries (United Nations, 2019). The largest amount of dementia worry documented from the general population surveys with around 2000 respondents was reported in the study based in China. Zeng et al. (2015) found 76.6% of the population studied reported concern about developing dementia, compared to the other cross-sectional surveys conducted in Japan and France where 62.1% and 59.97% of dementia worry was reported respectively. In contrast, Jang et al. (2018) who recruited 2609 Asian American participants in the U.S.A found the lowest level of dementia worry across the included studies, with only 17.7% reported to be concerned about developing dementia. It is difficult, however, to distinguish from these studies whether this is an indication of a relationship between dementia worry and ageing populations; China's population of adults aged over 60 is predicted to rise to 35.1% in 2050 compared to 27.8% in the U.S.A (United Nations, 2017). Conversely, these differences could be due to differing cultural beliefs about dementia or methodological design.

Two studies compared the level of dementia worry across different ethnicities within their recruited participants. Ayalon (2013) recruited three different ethnic groups including White, Latino, and Black participants. They found no significant differences in the number of participants who worried about developing dementia, with approximately one-quarter to one third of participants in each ethnic group reporting either "strong" or "some" degree of dementia worry (27.1%, 36.5%, 24.2% respectively). Jang et al. (2018) tried to ensure their sample resembled the ethnic composition of the area by recruiting Asian Indian, Chinese, Vietnamese, Korean and Filipino participants. In this study variations in dementia worry were found, with significantly higher levels reported by Koreans (29%), followed by Filipinos (24.6%), those who stated their ethnicity as 'Other Asian' (23.6%), Vietnamese

(19.6%), Chinese (11.5%), and Asian Indians (8.7%). Norman et al. (2018) was the only other study that mentioned ethnicity in its analysis and found fear of developing dementia was not associated with ethnicity. However, this sample was predominantly Caucasian (93%) and therefore may not have been able to reliably assess whether there were any differences between ethnic groups.

Other Factors.

A few of the other commonly explored factors that were described in less detail within the included studies were level of education, subjective memory concern and knowledge of dementia.

Education.

Three studies found no significant association between level of dementia worry and education (Zeng et al., 2015; Cutler, 2015; Norman et al., 2018). However, two studies did find a link between these two factors, both of which concluded that lower levels of education were related to higher levels of dementia worry (Fresson et al., 2017; Bowen et al., 2019). However, it should also be taken into consideration that the method of recording education level varied between studies (e.g. number of years in school, highest completed education level), as well as being conducted across a range of different countries (e.g. China, Germany, U.S.A) and therefore differing educational systems.

Dementia knowledge.

Mixed results were found in the relationship between knowledge of dementia and level of dementia worry. Two of the 'fair' quality large sample cross-sectional studies found no difference in the level of knowledge about dementia between those who did or did not fear developing dementia (Cantegreil-Kallen & Pin; 2012; Zeng

et al., 2015). Conversely, another 'fair' quality large cross-sectional study, in addition to an older adult study, both reported a significant association, finding those with greater dementia knowledge indicated higher fear of developing dementia (Scerri & Scerri, 2017; Jang et al., 2018). Scerri and Scerri (2017) investigated the effect of knowledge on dementia worry. Although finding the above association pre-training, they also found that fear of developing dementia did not change post training when an increase in dementia knowledge was reported (Scerri & Scerri, 2005). However, this finding may be due to participants already scoring quite highly on the FADS at pre-training.

Memory concern.

All four studies that explored the association between participants' self-perceived memory concerns and dementia worry, found a significant effect, with higher dementia worry being related to more memory concern (Cutler, 2015; Kinzer & Suhr, 2016; Norman et al., 2018; Bowen et al., 2019). More specifically, Cutler (2015) reported that memory concern (belief that their memory had deteriorated over the previous two years or self-reported poor memory) was the second strongest correlate with dementia worry. Bowen et al. (2019) established this further reporting that it is an individual's perception of memory change over time that they found is associated with dementia worry, rather than perceiving memory capacity to be poor.

Numerous other variables have been investigated in their association with fear of developing dementia, for example: religious beliefs, mental health, physical health, beliefs about dementia, objective memory performance, and income. However, as only a minority of studies have addressed any of these factors in detail these will not be discussed in the current review.

Discussion

The aim of this systematic review was to undertake a comprehensive search of the literature to assess the level of 'dementia worry' or fear of developing dementia in the general population. Identifying and reducing the literature to relevant studies was challenging for several reasons. Firstly, the vast amount of literature researching dementia. With the increase in dementia prevalence and becoming a health priority, dementia research has been highlighted as a necessity (WHO, 2012). A 63% increase in publications worldwide on dementia has been reported between 2008/9 and 2014/15, with a total of 29,074 publications recorded in 2014/15 alone (Alzheimer's Research UK, 2017). Dementia worry, therefore, has also become a large area of research. However, many of these studies appear to add an additional question about dementia worry rather than investigating this as a primary aim. Secondly, as previously discussed, there are several ways of conceptualising 'dementia worry' within the literature. This means that many of the studies vary in which aspects of dementia worry they assess (e.g. perceived threat, severity of dementia, frequency of worries) and thus, the research design. Finally, due to this variation in conceptualisation, the methods used to assess or measure the concept are also highly diverse.

Despite these factors, the current review employed a comprehensive search strategy with clear and pre-defined inclusion and exclusion criteria to enable a robust but focused review. Additionally, a clear definition of 'dementia worry' was adopted as provided in a previous conceptual review (Kessler et al., 2012) to help ascertain eligible studies. This resulted in fifteen studies included in the review, of which eleven were deemed to be of fair quality. All studies clearly stated the research aims, population recruited and method of measurement, however, many

studies failed to state the participation rate, and none compared those that took part in the study to non-respondents. Analysis of this would have made more transparent whether there was any bias amongst recruited participants and thus improved the quality of the study.

Prevalence of Dementia Worry

Across all 15 studies included in the review, a proportion of participants reported to worry or fear personally developing dementia. This figure varied across studies, however, ranging from 17.7% to 76.6% of the population sampled. Furthermore, studies that used validated measures, found participants were on average scoring on a quarter to a third of items, indicating the presence of dementia worry. Where the results allowed, the number of participants across studies reporting dementia worry in relation to the total sample recruited were collated, which resulted in a prevalence of 53.3% reporting 'dementia worry' from a combined sample of 8460 participants. Thus, showing that there is a high prevalence of fear of developing dementia in the general population.

Most studies within the review found a similar level of dementia worry amongst the populations examined, except three studies who found lower rates between approximately 20%-30% (Ayalon, 2013; Cutler, 2015; Jang et al., 2018). The varied range found within the included papers is similar to that reported in Kessler et al. (2012). Within their paper, the results of two voluntary organisation surveys and one empirical paper, found dementia worry was reported in 26%-49% of the U.S population, with other studies across countries reporting similar proportions (Kessler et al., 2012).

Although the Kessler et al. (2012) paper is extremely useful in providing a theoretical understanding and overview of 'dementia worry', there were several studies that were found within the current review that were not included in their paper. Therefore, indicating the benefits of a systematic search strategy as used within this review. As the results included in the current study represent a diverse range of study location and participants in terms of age, gender, ethnicity, health and education, these results may be generalisable to the general population of developed countries. As there was a lack of studies conducted in developing countries within this review these results may not be representative for the composition of the general population in these areas.

Correlates of Dementia Worry

Further to assessing the presence of dementia worry in the general population, several articles also explored potential factors which may correlate with this concern. The factors that achieved most consensus across the included studies were gender, proximity to dementia and memory concern.

Most studies within the review found that female participants reported higher levels of dementia worry in comparison to the male participants. This finding was more pronounced than previous studies (Kessler et al., 2012). It has been hypothesised that this finding could be due to women being at higher risk of developing dementia or tending to have a caregiver role in society and thus, may be more aware of the consequences to this role should they become unwell (Werner et al., 2013). However, a further hypothesis for this difference may be due to gender differences seen in general levels of worry. Women are shown to have higher prevalence of anxiety disorders compared to men (McLean, Asnaani, Litz, &

Hofmann, 2011). Additionally, women have been found to report higher levels of non-clinical worry (e.g. finances, work) and attend more to negative thoughts in comparison to men (Robichaud, Dugas, & Conway, 2003). Conversely, the results may not be a true reflection of the amount of worry experienced within the male population, as described later, the wording of the question may be particularly relevant in identifying 'dementia worry' in this group.

The review also found several studies reported that the more experience an individual has with dementia (e.g. caregiver, relative), and those with concerns regarding their memory performance over time, report significantly higher dementia worry. Those who are more focused on their own memory performance and those who have experience of dementia, may therefore be more conscious of the condition and its implications. It has been highlighted, however, that although this may be expected, those with concerns seeking help from clinicians should be investigated as due to their insight or prior experience, they may have identified objective memory difficulties (Iliffe & Pealing, 2010).

There were conflicting results amongst the studies on several correlating factors including age, education, knowledge of dementia and ethnicity.

'Dementia worry' was seen to be present across the age span, although several studies found no significant association between age and dementia worry. A similar amount of studies did find age to correlate, with older age linked to higher rates of dementia worry. This could be understood with those in older age groups being more aware of dementia due to it being a condition often developed in later life, as well as the natural increase of memory lapses with age. Thus, older adults may report more pressing concerns about personally developing the disease.

However, one study found the opposite finding with younger participants rating higher dementia worry. Therefore, at present a consensus cannot be ascertained on the link between age and dementia worry.

Variations in the level of dementia worry were also shown across study locations which could indicate culture and ethnicity as possible factors influencing the degree of dementia worry. Previous studies have found differing cultural beliefs and understanding about dementia (Cipriani & Borin, 2015), which may contribute to the disparities in the degree of dementia worry reported across locations. Knowledge of dementia and level of education produced mixed results, and so the impact of these factors on dementia worry is unable to be determined, with further research needed to provide more clarity.

Measures

Several different methods of assessing 'dementia worry' were used in the included papers including the FADS, DWS, ten-item and single question approaches. Each method encompassing different advantages and disadvantages.

The FADS is reported to have good overall internal consistency (Cronbach's $\alpha = 0.94$) and across the three domains (Cronbach's α of 0.94, 0.85 and 0.80 respectively) (French et al., 2012). However, it only explores fear of developing Alzheimer's disease rather than fear of all types of dementia, which may be a limitation. The original 15-item DWS has been reported to have a good internal consistency (Cronbach's $\alpha = 0.93$; Molden, Maxfield, & Gavett, 2015), with the 12-item version used within this review reporting similar outcomes (Cronbach's $\alpha = 0.91$; Kinzer & Suhr, 2016). Although this measure does assess worry about developing all types of dementia, it is mainly focused on the cognitive aspects of

dementia worry. Both the FADS and DWS assess additional aspects of dementia worry that would not be ascertained with a single question approach.

To the authors knowledge there are no defined cut-off scores for either of these measures to differentiate between different levels of 'dementia worry'. Therefore, the outcome of these could be interpreted differently by different researchers or clinicians. Mean total scores on these measures were primarily reported, however, breaking down responses to each of the individual items or domains may be more helpful in identifying the more common features (e.g. cognitive or physiological) experienced when someone fears developing dementia. With this in mind, these tools may be useful in guiding clinicians to identify the types of worries or symptoms their patients are experiencing (e.g. When I can't remember something, I find myself wondering whether I have dementia; Once I start worrying about dementia, I just cannot stop) and therefore, highlight intervention needs.

Most of the studies within this review used a single question, which provides a clearer assessment of the amount of the population who worry or fear developing dementia. However, there was again high variation in how this question was worded and answered. The different subtleties used within each question variation may lead to differences in the amount of people who relate to that statement, and thus impact how many people report to have 'dementia worry'. For example, asking whether you worry about developing dementia in contrast to fear, or concern. Although these are theoretically considered conceptually similar for our understanding and classification of 'dementia worry', as well as overlap between these terms, to the individual completing the study these may feel like three very different statements. Thus, someone may respond positively to the statement do you worry about

developing dementia but may answer negatively if asked if they fear developing the condition. This can be seen to some extent in the male participants in Werner et al. (2013). When males were asked how much they worried about developing dementia, 33.3% responded that they "very" or "somewhat worried"; whereas 46.6% reported to be "somewhat" or "very fearful" of developing dementia (Werner et al., 2013). This indicates that studies should consider the focus of their investigation closely with the method of assessment, particularly if this is a one question approach.

Furthermore, each of these methods of assessment varied in whether they assessed worry towards dementia as an umbrella term or towards a single subtype of dementia. There are numerous types of dementia and the domains of functioning which are impacted differ within each subtype (WHO, 1992). However, research has shown that the lay populations knowledge of dementia is poor (Cahill et al., 2015) and they may therefore not hold a clear understanding of these variations. Thus, although 'dementia worry' and 'worry about Alzheimer's Disease' may reflect distinct concerns for health professionals these may not be considered differently amongst the lay population. However, further research may be beneficial to explore this further to extract which aspect of "dementia" may be associated with the general populations concerns or fears and whether when asked about 'dementia' this is recognised as incorporating all subtypes in the lay population.

Limitations

The exclusion criteria ensured a robust review of peer-reviewed papers, aimed at assessing dementia worry, to increase scientific validity. However, the removal of 'grey literature' and articles written in other languages may have meant some relevant papers were not included in the current review. The inclusion of 'grey

literature' could also have reduced possible publication bias also known as the 'file drawer phenomenon' (Paez, 2017). Inclusion of this literature could have provided further evidence and strengthened any conclusions that could have been drawn. Furthermore, as this review was the first systematic review assessing prevalence of dementia worry, it was agreed that the focus would be on quantitative research in the first instance. However, a number of qualitative studies have been conducted within this area which may have provided a further insight into those with dementia worry.

A specific definition of 'dementia worry' was used to ascertain relevant articles that identified a unified understanding of the concept. Operationalising the concept in this way was helpful in providing a more structured method to identify studies which met exclusion criteria, reduced the heterogeneity of included articles and enabled conclusions to be drawn from a vast area of literature which were aligned with this definition. However, as discussed previously this conceptualisation may still be considered quite broad and therefore there remains some subjectivity in assessing which articles meet inclusion criteria. Furthermore, the conclusions drawn within this review may not correspond with research that has used other models to understand this concept, such as the health belief model.

The literature search, data extraction and synthesis were conducted by one author and, therefore, could be subject to a risk of bias or for potential eligible articles to have been missed. However, thorough inclusion and exclusion criteria were set to enable identification of eligible studies, which was evidenced by papers identified in the current search that were not included in previous papers (Kessler et al., 2012). In addition to this, the high inter-rater reliability indicates consistency amongst researchers in their critique of included studies.

Finally, within this review changes in the prevalence of dementia worry across time was not explored. This may have provided insights into whether any fluctuations in dementia worry have been observed, as well as whether any possible relationships exist between factors such as the increase in diagnosis rates or dementia campaigns to improve dementia awareness, and the prevalence of dementia worry across time.

Implications and Future Research

This review has highlighted even further the variation in the literature when assessing dementia worry, even in those articles where the conceptualisation of the notion is similar. The concept of 'dementia worry' incorporating emotional and cognitive aspects of worry, fear or concern about personally developing the disease makes theoretical sense as a conceptualisation. However, it may be that this definition still remains too broad, and these three factors are considered distinct amongst respondents. Furthermore, the variation in other concepts of dementia worry (e.g. perceived threat of dementia), and whether worry is assessed towards a single subtype of dementia or an overall umbrella term, means that it is difficult to unify the research to provide a full understanding of the correlates and prevalence of dementia worry. Thus, this review highlights how methods of assessing and understanding dementia worry requires further refinement. Future research should investigate the effects of measuring dementia worry using different terms amongst the same population. This could inform a more cohesive method of evaluating and understanding how the general population perceive dementia worry. This may also expand theoretical understandings of whether there is a relationship between the concept of dementia worry and other mental health disorders, such as health anxiety.

This review has shown a high prevalence of dementia worry across age groups and countries, as well as these concerns being higher in certain sociodemographic characteristics. The clinical implications of these results may support clinicians, particularly GP's or memory assessment teams, identify the key demographics where dementia worry may be greatest. With this knowledge, they may be able to provide clear psychoeducation around dementia symptoms and normal ageing or provide strategies to manage high levels of worry. These interventions may therefore help to reduce 'dementia worry'. Furthermore, although those expressing memory concerns should be taken seriously and assessed, if no objective deficits are found it may be beneficial to explore their degree of fear around developing dementia to see if this is contributing to their memory concerns. Additionally, as results showed no conclusive evidence that increased knowledge causes increased fear, awareness campaigns should aim to reach all ages and cultures, although these results may again highlight key target demographics.

A systematic review of the qualitative research would be helpful to consider along with the current review. A synthesis of qualitative findings would help ascertain whether the prevalence of dementia worry in the general population within this study were corroborated. These findings may also provide us with greater insight into dementia worry. A qualitative understanding may identify whether there is an agreed consensus of what individuals believe 'dementia worry' is and what it is not, why dementia worry is higher in certain demographics, as well the potential to identify the factors that may exacerbate or initiate dementia worry. Finally, these qualitative insights may help clinicians to provide more valid assessment of dementia worry symptoms or concerns.

Conclusion

Dementia worry is a frequent and relevant research topic within the current literature. This review evidenced the high prevalence of dementia worry amongst the general population, and the characteristics that are more likely to be associated with these concerns. This can help support clinicians and campaigns target appropriate populations to address these concerns and provide education with an aim to reduce stigma and fear. However, more research is needed, in addition to synthesising qualitative research findings, to gain further understanding into the reasons underpinning and contributing to dementia worry. Furthermore, exploration of the implications of assessment method and a consistent methodological approach will be essential to aid the conclusions that can be drawn from this area of research.

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Extended Methodology for Systematic Review

Quality Assessment

Due to there being no current consensus on the best quality assessment tool to use within cross-sectional studies (Zeng et al., 2015), as well as a lack of tools for studies with an observational study design, the Newcastle-Ottawa Quality Assessment Scale (NOS; Wells et al., 2019) has been found to be more commonly used and adapted for these types of studies (Luchini, Stubbs, Solmi & Veronese, 2017). However, due to the NOS being developed with cohort or case-control study designs, the National Institute for Health Quality Assessment Tool (2014) was also explored as a potential measure as this had been developed to review the methodological quality of observational and cross-sectional studies.

The NOS for cohort studies (Wells et al., 2019) and National Institute for Health (2014) Quality Assessment Tool for Observational Cohort and Cross-sectional Studies were both piloted as quality measurement tools on similar articles in terms of study design to those that were predicted to be included in the current review. The purpose of the pilot was to test their clinical utility. However, during piloting of these measures, it became apparent that some of the questions were unable to be answered or were irrelevant in relation to study design. For example, exposure time and follow-up periods would hold no relevance to the type of studies included in the systematic review. To address this shortcoming, only the questions which were applicable were included, and additional questions were added to make the measure fit for purpose. Additional questions were selected through assessing other aspects relevant to cross-sectional studies, for example, participation rate. Some additional questions were based on a previously used adaptation of the NOS

tool, as used by Modesti et al. (2016). The new adapted measure was piloted and considered to be more applicable to a cross-sectional study design. The quality assessment tool assessed areas including: clarity of the research question, selection and representation of study populations, sample size, participation rate, measurement tool, comparability of groups, and analysis (see appendix B). For each item, higher quality responses were attributed one or two stars. Items were attributed zero stars if the item was not suitably addressed or not reported. The tool comprised of 10 items, with a possible total score of 12 points. Higher scores indicated a higher level of study quality. Threshold scores for the original NOS (scored out of nine points) were published by McPheeters et al. (2012). They determined that a total score of seven points was deemed to be a "good quality" study, five points for "fair" and two or below for "poor quality" (McPheeters et al., 2012). These score points equate to approximately 75%, 50% and 20% respectively. As the newly developed measure had a higher total score, this was segregated into four quality levels, however, similar cut-off points were used based on those reported in McPheeters et al. (2012). Thus, using the new adapted measure, a total score of ten or above was considered "good quality" (80%), between nine and seven points equated to a "fair quality" study (75%), between four and six points was deemed "poor-fair" quality (50%) and a score of three of below was considered "poor quality" (25%).

Quality assessment on all studies were undertaken by the first author, with a subset of articles (27%) randomly selected and assessed by the second author to ensure inter-rater reliability. After the second author had rated the subset of articles, the results of both authors quality assessment were discussed. Both authors were in exact agreement on all items on two of the studies. The final two articles showed only one-point difference in total quality score. However, during this process it

became clear that each author was interpreting one item on the quality assessment tool differently (item 4: Sample Size) which was causing differing responses. This item was discussed, and it was agreed that an additional response option to this item was needed. In the original format, sample size was only awarded a star for being "justified and satisfactory", however, it was deemed appropriate for the study design to be awarded a star if the sample size was "satisfactory" even if they had not explicitly provided a justification. Therefore, this was addressed, and the quality assessment tool updated. A Cohen's Kappa score was calculated (Cohen's Kappa (k) = 0.83), indicating strong inter-rater reliability as per the interpretation guides reported by McHugh (2012). There were no major disagreements in ratings between authors and therefore, further rating by the second author was not deemed necessary.

Bridging Chapter

A high prevalence of fear or worry about developing dementia, also known as 'dementia worry', is reported amongst the general population, as demonstrated in the previous systematic review. This degree of 'dementia worry' varies between studies, however a combined estimate from several large sample papers included in the previous review equated to approximately 53.3% of the population reporting to experience these concerns. Dementia worry was found to be experienced across the lifespan in the previous review, but mixed results were found in whether age was a predictor of dementia worry, and therefore a consensus could not be drawn. However, several studies reported to find dementia worry was higher amongst middle-age to older participants (Cantegreil-Kallen & Pin, 2012). Furthermore, it has been found that dementia worry is more likely to be reported in those who are closer in proximity to someone with a diagnosis of dementia (Cutler, 2015), or have concerns about deterioration in their own personal memory performance (Bowen et al., 2019).

A recent large sample study exploring prevalence of concerns about memory performance in middle to old age participants found that 53% reported having subjective memory-related problems (Luck et al., 2018). A decline in cognitive skills in adults aged 60 years and over are shown to occur as a normal part of ageing, particularly within memory and executive functions (Fjell, McEvoy, Holland, Dale & Walhovd, 2014). Although the majority of older adults do not develop dementia, age has been reported as the biggest risk factor for the development of the disease (World Health Organisation, 2019). With more campaigns aimed at raising awareness of dementia symptoms, risk factors, and promoting earlier diagnosis (Department of Health, 2009), it is theorised that older adults may become more

vigilant to everyday memory lapses, and therefore, may be more likely to link these with their concerns about developing dementia (Kinzer & Suhr, 2016). Conversely, a qualitative study found that although some older adults reported concerns regarding their subjective memory problems, others associated memory deficits with ageing (Begum et al., 2013). Nevertheless, all the participants within this study reported to either seek formal help or engage in self-help for their perceived memory difficulties, such as talking to friends, keeping active and engaging in memory training activities (Begum et al., 2013). Other studies have also reported an increase in memory strategies and aids to compensate for perceived memory changes in older adults (Parikh, Troyer, Maione, & Murphy, 2016; Frankenmolen et al., 2017). Further to this, a fifth of the participants with subjective memory performance concerns recruited into a large sample study (n = 4678) wanted to, or had, sought help from clinicians for their perceived memory difficulties (Luck et al., 2018). This research therefore demonstrates that an increase in awareness of memory changes, with or without associated concerns, may initiate help-seeking from clinicians and increased use of memory aids or strategies.

Healthy older adults are reported to more frequently utilise external strategies (e.g. using a calendar, making lists) compared to internal strategies (e.g. visual imagery) to compensate for memory difficulties (Bouazzaoui et al., 2010). A similar uptake of external and environmental strategies, including repeated checking, routines and writing notes, were reported to be used by individuals with a diagnosis of dementia (Nygård & Öhman, 2002). Furthermore, various memory strategies are commonly recommended by support organisations to those with a diagnosis of dementia to manage memory impairments (Alzheimer's Society, 2017).

Many studies have assessed the efficacy of formal memory training groups on objective memory. A meta-analysis of these interventions provides some evidence to support the efficacy of these groups, although no single strategy has been found to be more effective in providing improvements (Gross et al., 2012). However, these memory training studies have been questioned on their generalisability to support everyday functioning (Gross et al., 2012). Further to this, when investigated in more detail, some strategies have shown mixed results in their ability to support memory deficits. For example, using a self-referencing strategy has been shown to improve memory accuracy amongst younger and older adults (Rosa & Gutchess, 2013). However, it has also been shown to increase memory errors, particularly within older groups, which may counteract the improvements (Rosa & Gutchess, 2013). Thus, showing that some memory strategies may actually hinder memory performance within some populations, and that the relationship between memory strategies and age might be more complicated than first thought.

Due to older adults utilising more memory strategies when they perceive declines in their memory, in addition to clinicians recommending strategies to older populations both with and without objective memory difficulties, a greater understanding of individual strategies is needed. Further investigation should evaluate the impact of these strategies, to ensure the most beneficial techniques are being recommended and that strategies employed by these populations are not exacerbating memory difficulties. Therefore, the empirical paper aims to assess the implications of one of these strategies within older adults and those with a diagnosis of dementia.

The Effects of Repeated Checking on Memory in Older Adults and Dementia.

Miss Deborah A. E. Green[1]*

Dr Adrian Leddy[1]

Dr Fergus Gracey[1]

Professor Ken Laidlaw[2]

[1] Department of Clinical Psychology, Norwich Medical School, University of East Anglia,

Norwich, NR4 7TJ, UK.

[2] Psychology Department, University of Exeter, Exeter, EX4 4QG, UK.

*Corresponding author e-mail: d.green2@uea.ac.uk

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(See Appendix A for Author Guidelines)

Abstract

Many older adults and those with a diagnosis of dementia report using strategies to support their memory, including repeated checking. However, most research into the effects of repeated checking has been undertaken with undergraduate samples and those with a diagnosis of Obsessive-Compulsive Disorder. These studies found that repeated checking paradoxically caused a deterioration in memory confidence, vividness and detail (meta-memory), although memory accuracy remained unaffected. The current study investigated whether a similar phenomenon is shown within older populations. Thirty healthy older adults and five older adults with a diagnosis of dementia were recruited. Participants were asked to either repeatedly turn on, off and check a replica stove top (relevant checking) or open, remove a tablet, close and check a compartment on a dosette box (irrelevant checking). Memory accuracy and meta-memory were assessed at pre-and-post checking trials. Following repeated 'relevant checking', older adults reported significantly reduced memory confidence and a deterioration in memory vividness and detail compared to the 'irrelevant checking' condition. A significant reduction in memory accuracy was also noted in the 'relevant checking' group. Although dementia participants showed lower initial memory confidence and accuracy scores, they also showed similar patterns of reduction in memory accuracy and meta-memory following repeated 'relevant checking'. Thus, repeated checking led to increased memory errors and memory doubt in older adults and those with a diagnosis of dementia, indicating that this strategy may exacerbate memory difficulties in these populations. Although further research is needed, recommendations of checking as a strategy need to be revisited.

Keywords: Memory, Dementia, Older Adults, Checking, Confidence.

Introduction

Dementia Prevalence

There are estimated to be 850,000 people currently living with dementia in the U.K. and this number is predicted to rise (Prince et al., 2014), due to medical developments and increased life expectancy, leading to an ageing population (National Institute on Aging, 2011). Dementia is defined as a chronic or progressive disease affecting the higher cognitive functions of the brain, including memory, attention, visuospatial, language, executive function, orientation and praxis, beyond that of normal ageing (World Health Organisation; WHO, 1992). It is also associated with changes in emotional control, social and daily functioning skills (WHO, 1992). Decline in these areas are shown over time, with the progression and presentation of the disease being influenced by the specific variant of dementia. In the U.K., the most common variants of dementia are Alzheimer's Disease and Vascular Dementia, affecting approximately 62% and 17% of the population respectively. However, many can have mixed Alzheimer's and Vascular subtypes (Public Health England, 2016), and there is some evidence from a recent systematic review that other subtypes such as Dementia with Lewy Bodies might be underdiagnosed (Vann Jones & O'Brien, 2014).

Memory Concerns

Due to the high prevalence of dementia worldwide, it has been made a global health priority to raise awareness of the condition (Wortmann, 2012) and promote cognitive health (Public Health England, 2018) in the general population. These campaigns aim to provide information on signs and symptoms of dementia to increase identification of illness and encourage earlier help-seeking behaviour.

However, they also have the potential to increase fear of the condition leading to over-recognition of symptoms (Devlin, MacAskill & Stead, 2007). Some research has shown that with increased knowledge of dementia comes increased concern regarding development of the condition (Cutler & Hodgson, 2001). Furthermore, older adults who perceive they have poorer memory and monitor their cognitive lapses have also been shown to have heightened concerns (Cutler, 2015).

Mild memory deterioration, although differentiated from conditions such as dementia, has been shown on neuropsychological testing as a part of normal healthy ageing (Salthouse, 2012). Although some aspects of memory tend to be somewhat preserved in older age, declines in working memory, episodic memory and prospective memory have often been shown to occur in normal ageing (Luo & Craik, 2008). But many older adults struggle to understand the difference between normal cognitive ageing and more substantial decline in the form of a dementia (Cahill, Pierce, Werner, Darley & Bobersky, 2015). Although there has been some accuracy shown between self-reported cognitive ability and actual cognitive performance in the community (Jonker, Geerlings & Schmand, 2000), many older adults who expressed subjective memory concerns did not show objective cognitive deficits (Mitchell, 2008; Mendonça, Alves & Bugalho, 2015). This indicates their subjective view of impairment was inconsistent with objective memory assessment outcomes. It has been hypothesised that due to the expectation that memory declines with age, older adults often associate memory lapses with evidence of cognitive functioning decline, whereas younger adults may associate the same memory lapse with alternative explanations (Zarit, Cole & Guider, 1981). Older adults often report lower confidence and trust in their memory (Wells & Esopenko, 2008) which may add to the growing concern about their cognitive performance and cognitive health.

Memory Strategies

As memory performance and memory confidence deteriorates, many older adults and those with dementia often use strategies to cope with their memory difficulties. In the early stages of dementia, where there is a greater awareness of cognitive decline, compensation strategies are more commonly used to support memory and promote independence (Unkenstein, 2017). Memory aids, tools and strategies are also frequently recommended by support agencies such as the Alzheimers Society to support those with dementia (Alzheimer's Society, 2017). Memory strategies used by those with dementia are reported to include environmental or visual reminders, routine, repetition and checking (Nygård & Borell, 1995; Clare, 2002). For example, using strategic locations for objects or repeatedly checking that the door is locked (Nygård & Öhman, 2002). Older adults also reported to engage in a similar variety of memory strategies, including repetition and external memory aids, to compensate for perceived memory difficulties (Dixon, Hopp, Cohen, de Frias & Bäckman, 2003). Further to this, supports to help manage and remember multiple medications such as multi-compartment compliance aids, or dosette boxes, are frequently reported to be used by older populations and individuals with cognitive impairments (Furmedge, Stevenson, Schiff, & Davies, 2018).

Prospective and retrospective memory errors have been reported in both older adults and those with Alzheimer's disease, with more prospective errors reported in both groups (Smith, Del Sala, Logie & Maylor, 2000). Furthermore, a study testing younger and middle-aged participants, showed those with negative beliefs and lower confidence in prospective memory report higher levels of memory doubt and an increased urge to check (Cuttler, Sirois-Delisle, Alcolado, Radomsky, & Taylor,

2013). When interviewed, 80% of older adults reported that they were often unsure that they had completed a task, with 15% reporting this occurring weekly, and that this specific uncertainty in their memory had increased with age (Lovelace & Twohig, 1990). Self-reported problems with prospective memory in everyday life has been shown to be linked to intrusive memory doubts and an increased use of checking as a memory strategy (Cuttler & Taylor, 2012).

Previous Checking Research

Research into repeated checking has mostly been conducted within obsessive-compulsive disorder (OCD) populations, as checking is a common behavioural feature of this disorder. Due to OCD sufferers reporting high levels of doubt in their memory accuracy, it was initially hypothesised that repeated checking was caused by having objective memory impairments (Tallis, Pratt, & Jamani, 1999). However, this theory was unsubstantiated as subsequent research found no evidence of memory impairment on neuropsychological testing for those with OCD (Tolin et al., 2001). It was found that following repeated exposure of a stimulus, OCD sufferers showed progressive decline in memory confidence whilst their memory accuracy remained unaffected (Tolin et al., 2001). It was therefore proposed that it was a meta-memory deficit, rather than a memory impairment leading to the use of repeated checking (van den Hout & Kindt, 2003a). 'Meta-memory' has been defined as the components that describe one's knowledge of a memory, including its nature, quality, vividness and detail (Radomsky & Alcolado, 2011). Thus, the more a person checks, the more familiar each checking event becomes due to a reduction in the processing of specific perceptual details (e.g. colours, shapes) for each similar event (van den Hout & Kindt, 2003a). Therefore, each event has a lower level of memory vividness and detail leading to a reduced

level of confidence when trying to recall a specific event episode (van den Hout & Kindt, 2003a).

Van den Hout and Kindt (2003a) investigated whether repeated checking effects meta-memory using a sample of undergraduate students. Following turning on, off and checking a series of three hobs on a virtual gas stove, participants were asked regarding their memory accuracy, vividness, detail, and confidence for the checking event. Participants were then split into two conditions; 'irrelevant checking', where 20 checking trials on a set of virtual light bulbs was completed, and 'relevant checking', where 20 checking trials on the virtual stove top were completed. Subsequently, all participants completed a final checking trial on the stove and were given the same memory measures. Results showed that participants within the 'relevant checking' condition reported a reduction in memory vividness, detail and confidence compared to the 'irrelevant checking' condition, although memory accuracy was unaffected (van den Hout & Kindt, 2003a). However, a limitation of this study was the lack of ecological validity due to using a computerised task, and therefore the absence of threat or responsibility for participants, which is often thought to be relevant in compulsive checking (Radomsky, Gilchrist, & Dussault, 2006).

This study was adapted by Radomsky et al. (2006) who used a real-life stove and kitchen taps ('irrelevant' condition) to increase ecological validity and participant responsibility. Again, following repeated 'relevant checking', memory confidence, vividness, and detail had decreased compared to those within the 'irrelevant checking' condition. Furthermore, following repeated 'relevant checking', participants reported the quality of memory had shifted from 'remembering' to 'knowing', supporting earlier theories that due to repeated

exposure each checking event had increased in familiarity. This phenomenon has subsequently been tested and corroborated in multiple experiments with both clinical OCD and non-clinical undergraduate samples (for example: van den Hout & Kindt, 2003b; Boschen & Vuksanovic, 2007; Dek, van den Hout, Giele, & Engelhard, 2010; Radomsky, Dugas, Alcolado, & Lavoie 2014).

In summary, these studies have shown the impact of repeated checking on meta-memory and provide support to the self-perpetuating mechanism theory that repeated checking may be a consequence of and lead to further memory distrust (Rachman, 2002).

Checking in Older Populations

As previously discussed, those with a diagnosis of dementia and older adults have both been shown to use checking as a strategy to support their memory difficulties. Research has indicated that older adults may have lower confidence in their memory (Wells & Esopenko, 2008), and increased doubts as to whether they have completed tasks (Lovelace & Twohig, 1990). Therefore, as proposed within OCD populations, checking may similarly be used as a strategy within older adult populations to regain confidence in their memory and provide confirmation that they have completed the task. This strategy may be beneficial if used infrequently or with minimal repetitions, however, if the same repeated checking paradigm effect on meta-memory also occurs within older populations this may be having a paradoxical effect, contributing to further memory distrust, exasperating their memory difficulties and could lead to excessive disability within these populations.

To date, only one study has adopted the Radomsky et al. (2006) paradigm and investigated the effects of this with older adults and those with a diagnosis of

mild cognitive impairment (MCI; Lattimer, 2016). Although this study indicated that both older adults and those with a diagnosis of MCI showed lower levels of memory confidence, vividness and detail following repeated checking, along with higher levels of familiarity, this study was under-powered (Lattimer, 2016). Furthermore, no studies have currently investigated this paradigm in those with a diagnosis of dementia.

Considering the level of engagement in memory strategies in older populations, such as checking, it is important to investigate whether this strategy is a helpful memory support or is actually leading to more memory distrust. To our knowledge this has only ever been investigated in a currently unpublished study (Lattimer, 2016). Therefore, this study aims to investigate the effects of repeated checking on memory accuracy and meta-memory (confidence, vividness and detail) in both older adults and those with a diagnosis of dementia using an adapted version of the Radomsky et al. (2006) paradigm.

Research Questions and Hypotheses

The primary research question which the current study aimed to address was whether repeated relevant checking impacts on ratings of meta-memory (confidence, vividness and detail) in older adults and those with a diagnosis of dementia? Considering prior research with non-clinical populations it was hypothesised that repeated relevant checking would cause a deterioration in meta-memory in healthy older adults. However, due to the lack of research conducted on this phenomenon within dementia populations a directional hypothesis was not made.

Secondary research questions for the study were as follows:

- Does repeated checking affect memory accuracy in older adults and those with a diagnosis of dementia?
- Does repeated checking affect the quality of recollection in older adults and those with diagnosis of dementia?
- Is there a relationship between reported memory errors and meta-memory within the checking task?
- Is there a relationship between attitudes to ageing and meta-memory within the checking task?

Due to minimal research conducted within the target populations within these secondary research areas, no directional hypotheses were made.

Method

Design

The study utilised a 2 x 2 mixed experimental design to address the research hypotheses outlined. Participants were randomly allocated into two conditions; repeated 'relevant checking' or repeated 'irrelevant checking' (between-groups factors), and completed memory measures at two time points, pre-and-post a repeated checking phase (within-group factor). The dependent variables were measures of meta-memory including memory confidence, vividness, detail, familiarity and accuracy.

Participants

Participants were 30 healthy older adult controls (19 Females; $\bar{X}$ age 72 years) and five older adults with a diagnosis of dementia (4 Females; $\bar{X}$ age 78 years). Only those diagnosed with Alzheimer's Disease, Vascular Dementia or

Mixed Dementia, within the mild to moderate stages as defined by the screening measure, were included in the study. Rarer types of dementia such as Frontotemporal dementia, Progressive supranuclear palsy or Corticobasal degeneration were excluded. Although Dementia with Lewy Bodies is the third most prevalent dementia diagnosis (NICE, 2009), those diagnosed with this subtype were also excluded due to the significant impairments often found within visuospatial functioning which may have impacted ability to manipulate the apparatus during the checking task. All participants were aged 60 years and over, fluent in English, with no reported learning or developmental difficulties or further neurological disorders. Healthy older adult controls were recruited via local community groups and those with dementia were recruited via NHS Older People's Mental Health and Memory Assessment services within East Anglia referred by clinicians within the service.

Measures

A demographic questionnaire (see Appendix C) gathered information on age, gender and education. Data regarding housing, health and quality of life were also gathered. Further to this, diagnosis type, date of diagnosis, medication and service input were collated for the dementia group.

Montreal cognitive assessment.

The Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005) was used to screen participants. The MoCA (see Appendix D) is a 30-point clinician administered test developed to screen for Mild Cognitive Impairment (MCI) and Alzheimers Disease (AD). The test assesses cognitive functions including attention, visuospatial, executive function, language, orientation and memory. A score of 25 or below is indicative of an impairment, with average scores between 19 and 25 shown

by those with MCI and between 11 and 21 shown by those with AD (Nasreddine et al., 2005). The MoCA has good internal consistency (Cronbach α = 0.83), a sensitivity score to MCI of 90%, 100% to AD, and a specificity to both groups of 87% (Nasreddine et al., 2005). All those included within the control group scored ≥26 points on the MoCA, in line with the cut-off score. Four participants within the control group scored below this and were therefore excluded from the study. Within the Dementia group, those scoring ≤10 points on the MoCA were deemed as having 'severe' dementia and were excluded from the study. It was felt the task may be too distressing or difficult to follow for those with more significant impairment. No participants that were referred into the study, however, scored below the ≤10 points cut-off score.

Mood and anxiety measures.

The five-item Geriatric Depression Scale (5-item GDS; Hoyl et al., 1999) and Geriatric Anxiety Inventory-Short Form (GAI-SF; Byrne & Pachana, 2011) were used to assess anxiety and depression symptoms in the study sample. The 5-item GDS (see Appendix E) is a shortened self-report questionnaire developed from the 15-item version (Sheikh & Yesavage, 1986) used to screen for the presence of depression in older adults. A score of two or more is indicative of depression. The five-item GDS is reported to be as effective as the 15-item version with an alpha coefficient of 0.80, sensitivity of 0.94, specificity of 0.82, positive predictive value of 0.82 and negative predictive value of 0.94 (Hoyl et al, 1999).

The Geriatric Anxiety Inventory-Short Form (GAI-SF; Byrne & Pachana, 2011) is a 5-item self-report questionnaire used to screen for the presence of anxiety symptoms within an older adult population, developed from the 20-item GAI

(Pachana et al., 2007). A score of three or more is indicative of an anxiety disorder. The GAI-SF has been shown to be psychometrically sound with a sensitivity of 75%, specificity of 87%, and good internal consistency (Cronbach's $\alpha = 0.81$) (Byrne & Pachana, 2011). A licence to use this measure was acquired.

Attitude to ageing questionnaire.

The short form attitudes to ageing questionnaire (AAQ-SF; Laidlaw, Kishita, Shenkins, & Power, 2017) is a 12-item self-report measure (see Appendix F), which was used to explore personal experience and attitudes towards ageing and whether this influenced memory confidence and meta-memory ratings within the checking task. It was developed from the 24-item AAQ (Laidlaw, Power, & Schmidt, 2007) and covers domains of psychosocial loss (PL), physical change (PC) and psychological growth (PG). Each domain includes four items and is scored on a Likert scale of 1 – 5 (1 being strongly disagree, 5 being strongly agree). Each domain produces a minimum score of 4 and maximum of 20. The 12-item AAQ-SF demonstrates good internal consistency with Cronbach's alpha of 0.72 (PL), 0.72 (PC) and 0.62 (PG) and is reported to be as consistent as the 24-item AAQ (Laidlaw et al., 2017).

Prospective and retrospective memory questionnaire.

The prospective and retrospective memory questionnaire (PRMQ) is a self-report measure used to assess the frequency of memory errors in everyday life (Smith et al., 2000). The measure includes 16 items (8 prospective, 8 retrospective) rated on a five-point Likert scale (see Appendix G). The PRMQ demonstrates good internal consistency with Cronbach's alpha scores as follows: Total scale (0.89),

Prospective Memory Scale (0.84) and Retrospective Memory Scale (0.80) (Crawford, Smith, Maylor, Della Sala, & Logie, 2003).

Checking task measures.

To gather data on any changes in meta-memory within the experimental task three questions were asked following pre and post checking trials. Participants rated their level of memory confidence, vividness and detail on a visual scale of 0-100 (with 0 being 'not at all' and 100 being 'extremely') as in previous studies using this paradigm (Radomsky et al., 2006; Lattimer, 2016).

Furthermore, based on descriptions by Tulving (1985) participants were asked to indicate whether their recollection of these checking trials was based on direct recall or familiarity. They stated "remember" if they had a concrete memory and could recall specific details of the checking event or "know" if they had no definitive memory of the event but had a general sense of knowing it was completed.

To assess memory accuracy participants were asked to identify, in the correct order, the hobs that were manipulated using a pictorial representation of the stove. Scores range from zero to six, gaining a mark for each hob correctly identified and an additional mark for each hob identified in the correct order. See Appendix H for the checking task memory questionnaire.

Apparatus

A replica stove top, based on Radomsky et al. (2006), used by Lattimer (2016) was used in the current study. The replica stove top consisted of six hobs and six associated dials which could be turned from zero to five. Participants were provided with a pictorial representation to indicate which dial was linked to which

hob. One checking trial on the stove top comprised of turning on, off, and checking a series of three hobs.

A dosette box was used which consisted of 7 x 4 individual opaque compartments, split into days of the week and four periods of day (morning, noon, evening, and bed), with each compartment containing a gelatine capsule. One checking trial on the dosette box comprised of opening, removing the tablet, closing and checking a single compartment. Both pieces of apparatus were designed to be easily transportable, ecologically valid and have previously been shown to be comparable in difficulty by Lattimer (2016).

Procedure

All participants completed the experimental session either within their home or in a private clinic space, as preferred by the participant. The first participant from each sample was randomised into either 'relevant' or 'irrelevant' checking conditions prior to the experimental session by an external research member who was blind to conditions. All following participants were then counterbalanced across conditions prior to the experimental session.

During the experimental session, participants were again given study information (see appendix I and J) and provided with the opportunity to ask any questions. After indicating they were happy to continue, participants then completed the consent form (see appendix K and L), demographic questionnaire, and MoCA. If they scored within the screening parameters of the MoCA they were enrolled into the study.

All participants were trained on both the stove top and dosette box 'checking' procedures and given time to practice. Once participants were confident with both

apparatus they undertook the main checking task (see Figure 2) which was based upon the paradigm developed by Radomsky et al. (2006) and previously used by Lattimer (2016).

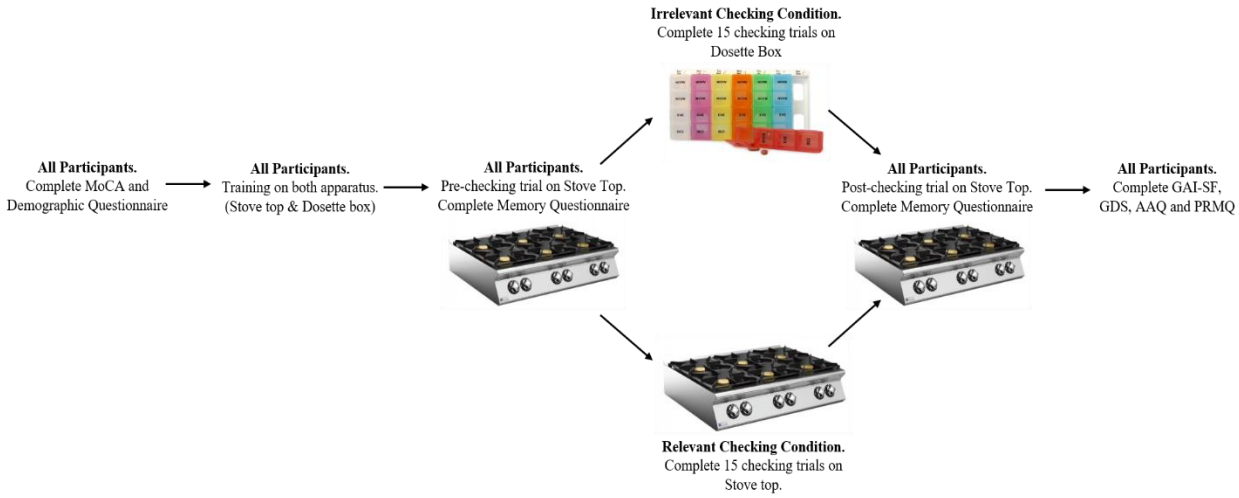

Figure 2. Experimental procedure.

All participants completed a pre-checking trial on the stove top which involved turning on, off and checking a set of three hobs. The stove top was then removed from participants' view and they were asked to complete the checking task measures assessing their memory (meta-memory, accuracy and familiarity) regarding this initial trial. Following this, participants within the 'relevant checking' condition completed 15 checking trials on the stove top. Participants within the 'irrelevant checking' condition completed 15 checking trials on the dosette box. Once all trials were complete, all participants completed a final post-checking trial on the stove top. Again, once the stove top was removed from view, participants completed the same checking task measures for their memory of this final trial The current study used 15 trials, rather than 19 as used by Radomsky et al. (2006), due to the sample being older and some having cognitive deficits, this was felt to be a more

manageable length of task and would be comparable to the amount of trials used by Lattimer (2016). Furthermore, previous experimental studies have shown significant reductions in meta-memory following ten and 15 checking trials (Coles, Radomsky, & Horng, 2006), and therefore, the validity of the checking task should be upheld in the current study.

Following the checking task, participants completed the five-item GDS, GAI-SF, AAQ and PRMQ measures. Whilst the entire experimental session lasted between 60 and 90 minutes, the checking task procedure took approximately 20-25 minutes to complete, irrespective of task condition. Participants were fully debriefed and given the opportunity to ask any questions. For those within the dementia group, a letter was sent to their General Practitioner (GP) to inform them of their participation. All participants were given the opportunity to receive a summary of research findings and enter a prize draw to win a shopping voucher.

Ethical Approval

Ethical approval for the study was granted by the West Midlands – Black Country Research Ethics Committee prior to the study commencing (see appendix M).

Results

Demographic Information

All data was entered into IBM SPSS Statistics (version 25; IBM Corp 2017) for analysis and checked for errors or missing data, of which there were none. Key demographic information is presented below (see Table 3).

Table 3

Demographic Information

Measure	***Healthy Older Adult Group (n = 30)***		***Dementia Group (n = 5)***		***Difference between groups***	
	$\overline{X}$	***SD***	$\overline{X}$	***SD***	**U**	***p***
Age	72.33	6.92	78.60	5.03	30.5	0.033
Years of Education	16.53	3.09	12.4	2.30	21	0.008*
Overall Health	8.40	1.10	8.80	1.09	63.5	0.598
Quality of Life	8.50	1.01	9.20	1.09	0.598	0.219
MoCA	28.00	1.46	17.6	3.05	0.00	0.001*

Note: n= number of participants, $\overline{X}$ = Mean, *SD* = Standard Deviation, U = Mann Whitney U score, *p* = significance value, * = significant finding.

Due to data failing parametric assumptions (not normally distributed and unequal sample sizes) Mann Whitney U tests were undertaken. To account for Type 1 error a Bonferroni correction was applied providing an adjusted significance level of 0.01, as recommended by Dancey and Reidy (2004). Tests showed no significant differences between the two groups on age, overall health and quality of life ratings. There was a significant difference in years of education with a small effect size (r^2 = 0.18). Furthermore, as expected there was a significant difference between MoCA score, showing the two groups were recruited to appropriately, with no cognitive impairment in the Healthy Older Adult Group and no severe levels of dementia recruited to the Dementia Group.

Further psychological measures were administered to gather information on psychiatric symptoms, perceptions of ageing and memory errors (see Table 4). With an adjusted significance level of 0.006 (Dancey & Reidy, 2004), Mann-Whitney U tests showed no significant difference between the two groups on the GAI or GDS, showing no confounding factors of depression or anxiety within the two groups.

Additionally, no significant differences were found between the two groups across AAQ domains or the PRMQ, despite the dementia group reporting slightly higher retrospective errors and overall total error score.

Table 4

Psychological Measures

Measure	***Healthy Older Adult Group (n = 30)***		***Dementia Group (n = 5)***		***Difference between groups***	
	$\overline{X}$	***SD***	$\overline{X}$	***SD***	**U**	***p***
GAI	1.37	1.52	1.20	1.30	73.5	0.945
GDS	0.63	0.76	0.20	0.45	52.5	0.299
AAQ Psychosocial Loss	8.66	2.72	6.40	3.29	36	0.069
AAQ Physical Change	12.93	2.83	14.20	3.42	65.5	0.664
AAQ Psychological Gain	13.40	2.89	16.00	2.34	41	0.732
PRMQ Total	37.40	5.99	39.60	11.28	67.5	0.732
PRMQ Prospective Errors	18.63	3.06	18.00	6.63	60	0.506
PRMQ Retrospective Errors	18.80	3.57	21.60	5.64	49	0.237

Note: n= number of participants, $\overline{X}$ = Mean, *SD* = Standard Deviation, U = Mann Whitney U Score, *p* = significance value.

Checking Task: Healthy Older Adult Group

Firstly, descriptive statistics and inferential comparisons were undertaken on the demographic characteristics between the two conditions; ‘relevant checking’ and ‘irrelevant checking’. Although there were more females in the ‘relevant checking’ group (73%) compared to the ‘irrelevant checking’ group (53%), the groups were similar in other characteristics of age, years of education and MoCA performance (see Table 5). Using Bonferroni adjustment to reduce Type 1 error (Dancey & Reidy, 2004), significance level was reduced to 0.016.

Table 5

Demographic Characteristics for the two Checking Conditions

Measure	***Relevant Checking (n = 15)***		***Irrelevant Checking (n = 15)***		***Difference between groups***	
	$\overline{X}$	***SD***	$\overline{X}$	***SD***	***t***	***p***
Age	71.00	5.28	73.67	8.22	-1.06	0.30
Years of Education	16.27	2.60	16.80	3.59	-0.47	0.64
MoCA	27.53	1.24	28.47	1.55	-1.82	0.08

Note: n= number of participants, $\overline{X}$ = Mean, *SD* = Standard Deviation, *t* = T value, *p* = significance level.

Data from the checking task memory questionnaire were assessed for outliers and parametric analysis assumptions. Using Clark-Carter's (2010) criteria which defines outliers as standardised scores above 3 or below -3, four outliers were found within the same 'irrelevant checking' condition participant. These scores were adjusted using the 'Winsorising' method of substituting significant outliers to the next lowest value minus one (Clark-Carter, 2010), whilst the pre-post score change direction was preserved. Descriptive statistics for the four memory checking variables were conducted and are presented in Table 6.

Table 6

Descriptive Statistics from the Checking Task Memory Questionnaire

Memory Checking Variable	***Relevant Checking (n = 15)***		***Irrelevant Checking (n = 15)***	
	Pre-checking $\overline{X}$ ***(SD)***	Post-checking $\overline{X}$ ***(SD)***	Pre-checking $\overline{X}$ ***(SD)***	Post-checking $\overline{X}$ ***(SD)***
Accuracy	5.87 (0.52)	4.60 (1.05)	5.73 (0.70)	5.93 (0.26)
Confidence	90.07 (15.82)	70.00 (25.14)	97.87 (4.50)	98.67 (5.16)
Vividness	89.53 (15.32)	69.20 (28.06)	98.2 (3.03)	97.33 (5.94)
Detail	88.00 (18.50)	68.00 (25.48)	90.87 (10.44)	96.67 (9.00)

Note: n= number of participants, $\overline{X}$ = Mean, *SD* = Standard Deviation.

All variables within the checking questionnaire were found to show high levels of negative skew and did not meet tests for homogeneity of variance,

therefore, conducting mixed ANOVA's was unsuitable. Following advice from statistical experts, individual Mann Whitney U and Wilcoxon signed-rank tests were deemed the most appropriate method to analyse these variables. As four comparisons were being made within each variable, the significance level was adjusted to 0.0125 using the Bonferroni method to reduce Type 1 error (Dancey & Reidy, 2004).

Memory accuracy.

Mann Whitney U tests showed no significant difference between 'relevant' and 'irrelevant' conditions in memory accuracy at the pre-checking trial (U = 105, z = -0.60, p = 0.78) but a significant difference was found between conditions at the post-checking trial (U = 40, z = -3.55, p = 0.002). Wilcoxon's test showed a significant difference in memory accuracy between pre-and-post checking trials for the 'relevant checking' condition (Z = -2.89, p = 0.004), producing a large effect size (d = 0.74), but no significant difference in the 'irrelevant checking' condition (Z = -1.09, p = 0.276). Thus, a reduction in memory accuracy was shown following repeated 'relevant' checking but not following repeated 'irrelevant' checking.

Memory confidence.

There was no significant difference found between 'relevant' and 'irrelevant' conditions in memory confidence at the pre-checking trial (U = 75, z = -1.69, p = 0.13), although, a significant difference was shown between conditions at the post-checking trial (U = 27, z = -3.92, p = <0.001). Wilcoxon's test showed a significant difference in memory confidence between pre-and-post checking trials following 'relevant checking' (Z = -2.59, p = 0.010), producing a medium effect size (d = 0.67), but no significant difference in the 'irrelevant checking' condition (Z = -0.948,

p = 0.343). Thus, again showing a reduction in memory confidence following repeated 'relevant' checking but not repeated 'irrelevant' checking.

Memory vividness.

Mann Whitney U tests found no significant difference between 'relevant' and 'irrelevant' conditions in memory vividness at the pre-checking trial (U = 71.5, z = -1.83, p = 0.089) but was found between conditions at the post-checking trial (U = 34.5, z = -3.46, p = 0.001). Wilcoxon's test was approaching significant difference in memory vividness between pre-and-post checking trials for the 'relevant checking' condition (Z = -2.404, p = 0.016), whereas no significant difference was found in the 'irrelevant checking' condition (Z = -0.282, p = 0.778). Therefore, although greater reduction in memory vividness was shown following repeated 'relevant' checking compared to 'irrelevant checking', this did not reach significance.

Memory detail.

No significant difference was found between 'relevant' and 'irrelevant' conditions in memory detail at the pre-checking trial (U = 101.5, z = -0.471, p = 0.653), but again was shown between conditions at the post-checking trial (U = 38, z = -3.421, p = 0.001). Wilcoxon's test showed a near significant difference in memory detail between pre-and-post checking trials for the 'relevant checking' condition (Z = -2.347, p = 0.019), and no significant difference in the 'irrelevant checking' condition (Z = -2.147, p = 0.032).

Checking Task: Dementia Group

The five participants recruited into the Dementia group, were again randomised into either 'relevant' or 'irrelevant' checking conditions. Descriptive

statistics were conducted, and no significant differences were found between groups (see Table 7). Significance level was reduced to 0.016 following Bonferroni adjustment (Dancey & Reidy, 2004).

Table 7

Demographic Characteristics for the two Checking Conditions

Measure	***Relevant Checking (n = 3)***		***Irrelevant Checking (n = 2)***		***Difference between groups***	
	$\overline{X}$	***SD***	$\overline{X}$	***SD***	**U**	***p***
Age	77.67	4.73	80.00	7.07	2.00	0.56
Years of Education	12.00	1.00	13.00	4.24	3.00	1.00
MoCA	19.33	2.52	15.00	1.41	0.00	0.08

Note: n= number of participants, $\overline{X}$ = Mean, *SD* = Standard Deviation, U = Mann Whitney U Score, *p* = significance value.

Variables from the checking task memory questionnaire were explored using descriptive statistics (see Table 8). Variability is extremely high and therefore caution needs to be taken when interpreting the statistical analysis results on this data. Descriptive data shows some decline in memory vividness and memory detail following repeated 'relevant checking' compared to the 'irrelevant checking' condition. Scores within memory accuracy and memory confidence did not appear to show much change following repeated 'relevant checking', and although highly variable, appeared to be scored lower initially in comparison to those within the 'irrelevant checking' condition.

Table 8

Descriptive Statistics from the Checking Task Memory Questionnaire

Memory Checking Variables	***Relevant Checking (n = 3)***		***Irrelevant Checking (n = 2)***	
	Pre-checking $\overline{X}$ ***(SD)***	Post-checking $\overline{X}$ ***(SD)***	Pre-checking $\overline{X}$ ***(SD)***	Post-checking $\overline{X}$ ***(SD)***
Accuracy	4.00 (2.00)	5.33 (1.15)	6.00 (0.0)	6.00 (0.0)
Confidence	31.67 (38.84)	33.33 (28.86)	80.00 (28.28)	100.00 (0.0)
Vividness	53.33 (20.20)	41.67 (38.18)	75.00 (35.36)	75.00 (35.36)
Detail	60.00 (10.00)	28.33 (40.72)	50.50 (70.00)	50.00 (70.71)

Note: n= number of participants, $\overline{X}$ = Mean, *SD* = Standard Deviation.

Due to the small sample size, comparisons between the two groups within the Dementia group were not deemed to be appropriate. However, case-control comparisons are frequently carried out in the field of neuropsychology and therefore this method was utilised in the current study. Crawford and Howell (1998) developed methodology which compares an individual participants' score with a control sample to evaluate whether their score shows a statistically significant difference to the control group. This method has been shown through Monte Carlo simulations to be robust against small control group sizes, severe skew and controls for Type 1 error (Crawford & Garthwaite, 2005). This method will be used to assess whether the pre-and-post checking scores from the Dementia group differ to those within the Healthy Older Adult Group within the same checking conditions. Furthermore, Crawford and Garthwaite (2005) devised a methodology to assess whether the difference between a participant's performance on two tasks is significantly different from the difference seen in a control group. Therefore, this method will be used to assess whether the pre-to-post change scores from the Dementia group differ from the Healthy Older Adult group. Due to multiple tests

being undertaken, significance level was adjusted to 0.006 for each variable (Dancey & Reidy, 2004).

Relevant checking condition.

Memory accuracy.

Two participants pre-checking memory accuracy scores were significantly lower (t = -3.482, p = 0.004; t = -7.206, p = <0.001) than the healthy older adult group, with the other participant showing no significant difference (t = 0.242, p = 0.81). Post-checking memory accuracy was not significantly different to the healthy older adult group for all participants (t = -0.55, p = 0.59; t = 1.29, p = 0.22). Finally, two participants showed no significant difference in the degree of change in memory accuracy following repeated 'relevant' checking, thus, showing a similar pattern to the healthy older adult group (t = 2.156, p = 0.049; t = 0.775, p = 0.45). However, the remaining participant did show a significant increase in memory accuracy (t = 6.101, p = <0.001).

Memory confidence.

Two participants showed significantly lower pre-checking trial scores for memory confidence to the older adult group (t = -5.51, p = <0.001; t = -4.29, p = <0.001). However, the final participants pre-checking confidence score was not significantly different (t = -0.92, p = 0.372). Memory confidence scores were not significantly different to the healthy older adult group for all participants at the post-checking trial. All three participants showed no significant difference in the degree of change in memory confidence following repeated checking, indicating a similar pattern to those within the healthy older adult group (t = 2.272, p = 0.039; t = 2.830, p = 0.013; t = 0.123, p = 0.903).

Memory vividness.

One participant showed significantly lower pre-checking trial scores for memory vividness (t = -3.446, p = 0.004), although two participants' scores were not significantly different (t = -2.50, p = 0.026; t = -0.918, p = 0.374). Within post-checking trials, memory vividness scores were not significantly different to the healthy older adult group for all participants. Again, all three participants showed no significant difference in the degree of change in memory vividness following repeated checking, indicating a similar pattern to the healthy older adults (t = 0.09, p = 0.93, t = 2.147, p = 0.049; t = 0.866, p = 0.401).

Memory detail.

All three participants pre-checking memory detail scores were not significantly different (t = -1.99, p = 0.067; t = -0.942, p = 0.36; t = -1.466, p = 0.17) to the healthy older adult group. Similarly, all three participants post-checking memory detail scores did not significantly differ (t = -2.584, p = 0.022; t = -2.204, p = 0.045; t = 0.266, p = 0.79). Finally, all three participants showed no significant difference in the degree of change in memory detail scores following repeated checking, again indicating a similar pattern to the healthy older adult group (t = 0.466, p = 0.65; t = 0.989, p = 0.34; t = 1.356, p = 0.20).

Irrelevant checking condition.

Due to only two participants being within the 'irrelevant checking' condition, mixed results were found across variables when compared to the healthy older adult group, and therefore it is difficult to derive conclusive findings.

Discussion

Demographic Characteristics

In terms of demographic characteristics among participants, these appeared to be well matched with minimal differences found between the two groups. There was a significant difference found between the healthy older adult group and dementia group on total years of education. This difference may be expected, however, as research investigating risk factors for dementia have shown years of formal education to be a protective factor (Baumgart et al., 2015). It has been found that those with more years of education reduce their risk of dementia by 7% per year of additional education (Xu et al., 2016). Interestingly, no difference was found between the two groups on any of the three domains of the Attitudes to Ageing questionnaire, quality of life or overall health ratings. Both groups reported a good level of overall health and quality of life in addition to a positive attitude towards ageing. Thus, although only based on a small sample of recently diagnosed dementia participants, those with a diagnosis of dementia continued to view their quality of life and experience of ageing positively. This reflects similar results found in a recent survey by the Alzheimers Society (2015) which found 68% of people believed they were living well with dementia. Finally, there was no difference found between each group on memory errors assessed by the PRMQ.

Checking Task Implications

The negative impact of repeated checking on meta-memory has been well reported within undergraduate samples and those with a diagnosis of OCD in a recent meta-analysis (van den Hout, van Dis, van Woudenberg, & van de Groep, 2019). As far as we are aware there is no published research investigating the checking paradigm within older populations and those with a diagnosis of dementia.

This is interesting, as this is a cohort that are reported to use checking as a memory strategy (Nygård & Öhman, 2002).

Consistent with the previous research in this area (Radomsky et al., 2006; van den Hout & Kindt, 2003; Lattimer, 2016), the results of the current study showed that following repeated 'relevant checking', healthy older adults showed a significant deterioration in their memory confidence compared to those within the 'irrelevant checking' condition. A near significant reduction in memory vividness and detail were also shown following repeated 'relevant checking'. This somewhat contrasts with results found in previous studies where a significant and large effect on vividness and detail have been reported (van den Hout et al., 2019). However, a near significant effect on these variables was found using this paradigm in those with mild cognitive impairment (Lattimer, 2016). Although there was a reduction reported in vividness and detail, these factors may have been less affected than memory accuracy and confidence for several reasons. During the study, several older adults had some difficulty in understanding the concepts of memory vividness and detail, despite these being explained on the memory questionnaire and reiterated in the same standardised manner. This may infer that older adults find these concepts more abstract than memory confidence, and therefore, found it more difficult to evaluate their own memory against these factors. Alternatively, during each trial of the task participants are viewing the same stove top 'scene' although the order of hobs to manipulate are changed. Consistent with competitive trace theory, during each checking trial the memory of the stove top is re-visited and although may weaken with repeated exposure as fewer details are consolidated, some common features may be reinforced (Yassa & Reagh, 2013). In addition, it is theorised that recontextualised or false details may be added to memories of events with repeated

exposure (Yassa & Reagh, 2013). This may give rise to a sense that although they are reduced, the vividness and detail of the checking event feels somewhat preserved. Of course, this is one study and most other studies using younger samples have found comparable reductions across all aspects of meta-memory. It may be that with another or larger sample size of healthy older adults, the difference in vividness and detail found between pre-and-post checking trials could reach significance. Conversely, it may indicate a differing impact of checking on these areas of meta-memory for older populations.

In contrast to most previous research, memory accuracy was found to be significantly reduced in healthy older adults with a large effect size, following repeated 'relevant' checking but not 'irrelevant' checking. A very small reduction in memory accuracy has been shown in some studies (van den Hout et al., 2019), particularly when tasks have used more ecologically valid apparatus (e.g. Radomsky et al., 2006). However, this was linked to the increase in perceived threat that their apparatus included, which would not be as relevant in the current study. The additional detrimental effect repeated checking appears to have on memory accuracy indicates a significant clinical implication of this research. This deficit could be reflective of the reported increase in uncertainty in memory with age, particularly with completing tasks (Lovelace & Twohig, 1990). Therefore, this increased uncertainty, in addition to hyper-vigilance around memory difficulties reported by older adults (Zarit, et al., 1981), could be exacerbated by repeated checking, which may not be seen with the younger participants recruited in previous studies.

Overall, these results indicate that the use of repeatedly checking as a strategy may paradoxically lead to increased memory errors and memory doubt, rather than supporting memory in older adults. The use of this strategy may

therefore be causing excessive disability, reinforcing a low level of confidence and trust in memory, as well as any perceived memory deficits older adults may hold. Therefore, recommendations for the use of this strategy by clinicians to older populations needs to be revisited.

Although it is a small sample and caution needs be taken in interpretation of the results, some participants within the Dementia group showed a similar pattern following repeated 'relevant checking' to those in the healthy older adult group. All three participants within the repeated 'relevant checking' group showed a similar pattern of difference in memory confidence, vividness and detail scores following multiple checking trials. Due to only having two participants within the 'irrelevant checking' condition, and each participant responding differently to the task, conclusions cannot be drawn as to whether 'irrelevant checking' may or may not have an impact on memory. Interestingly, however, there was some consistency found within the memory accuracy variable. Despite descriptive results showing slight improvement on memory scores, when compared, two of the three participants within the repeated 'relevant checking' condition showed a similar change in pre-to-post memory accuracy scores to the healthy older adult group, whereas both participants within the 'irrelevant checking' condition showed no significant change. These results may indicate that using checking as a strategy could also cause detrimental effects to memory accuracy and meta-memory for those with a diagnosis of dementia.

During the debriefing of the study following the checking task, despite not being prompted to do so, several participants reported to use strategies to support their memory during the task, such as remembering the numbers relating to the stove tops manipulated. This interesting observation may highlight the spontaneous

utilisation of strategies that older adults may incorporate as a response to being given a complex task. Previous research has also shown that spontaneous strategy use is common in both younger and older adults to support memory, however, older adults were found to use more ineffective strategies compared to younger participants (Fabricio & Yassuda, 2011). This highlights further the need to ensure that advice regarding effective strategies for memory are being shared with this population.

Limitations and Future Research

There are limitations within the current research project. Due to difficulties with recruitment to the Dementia group, the sample size of this group is extremely small despite having minimal exclusion criteria. One of the common difficulties in recruiting individuals with a diagnosis of dementia, as in the case of the current study, was recruiting participants through services or "gatekeepers" (Lepore, Shuman, Wiener, & Gould, 2017). Recruiting via "gatekeepers" can be dependent on their views of the research project, their judgement on which individuals would want to be involved and their own relationship with their patients (Lepore et al., 2017). Additionally, NHS workers may feel responsible if the research has a negative impact on patients, as well as research being a low priority in relation to their routine work, and thus, resulting in less promotion of the research (Lowery, Warner, Cerga-Pashoia, Thune-Boyle, & Iliffe, 2011). This may be a particular concern for workers under the current pressures within the NHS. Recruitment may be supported in future research by community outreach (Lepore et al., 2017), for example, by approaching community groups and organisations such as Dementia cafes. Furthermore, with small samples, conclusions can be difficult to ascertain, and caution needs to be taken in not over-interpreting results.

Accuracy in the degree of frequency of self-reported memory errors shown on the PRMQ in the dementia group could have been limited. Additional informant measures completed by carers or relatives could have been included, which may provide a more representative view of the frequency of memory errors. However, as this was only used as a descriptive measure within the current study this was not deemed necessary.

A recent review of the checking paradigm has highlighted a limitation in the lack of counterbalancing within the current design (Van den Hout et al., 2019). The current checking task has two conditions: a) 'relevant checking' in which the stimulus involved repeatedly checking the stove top in-between pre-and-post checks on the stove top, b) 'irrelevant checking' in which the stimulus involved repeatedly checking the dosette box in-between checking the stove top at pre-and-post checks. However, Van den Hout et al. (2019) highlighted that for the study to be fully balanced there should be an additional 'relevant checking' process and an additional 'irrelevant checking' process. The second 'relevant checking' condition being repeatedly checking the dosette box in between pre-and-post checks on the dosette box and the additional 'irrelevant checking' condition being to repeatedly check the stove top in between pre-and-post checks on the dosette box. However, as this was one of the first studies to explore whether this effect may also occur in older populations and the additional number of participants this would have required, it was considered to be beyond the scope of this study. Furthermore, previous studies that have utilised a fully balanced version of the checking paradigm have found that it produced similar effects on meta-memory (Dek et al., 2010) as seen in the current design.

As described previously, several participants used a numerical strategy to support their memory of which hobs were manipulated during the checking task, rather than attend to the more visual or practical aspects of the task. This factor could be reduced by using visual representations of the hobs that should be manipulated, for example, van den Hout and Kindt, (2003a) used a cross on a computer program to indicate which hobs to turn on. However, even by using this method participants could continue to utilise a number-based strategy. Moreover, the apparatus within the current study was chosen specifically to have a high level of ecological validity for the target population and, thus, adapting to use a visual system may diminish this.

Further research should investigate the effects of repeated checking on memory accuracy and meta-memory in healthy older adults to see if the results in the current study are replicated. Furthermore, more research is needed to examine this paradigm in individuals with a diagnosis of dementia. If future research shows that the results indicated in this study are replicated on a larger scale, then it would confirm that checking is causing excessive disability in these individuals and alternative strategies should be recommended. Of course, any future studies should consider making adaptations to address the limitations of this study including counterbalancing and methods of recruitment for participants with a diagnosis of dementia.

The observations reported by participants into the strategies used during the checking task may also highlight an interesting area for future investigation. Comparison between numerical and visual strategies and the impact this has on memory may be helpful in furthering our understanding into both the strategies used by older adults but also the efficacy of these.

Conclusion

This study has used a novel approach with high ecological validity to explore the relationship between checking, memory accuracy and meta-memory in older populations both with and without dementia. The findings support the notion that repeatedly checking paradoxically leads to more memory distrust, causing a negative impact on memory accuracy and aspects of meta-memory in older adult populations. In addition, this study highlights the potential negative implications of strategies that vulnerable populations may utilise for support and therefore the need for professionals who recommend memory strategies to have greater awareness of these. Further research is needed to provide evaluation of these strategies and thus enable professionals to recommend the most beneficial and effective strategies.

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Extended Methodology for Empirical Paper

Measures

Measures included in the study were chosen based on their psychometric properties (see main paper for details), relevance to the sample population and time to complete. Shorter measures, if provided similar psychometric properties to longer versions, were used to ensure the length of the experimental session was manageable for those with cognitive impairments. Most measures, except the demographic questionnaire and cognitive screen, were completed at the end of the experimental session to increase the likelihood that participants were focused and engaged in the checking task.

The Montreal Cognitive Assessment (MoCA) was chosen as it has shown to have good specificity and sensitivity to both Mild Cognitive Impairment and Alzheimer's Disease, as discussed further in the main paper (Nasreddine et al., 2005). Further to this, it has also been shown to be superior in discriminating between control samples (normal ageing) and those with Mild Cognitive Impairment, when compared to the Mini Mental State Examination, another short cognitive screen (Pinto et al., 2019). This distinction was important to ensure that the control sample was made up of individuals likely to have no cognitive impairment.

The five-item Geriatric Depression Scale (5-item GDS) and Geriatric Anxiety Inventory Short Form (GAI-SF) were used to assess for the presence of anxiety and depression symptoms. Both mood (Marvel & Paradiso, 2004) and anxiety (Airaksinen, Larsson, & Forsell, 2005) disorders have shown to cause measurable decreases in memory and executive functioning. If high levels of

depression or anxiety were shown amongst the participants, this would introduce a confounding factor which would affect the interpretation of results.

The Attitudes to Aging short form (AAQ-SF) and the Prospective and Retrospective Memory Questionnaire (PRMQ) were used to provide further information on self-reported views of ageing and everyday memory functioning across both older adult samples. Negative attitudes towards older people and ageing are still commonly found in the U.K. amongst younger generations and across the media (Royal Society for Public Health, 2018). However, when investigated some older adults are shown to report positive attitudes towards aging (Royal Society for Public Health, 2018). Older adults and those with dementia have also previously been found to report higher rates of prospective rather than retrospective errors, with more total errors reported by those with Alzheimer's dementia (Smith et al., 2000). These two measures enabled further exploration of these factors within the current study.

Ethical Considerations

To ensure all participant forms were accessible to the reader, they were based upon templates proposed by the Health Research Authority and were assessed to have a readability score of 11 (checked using http://gunning-fog-index.com/). All forms were sent to a Patient and Public Involvement committee specialising in Dementia research, following which, feedback was incorporated and the forms adjusted accordingly. As participants who may have cognitive difficulties were being recruited, additional considerations above and beyond typical protocols were made. It was ensured that all participants were given up to two weeks to read through and discuss the study information with others before being contacted again about

participating in the study, as per guidelines by the British Psychological Society (2014). All participants were provided with the opportunity to ask any questions before participating and were fully supported to understand the study information, ensuring full informed consent was gained. All participants were given the opportunity to consent or decline, without coercion.

Due to recruiting participants with a diagnosis of dementia, referring clinicians were asked to state whether they deemed participants to have capacity to make a decision regarding entering the study, as defined in the Mental Capacity Act (MCA) (Department of Health; DoH, 2005). However, as capacity can fluctuate, this was assessed again by the researcher, if deemed necessary, using the four stages of capacity outlined in the MCA (DoH, 2005) at the beginning of the experimental session. Any participants deemed to lack capacity to consent to participate in the study were excluded. During the study, one participant was found to be unable to provide consent at the beginning of the experimental session, although deemed to have capacity by clinicians on the consent to contact form. The participant was, therefore, excluded and the experimental session terminated. This was fully explained to both the participant and participants carer.

As the checking paradigm, using a replica stove top and dosette box, had been previously undertaken with similar populations (Mild Cognitive Impairment; Lattimer, 2016), no feasibility or practical issues were foreseen for the current study. Furthermore, during the study conducted by Lattimer (2016) no distress or negative feedback was received from participants undertaking the checking procedure, and therefore minimal distress within the current study was predicted. All participants were monitored by the researcher for signs of fatigue or distress and breaks offered if

needed. However, all participants were able to complete the study with no difficulties.

Prior to completing the psychological measures (GAI-SF, 5-item GDS and MoCA), participants were fully informed of what factors the questionnaires measured (e.g. anxiety), and thus, the possible outcomes of these. Participants scoring within clinical levels of the GAI-SF and 5-item GDS or ≤25 on the MoCA were advised to contact their GP for further assessment and advice.

Due to conducting home visits to participants for the experimental session, NHS guidance and trust policies were abided by in terms of reducing lone working risk (Health, Safety and Wellbeing Partnership Group, 2018). These varied based on which NHS trust participants were being recruited from, and the appropriate policy followed. Furthermore, NHS safeguarding procedures were identified should any safeguarding or reportable issue be disclosed. No lone working risks or safeguarding concerns were encountered during the study.

All data within the study abided by guidance outlined within the Data Protection Act (2018) including General Data Protection and Regulation (GDPR) legislation which came into force at the time of ethical approval. Participants were given research identification numbers and any identifiable data was kept securely on password protected databases separate to all other study data.

Participants

Sample size.

Two groups of participants were recruited; a healthy older adult group and a Dementia group. As calculated using G-Power (Faul, Erdfelder, Lang, & Buchner,

2007), to undertake a MANOVA analysis, a total sample size of 56 participants (28 within each group) were required, for an alpha level of 0.05, power of 0.8 and a medium effect size (f = 0.25). If this sample size was not reached, alternative analysis of undertaking separate 2 x 2 mixed ANOVA's would be conducted if parametric assumptions were met. A sample size of approximately 30 participants (15 in each group) were required again for an alpha level of 0.05, power of 0.8 and a medium effect size (Faul, et al., 2007).

Recruitment.

Healthy older adults were recruited using snowballing techniques and advertisements placed within community libraries and groups including the University of the 3rd age. Interested volunteers contacted the researcher to discuss the study further and were sent a participant information sheet. Fourteen community groups were approached directly, which resulted in 41 potential participants contacting the researcher for further information. Several participants declined to take part following receiving information, and four participants were excluded due to failing the MoCA assessment. These four participants were advised to speak to their GP. This resulted in 30 participants being included in the final Healthy Older Adult Group (see Figure 3). Of the 30 participants, 21 (70%) lived with their partners and 9 (30%) lived on their own. Participants were asked whether they had any other medical conditions to ensure no confounding variables of neurological difficulties were present. Fourteen (46%) participants reported to have other health conditions, such as high blood pressure or arthritis but no neurological conditions, and 16 (53%) participants reported no medical problems.

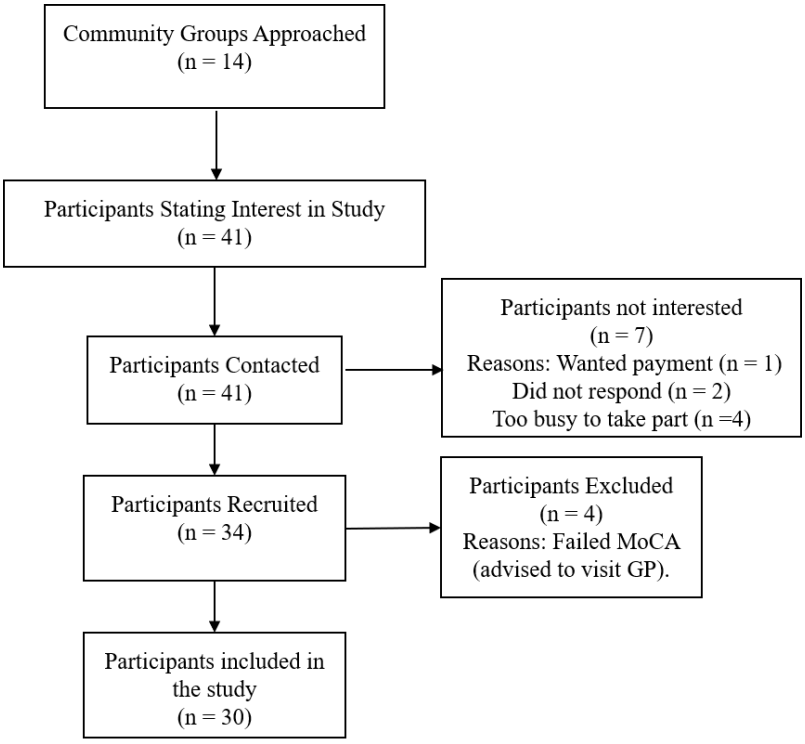

Figure 3. Consort flow diagram of participants recruited into the healthy older adult group.

Participants within the dementia group were recruited from two local NHS trusts: Norfolk and Suffolk NHS Foundation Trust and Cambridge and Peterborough NHS Foundation Trust. Meetings were held with five different Older People's Mental Health and Memory Assessment teams across East Anglia within the two NHS trusts. Clinicians were asked to consider which of their patients would be eligible to participate in the study and provide brief details of the study. Once the study was discussed with potential participants, clinicians completed a consent to contact form if the participant stated they wished to hear more about the study. The consent to contact form requested contact details of the potential participant to be documented including a signature to confirm the patient's interest. Additionally, clinicians recorded whether they considered the patient safe to be visited at home and by a single researcher. Finally, the form asked whether clinicians deemed the patient to have capacity to consent to participate in the study (see appendix N).

Eight referrals for potential participants were received from clinicians across all services. Following contacting all potential participants, two had recently become unwell and therefore did not wish to take part and one was deemed unable to provide consent to take part in the study. Therefore, five participants were recruited into the Dementia group (see Figure 4).

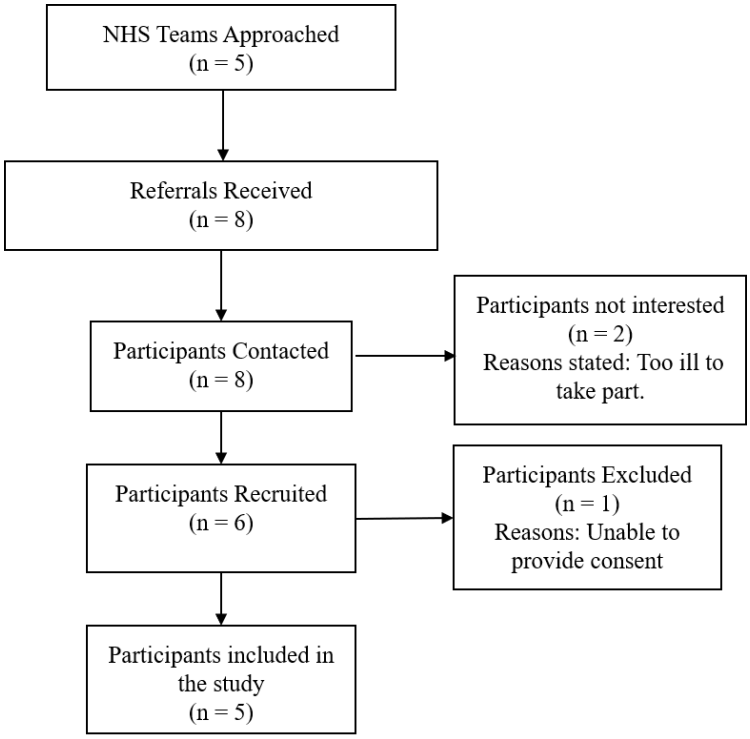

Figure 4. Consort flow diagram for participants recruited into the Dementia group.

Of the participants recruited into the Dementia group, four were diagnosed with Alzheimer's disease and one with Mixed Dementia (Alzheimer's and Vascular type). At the time of the experimental session, all participants reported to be within six months of gaining their diagnosis, and all but one participant had been prescribed medication for their memory (Cholinesterase inhibitors or Memantine). Three participants lived with their partners and two lived on their own, although were frequently visited by family members. Finally, three participants reported to have other health conditions, again including high blood pressure and arthritis.

On average between two and four hours were spent recruiting and completing the experimental session for each participant. This was regardless of whether participants were within the dementia or non-clinical group and extends to those who were excluded from the study. This was made up of time travelling to meet participants, going through consent, answering questions, screening and completing the experimental procedure.

Extended Results for Empirical Paper

Demographic Characteristics

Means and Standard deviations are used as standard within empirical research papers and have therefore been used within the main paper. However, due to the data not being normally distributed and having unequal sample sizes, it has been suggested that reporting the median and interquartile range (IQR) can provide a more representative view of the sample statistics (Dancey & Reidy, 2004). Therefore, the median and IQR for the demographic characteristics of the two groups have also been calculated below (see Table 9).

Table 9

Participant Demographic Information

	Healthy Older Adult Group (n = 30)		***Dementia Group (n = 5)***	
Females/Males (%)	63% / 37%		80% / 20%	
	M	**IQR**	***M***	**IQR**
Age	72.5	(8.25)	76	(9.5)
Years of Education	16	(3.0)	12	(4.0)
Overall Health Rating	8	(1.0)	8	(2.0)
Quality of Life Rating	8	(1.0)	10	(2.0)
MoCA	28	(2.25)	17	(5.5)

Note: n= number of participants, *M* = Median, IQR = Interquartile Range. Overall Health and Quality of Life Ratings are scored on a 10-point Likert Scale, with 10 meaning "Very Good".

As described in the main paper, psychological measures were also administered including the GAI-SF, 5-item GDS, AAQ and PRMQ. Descriptive statistics stating the median and IQR of these measures are presented in Table 10.

Table 10

Psychological Measures

	Healthy Older Adult Group (n = 30)		***Dementia Group (n = 5)***	
	M	**IQR**	***M***	**IQR**
GAI-SF	1	(2.0)	1	(2.5)
5-item GDS	0	(1.0)	0	(0.5)
AAQ Psychosocial Loss	8	(3.25)	6	(5.0)
AAQ Physical Change	13	(3.25)	13	(5.0)
AAQ Psychological Gain	14	(4.25)	15	(3.5)
PRMQ Total	37	(10.0)	40	(22.0)
PRMQ Prospective Errors	18	(4.0)	15	(11.5)
PRMQ Retrospective Errors	19	(4.75)	25	(10.5)

Note: n= number of participants, *M* = Median, IQR = Interquartile Range

Further to the comparisons made in the main paper between the two groups on these measures, further within group comparisons were made between the domains of the AAQ and PRMQ. Wilcoxon signed-rank tests showed no significant differences reported in prospective or retrospective errors between participants within the Healthy Older Adult group (Z = -0.23, p = 0.82) or participants within the Dementia group (Z = -1.48, p = 0.14). Due to non-parametric data, assumptions of the ANOVA were violated and therefore, three separate Wilcoxon signed-rank tests were conducted to assess differences between the domains of the AAQ for each group. As multiple comparisons were being calculated, a Bonferroni adjustment was used to reduce Type 1 error, resulting in an adjusted p-value of 0.017 (Dancey & Reidy, 2004). No significant differences were found between any of the three domains of the AAQ for participants within the Dementia group (Z = -0.14, p = 0.89*;* Z = -1.46, p = 0.14*;* Z = 1.84, p = 0.07*)*. No significant difference was found between the Psychological Gain and Physical Change or Psychosocial Loss and Physical Change domains on the AAQ for Healthy Older Adults (Z = -0.69, p =

0.49; Z = -0.69, p = 0.05). However, a significant difference was found between scores on the Psychological Gain and Psychosocial Loss domains (Z = -2.87, p = 0.004) with more psychological gains being reported than loss. Overall, both groups scored positively across the three domains of attitudes to ageing, with low reports of psychosocial loss and physical change, and high levels of psychological gain.

Checking Task

Due to difficulties in recruitment and the small sample size gained, planned analysis of a 2x2 MANOVA using variables of memory confidence, vividness and detail as a single wider construct of 'meta-memory' was unable to be conducted. Furthermore, due to data being highly skewed within the checking task variables and thus, failing to meet the parametric assumptions for a mixed 2 x 2 ANOVA, alternative analyses were undertaken.

Histograms and distribution curves were inspected for all variables from the checking task to detect any skew within the data. Skew values for each variable were converted to z-scores and any score greater than 2.58 or -2.58 (p = 0.01) were considered significantly skewed (Clark-Carter, 2010). Several of the variables met this criterion indicating significant levels of skew. This was also confirmed by significant results shown on the Shapiro-Wilk test included in the SPSS analysis. Following consultation with a Professor of statistics regarding transforming data and alternative non-parametric analyses, individual Mann Whitney U and Wilcoxon signed-rank tests were deemed the most appropriate method and were therefore undertaken to assess the effect of checking on these variables. Mann Whitney U tests analysed whether there were any differences between the two groups at the same time points, for example, 'relevant checking' pre-check trial vs 'irrelevant

checking' pre-check trial. Whereas, Wilcoxon tests analysed whether there were significant differences within conditions between the pre and post checking trials. See main paper for further results.

Healthy older adult group.

Within the main paper, descriptive statistics using the mean and standard deviation were reported for the demographic characteristics and the memory checking questionnaire variables for both 'relevant' and 'irrelevant' conditions. Therefore, as recommended by Dancey and Reidy (2004), the median and interquartile range of these variables have also been calculated (see Table 11 and Table 12 respectively)

Table 11

Demographic Characteristics for the two Checking Conditions

	Relevant Checking Group (n = 15)		***Irrelevant Checking Group (n = 15)***	
Females/Males (%)	73% / 27%		54% / 46%	
	M	**IQR**	***M***	**IQR**
Age	70	(8.0)	73	(9.0)
Years of Education	16	(3.0)	16	(4.0)
MoCA	28	(2.0)	29	(3.0)

Note: n= number of participants, *M* = Median, IQR = Interquartile Range

Table 12

Descriptive Statistics from the Checking Task Memory Questionnaire

Memory Checking Questionnaire	***Relevant Checking Group (n = 15)***		***Irrelevant Checking Group (n = 15)***	
	Pre-checking	Post-checking	Pre-checking	Post-checking
	M (IQR)	***M (IQR)***	***M (IQR)***	***M (IQR)***
Accuracy	6 (0.0)	4 (2.0)	6 (0.0)	6 (0.0)
Confidence	97 (10.0)	75 (40.0)	100 (1.0)	100 (0.0)
Vividness	95 (10.0)	75 (58.0)	100 (5.0)	100 (0.0)
Detail	95 (10.0)	70 (50.0)	95 (15.0)	100 (0.0)

Note: n= number of participants, *M* = Median, IQR = Interquartile Range

Overall, further to results described in the main paper, the healthy older adult group showed that following repeated 'relevant checking', memory accuracy and memory confidence were significantly reduced, compared to repeated 'irrelevant checking'. Memory vividness and memory detail also showed a deterioration following repeated 'relevant checking' compared to 'irrelevant checking'. However, whilst there were deteriorations these did not reach significance (see Figure 5).

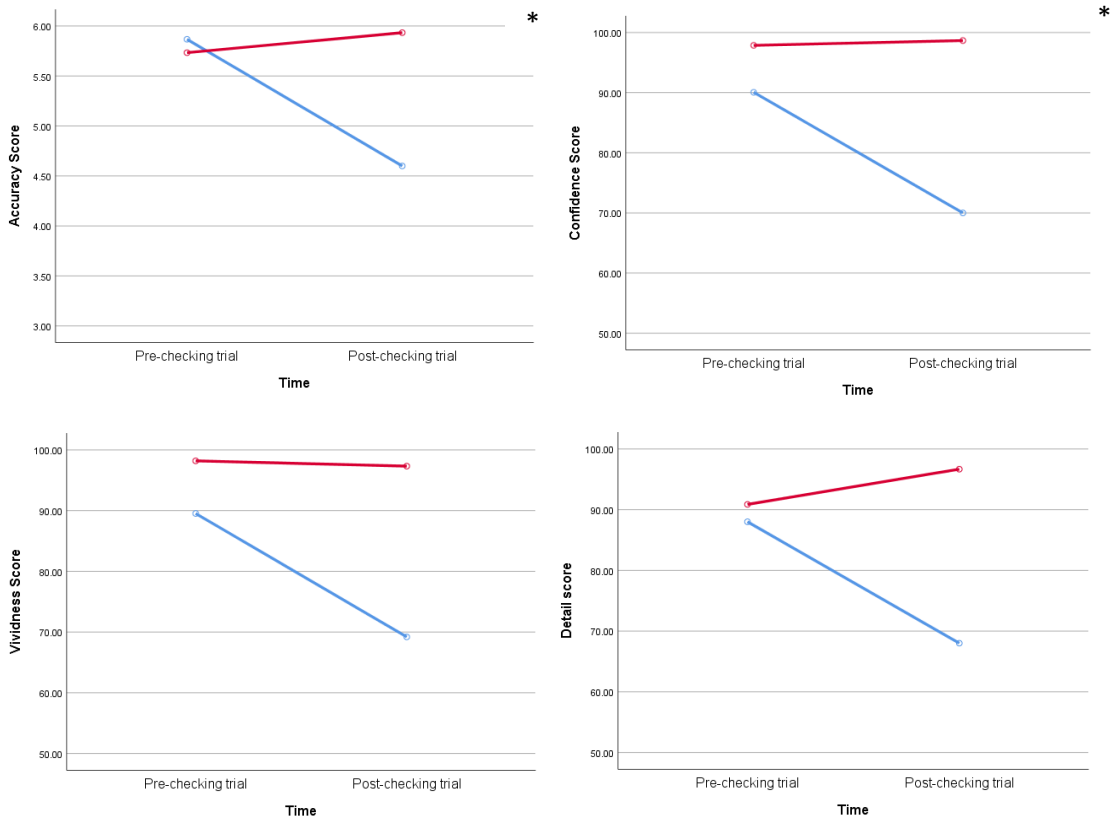

Figure 5. Line Graphs to show Healthy Older Adult Group's metamemory and accuracy scores across pre-and-post checking time points between conditions. * = significant result.

Familiarity.

To assess whether there were any changes in familiarity of the checking trials, using the 'remember/know' responses following repeated 'relevant' or

'irrelevant' checking within the healthy older adult group, a McNemar test was used. A McNemar test was used due to being a within-subject test of change (Clark-Carter, 2010). There was no significant difference found in responses following repeated 'relevant checking' (McNemar exact test, $p = 0.625$, 2-sided) or repeated 'irrelevant checking' (McNemar exact test, $p = 1.00$, 2-sided), with most participants stating that they could still 'remember' the tested checking trial. Following repeated 'relevant checking' 66% of participants still stated they 'remembered' the checking trial as compared to 80% at the pre-checking trial (see Figure 2). Participants within the 'irrelevant checking' trial did not show any change in responses with 93% stating 'remember' both pre-and-post checking. Therefore, repeated checking did not appear to affect the familiarity of the checking events.

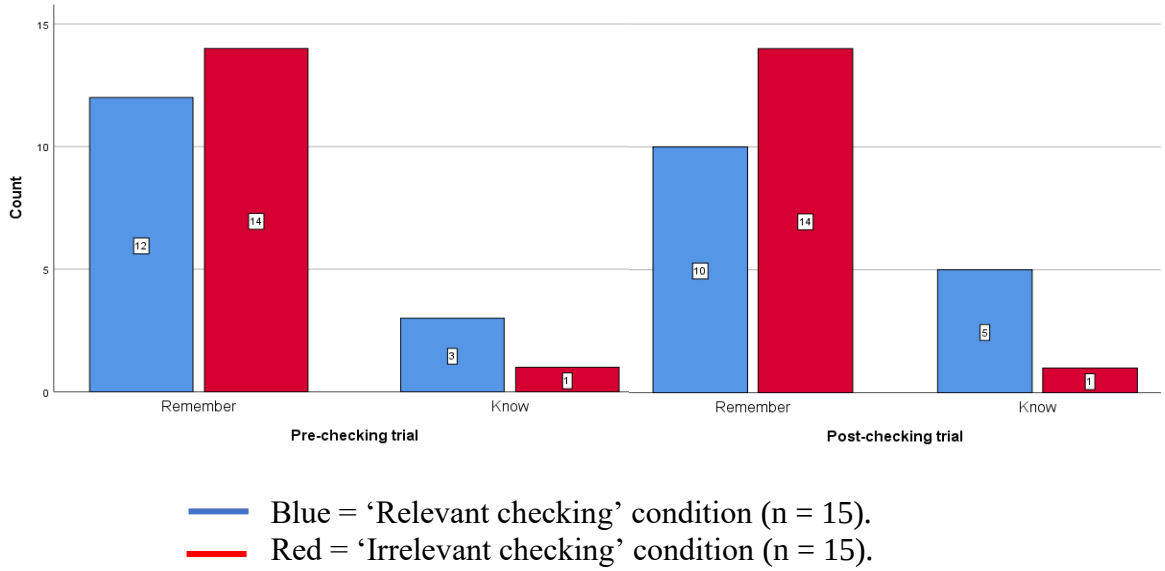

Figure 6. Bar graph to show the Healthy Older Adult Group's 'remember/know' responses across conditions and time points.

Dementia group.

Descriptive statistics using the median, minimum and maximum scores have been calculated and reported for the Dementia group demographic characteristics

and memory checking questionnaire variables for both 'relevant' and 'irrelevant' conditions (see Table 13 and Table 14 respectively).

Table 13

Demographic Characteristics for the two Checking Conditions

Measure	***Relevant Checking (n = 3)***		***Irrelevant Checking (n = 2)***	
	M	***Min-Max***	***M***	***Min-Max***
Age	76.0	74-83	80.0	75-85
Years of Education	12.0	11-13	13.0	10-16
MoCA	19.0	17-22	15.0	14-16

Note: n= number of participants, *M* = Median.

Table 14

Descriptive Statistics from the Checking Task Memory Questionnaire

Memory Checking Variables	***Relevant Checking (n = 3)***		***Irrelevant Checking (n = 2)***	
	Pre-checking ***M (Min-Max)***	Post-checking ***M (Min-Max)***	Pre-checking ***M (Min-Max)***	Post-checking ***M (Min-Max)***
Accuracy	4.00 (2-6)	6.00 (4-6)	6.00 (6-6)	6.00 (6-6)
Confidence	20.00 (0-75)	50.00 (0-50)	80.00 (60-100)	100 (100-100)
Vividness	50.00 (35-75)	50.00 (0-75)	75.00 (50-100)	75.00 (50-100)
Detail	60.00 (50-70)	10.00 (0-75)	50.50 (1-100)	50.00 (0-100)

Note: n= number of participants, *M* = Median.

Irrelevant checking condition.

Details regarding the comparison of variables on the memory checking questionnaire between the dementia group and healthy older adults within the 'relevant checking' condition were described in the main report. Due to only having two participants within the 'irrelevant checking' condition, it is difficult to draw conclusions from these results, but it is still important to examine and consider this data. Therefore, the comparisons made between those within the 'irrelevant

checking' condition for the dementia group and those within the healthy older adult group are detailed below. The same methodology as developed by Crawford and Garthwaite (2005) and Crawford and Howell (1998) described in the main report were also used with these participants. Due to multiple comparisons being undertaken, significance level was adjusted to 0.008 to reduce Type 1 error (Dancey & Reidy, 2004).

Memory accuracy.

Neither participant in the irrelevant checking condition showed a significantly different memory accuracy score either at the pre-checking trial ($t = 0.373$, $p = 0.71$) or post checking trial ($t = 0.261$, $p = 0.80$) compared to the healthy older adult group. Both participants also showed no significant difference in the degree of change in memory accuracy following 'irrelevant checking', indicating a similar pattern to those within the healthy older adult group ($t = 0.074$, $p = 0.94$).

Memory confidence.

One participant in the irrelevant condition showed a significantly lower pre-checking trial confidence score compared to the healthy older adult group ($t = -8.148$, $p = <0.001$), with the other participants score not being significantly different ($t = 0.458$, $p = 0.65$). At the post-checking trial, neither participant scored significantly different to the healthy older adult group ($t = 0.25$, $p = 0.81$). Finally, one participant showed no significant difference in the degree of change in memory confidence following 'irrelevant checking' ($t = 0.194$, $p = 0.84$). However, the other participant did show a significant difference as their confidence score improved following 'irrelevant checking' unlike those in the healthy older adults group whose scores remained similar ($t = -8.416$, $p = <0.001$).

Memory vividness.

One participant in the irrelevant condition showed a significantly lower pre-checking trial vividness score compared to the healthy older adult group (t = -15.402, p = <0.001), with the other participants score again not being significantly different (t = 0.575, p = 0.57). At the post-checking trial, one participants vividness score was significantly lower than the healthy older adult group (t = -7.715, p = <0.001), and the other participant showed no significant difference (t = 0.435, p = 0.67). Finally, both participants showed a significant difference in their pre-to-post memory vividness scores as they decreased (t = 5.82, p = <0.001) and increased (t = 10.567, p = <0.001), whereas scores in the healthy older adults 'irrelevant checking' group tended to remain similar.

Memory detail.

Again, one participant showed a significantly lower pre-checking trial detail score compared to the healthy older adult group (t = -8.335, p = <0.001), with the other participants' score not being significantly different (t = 0.847, p = 0.41). Similarly, at the post-checking trial, one participants detail score was significantly lower than the healthy older adult group (t = -10.40, p = <0.001), and one participant showed no significant difference (t = 0.358, p = 0.73). Finally, both participants showed a significant difference to healthy older adults in their pre-to-post repeated 'irrelevant checking' detail scores as they again either decreased (t = 9.252, p = <0.001) or increased (t = 7.384, p = <0.001).

Familiarity.

Formal analysis of the familiarity ratings ('remember/know' responses) between pre-and-post checking events for the dementia group were unable to be

calculated due to being a within-participant design with expected frequencies of below five (Clark-Carter, 2010). Descriptively, all participants reported only having a general sense of "knowing" regarding their memory of the pre-checking trial, with no participants rating this as "remembered" across both 'relevant' and 'irrelevant' conditions (see Figure 7). Following repeated checking, however, one participant from each condition reported to now "remember" the post-checking trial, with the remaining participants still only holding a general sense of "knowing" (see Figure 8). Thus, repeated checking did not appear to cause a deterioration in familiarity of the checking events, with lower familiarity already found at the initial checking trial.

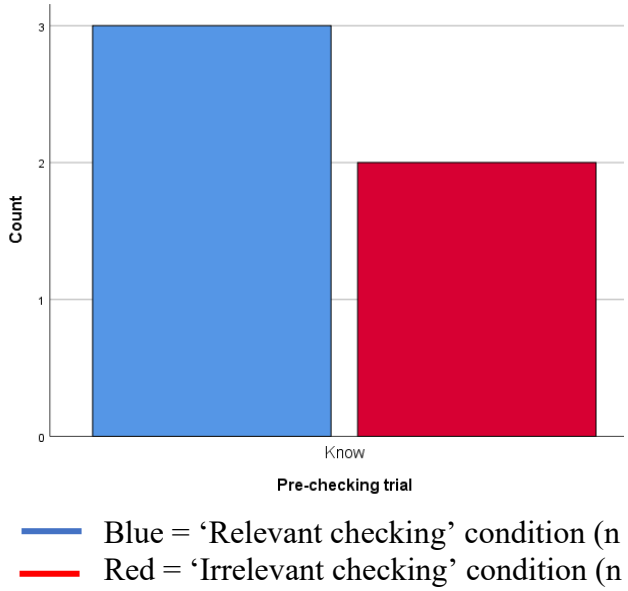

Figure 7. Bar graph to show the Dementia Groups 'remember/know' responses at the pre-checking trial.

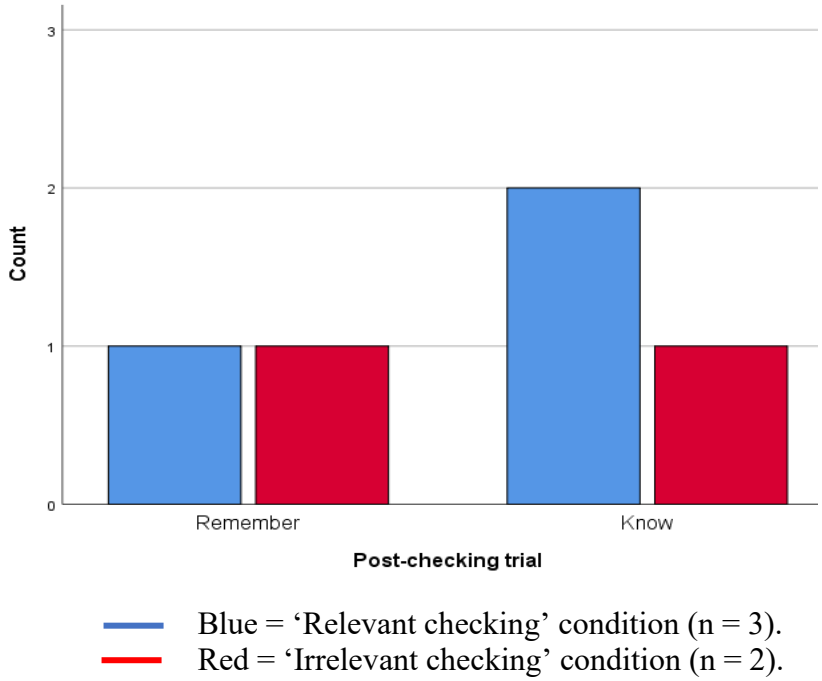

Figure 8. Bar graph to show the Dementia Groups 'remember/know' responses at the post-checking trial.

Dementia group summary.

In summary, most participants within the 'relevant checking' condition showed a similar pattern following repeated checking as the Healthy older adult group, although some variables, such as accuracy and confidence, were rated lower prior to any checking in the Dementia group. Mixed results were found within the 'irrelevant checking' condition within memory confidence, vividness and detail. As these results are based on small sample sizes they should be interpreted with caution.

Discussion and Critical Evaluation

This chapter will discuss the findings from both the systematic review and empirical research paper, including the strengths, limitations and implications of the research further to those previously discussed. Further to this it will also provide a reflection on the research process and consideration for future research directions.

Summary of Findings

Systematic review.

To our knowledge this systematic review was one of the first to investigate the prevalence of 'dementia worry' within the general population. This resulted in 15 studies included for review. As previously discussed, 'dementia worry' is a concept which has been classified in numerous ways and understood within various models. This review further highlighted the lack of homogeneity of research in this area, particularly within the assessment or measurement of dementia worry, even when a single conceptualisation was utilised. Some studies used validated measures such as the Fear of Dementia Scale (FADS) or the Dementia Worry Scale (DWS). However, the most common method was using a single question approach to ascertain degree of fear, worry or concern about developing dementia. Advantages to the validated measures are that these have been previously developed and various standardised psychometric properties determined. It was noted that whilst they assess level of 'dementia worry' they also incorporate wider cognitive or physiological symptoms associated with this concern. The potential clinical utility of these types of measures were discussed in the main paper. The single question provides less information regarding the experience of dementia worry, although it does provide a clear figure on the degree of dementia worry amongst participants.

However, as highlighted in the main paper, there was still high variation in the wording and response options to the single questions posed. Therefore, it is feasible that these questions could be interpreted differently across participants and demographic groups.

Despite these variations the systematic review found that some degree of 'dementia worry' was present in all populations, ages and cultures. The studies which allowed an estimate of prevalence to be combined resulted in 53.3% of participants reporting to fear or worry about developing dementia. This prevalence varied from 17.7% to 76.6% across the included studies. Whilst this suggests a range of 58.9%, this is consistent with previous findings on the range of 'dementia worry' present amongst the population (Kessler et al., 2012). The review was also able to further explore potential correlates of dementia worry, as a higher proportion of the studies investigated these factors compared to previous reviews. Multiple variables were explored, however, only those which had been researched by several studies were discussed. These findings built on previous knowledge to provide more evidence that dementia worry is higher in females. Previous studies had reported mixed results within this demographic characteristic, although some finding similar results to the current review (Low & Anstey, 2009). However, other studies have only found a significant gender difference in relatives of those with a diagnosis of dementia (Cutler & Hodgson, 1996). The current review found 81% (n = 9) of studies found significant gender differences in dementia worry, and therefore supports the conclusion that dementia worry is more prevalent within females.

Further evidence was shown, consistent with previous studies (Cutler & Hodgson, 2001; Kessler, et al., 2014), that those in closer proximity to dementia and those with self-perceived declines in memory performance also reported higher

levels of dementia worry. This latter factor was specified to relate to those who perceived a deterioration in memory across time, rather than those who perceive themselves as having poor memory generally, reporting more dementia worry (Bowen et al., 2019).

Other correlates indicating mixed results included, age, ethnicity, knowledge of dementia and education. Some studies found there to be no association between age and dementia worry, however, several papers found middle-age to older participants (50 years and over) to report significantly higher rates of dementia worry compared to younger participants (Jang et al., 2018; Tang et al., 2017; Arai et al., 2012). However, individual studies found higher rates of dementia worry in younger participants (Laforce & McLean, 2005), and decreased dementia worry in the oldest old (Cutler, 2015). These studies indicate that dementia worry is experienced across the lifespan, but it is unclear if it is more prevalent within a specific time of life.

Similarly, variations in the degree of dementia worry reported can be seen across study locations and thus, cultures, although those testing differences between ethnicities within its study design showed mixed results. The variables finding more mixed results may, therefore, require more investigation to gain further clarity. Overall, the systematic review added further knowledge to a growing research area, evidencing that dementia worry is highly prevalent across the general population, and providing stronger evidence for the demographic characteristics where dementia worry tends to be greatest.

Empirical paper.

The empirical paper investigated the effects of repeated checking on memory accuracy and meta-memory (confidence, vividness, detail) in older adults

without cognitive impairment and those with a diagnosis of dementia. Thirty 'healthy' older adults and five participants with a diagnosis of dementia participated in the study. Each participant was randomised into either a 'relevant checking' condition where they continuously checked the stove top, or the 'irrelevant checking' condition where they continuously checked the dosette box, in between pre-and-post trials on the stove top.

The main findings showed that following repeated 'relevant checking', the older adult group showed a significant deterioration in memory confidence compared to those within the 'irrelevant checking' condition. The significant reduction in memory confidence found in older adults within this study is consistent with previous research findings conducted on OCD, undergraduate samples and older adults (Radomsky, Dugas, Alcolado, & Lavoie, 2014; van den Hout & Kindt, 2003a; Lattimer, 2016). In addition, repeated 'relevant checking' caused deteriorations in memory vividness and detail in comparison to those in the 'irrelevant checking' condition, although this did not reach significance. Most other studies have consistently found this reduction in vividness and detail to be significant, with a meta-analysis reporting this finding showed a large effect size (van den Hout et al., 2019), contradicting results found in the current study. Lattimer (2016) investigated the checking effect in older adults and those with mild cognitive impairment (MCI) and although a significant reduction in vividness and detail was found following repeated 'relevant checking' in the older adults' group, a similar non-significant deterioration was found in the MCI group. The Lattimer (2016) study only had a very small sample and is therefore likely to be underpowered. Nevertheless, this finding in MCI participants, along with the current study, may indicate an element of

difference in the extent of effects checking has on these specific meta-memory aspects in some older adults.

Overall, consistent with the previous research these results showed that repeated 'relevant checking' does cause increased memory doubt with deteriorations in memory confidence, vividness and detail. As these reductions were not shown in the 'irrelevant checking' group it indicates it is the repetitive nature of repeated checking which is contributing to this deterioration.

The study also investigated the effect of repeated checking on memory accuracy. In contrast to most previous research, memory accuracy was found to be significantly reduced following repeated 'relevant checking' in comparison to 'irrelevant checking', resulting in a large effect size ($d = 0.74$). A recent meta-analysis by van den Hout et al. (2019) reported that only 17 out of 28 studies showed an interaction on memory accuracy scores between conditions and pre-post trials, and when pooled together, only produced a small effect size ($g = 0.34$). However, the authors state that when reviewed individually, many articles did not report any effect on memory accuracy (van den Hout et al., 2019). Similarly, this effect is not shown in the study by Lattimer (2016). However, with the increased sample size in the current study and such a large effect size, the current study may highlight a potential further detrimental effect of repeated checking on the accuracy of memory in older adults.

Due to a small sample of participants with a diagnosis of dementia, full comparisons within this group were unable to be undertaken. However, case-control analysis using the validated methods devised by Crawford and Howell (1998) and Crawford and Garthwaite (2005) allowed comparison of memory accuracy and meta-

memory scores between those in the older adult and dementia groups. Participants with a diagnosis of dementia showed similar degrees of change between pre-and-post checking trials on memory accuracy and meta-memory following repeated 'relevant checking' to the older adults within this condition. Two participants within the dementia group showed lower memory accuracy at the pre-checking trial but showed a similar deterioration in accuracy following repeated 'relevant' checking as seen in the healthy older adult group. Due to only two participants in the 'irrelevant condition' within the dementia group, each showing contrasting results, conclusions were difficult to ascertain. However, both participants in the 'irrelevant checking' condition showed no change in memory accuracy in line with those seen in the healthy older adult group. Thus, indicating that repeated checking could also cause deteriorations in memory accuracy and meta-memory, and thus, increased memory doubt for those with memory impairments.

Additional results found in the empirical study related to the familiarity of the checking memory reported by participants. Previous studies have evidenced both younger and older participants reporting their memory of the checking event changing from a clearly remembered experience to a general sense of knowing post repeated relevant checking (van den Hout & Kindt, 2003b; Radomsky et al., 2006; Lattimer, 2016). This was hypothesised to indicate that repeated checking causes an increase in the familiarity of each checking event resulting in each memory becoming less vivid and detailed. Thus, meaning participants only have a general sense of "knowing" rather than having a firm "remembered" memory of the checking event (van den Hout & Kindt, 2003b). However, within the current study no significant difference was found in familiarity ratings between pre-and-post checking trials in either the healthy older adult group or dementia group.

Furthermore, participants within the current study also reported higher levels of "knowing" at the pre-checking trial. This may correlate with the finding that deteriorations in vividness and detail were not as pronounced in the current study and therefore, participants may not have necessarily experienced a perceived change in familiarity.

Clinical Implications

One of the main clinical implications from the outcome of these two papers is highlighting the potential detrimental effects using repeated checking as a strategy may cause. The results of the empirical paper highlight that repeated checking causes a deterioration in memory accuracy and memory confidence along with reductions in other meta-memory elements in older adults. The same effects of repeated checking were also indicated as occurring in those with a diagnosis of dementia, although this was based on a small sample. Thus, despite older adults and those with memory impairments using repeated checking as a strategy to aid their memory, it paradoxically causes an increase in memory doubt and inaccuracy. This increase in memory doubt may be causing excessive disability in these populations. For example, individuals may experience more memory inaccuracies, which may enhance poorer beliefs regarding their memory performance, leading to reduced engagement or perceiving themselves as needing more support to complete cognitively demanding tasks, which they would in fact be able to achieve.

In addition to this, the systematic review found that those who are concerned about their memory performance are shown to have higher levels of fear or worry about developing dementia. These two factors in combination may make these individuals more likely to utilise strategies which they believe will aid and support

their memory, such as checking. However, as already established, this strategy leads to more memory doubt which may consolidate their concerns about memory performance. This may then increase their fear or worry about developing dementia, with a subsequent uptake of more memory strategies. Therefore, the results of these two papers may highlight a potential vicious cycle which maintains and perpetuates both fear of dementia and memory doubt (see Figure 9).

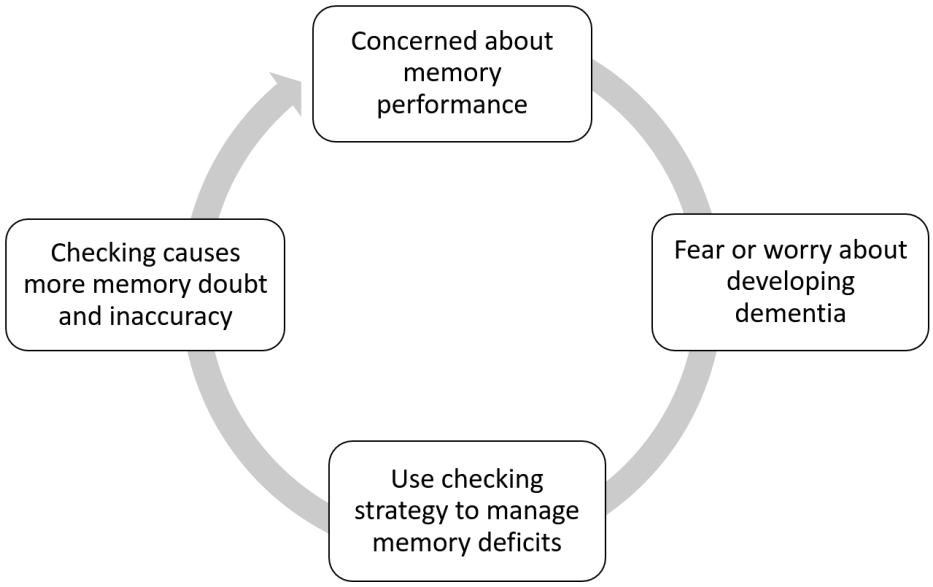

Figure 9. Cycle of dementia worry and checking.

This potential perpetuating cycle, although requiring further exploration, may be extremely beneficial for all healthcare professionals to be aware of, particularly those who may have first contact with individuals concerned about their memory. Educating service users regarding the negative consequences of repeated checking on their memory, as well as how this may be exacerbating their memory concerns and worry or fear of developing dementia, will be an important intervention to try

and reduce these compounding factors. Additionally, identifying individuals with dementia worry may be crucial so alternative methods to support any memory difficulties or excessive worry can be provided. This could be difficult to implement, as convincing staff to recommend their patients stop using checking strategies might be met with some resistance and anxiety.

This uncovers a further implication for clinical practice. Healthcare professionals and support agencies, particularly those within memory assessment services, are often asked to recommend memory strategies including both assistive technology and more traditional memory aids such as checking, visual cues, reminders and prompts (Alzheimer's Society, 2017). However, as clinicians, an understanding of the evidence base and potential negative implications behind these strategies, such as those highlighted with checking in the current study, are needed to ensure that the most beneficial strategies are being recommended. A brief search of the literature shows that several reviews have been undertaken on the use of electronic devices and memory training groups with older adults and adults with dementia. These reviews provide some evidence to support the use of electronic memory aids for individuals with a diagnosis of dementia (King & Dwan, 2017), and improvements in older participants following memory training (Gross et al., 2012). However, there are several limitations of this research that should be considered. Firstly, many of the studies investigating the effects of memory strategies lack ecological validity. Studies frequently report conducting their experiments in controlled environments or group settings rather than within the individuals home environment. Secondly, the effectiveness of the strategies learnt are often based on performance on objective memory tests, such as list learning or behavioural memory tasks. Both of these factors reduce the generalisability to everyday functioning and

therefore, how effective these strategies are within the individuals home environment. Furthermore, although improvements in memory performance are key, it is also important to consider whether these strategies are improving the quality of life and self-perception of these individuals. This would be an additional outcome of interest, particularly if the aim of supporting memory improvement is to increase opportunities for independent living and more positive self-perceptions. Clinicians having an awareness of this research and the evidence-base allows them to establish which are the most useful memory strategies for their patients.

One further finding, which may help to reinforce the campaigns aimed to reduce stigma and negative attitudes regarding dementia, was that all participants with a diagnosis of dementia rated their quality of life as "good" or "very good" and rated positive attitudes towards ageing. These were similar to those reported in the healthy older adult group. The public's perception of older people and ageing have been reported to be mostly negative in terms of older people's capabilities, although more positive views are held towards older people regarding more personal factors (Lyons, 2009). Qualitative interviews with older adults regarding their views of dementia were also mixed but showed negative attitudes were common regarding possible quality of life (Corner & Bond, 2004). Furthermore, negative stereotypes have frequently been shown to have harmful consequences on wellbeing (Dionigi, 2015) and cognitive performance in older adults (Lamont, Swift, & Abrams, 2015). Conversely, when investigated, older adults tend to report positive attitudes towards their experience of ageing (Bryant et al., 2012). Previous research has shown more negative attitudes are reported by older adults when physical or mental health difficulties are also present (Bryant et al., 2012). In addition, a study assessing attitudes towards ageing in older adults with a diagnosis of dementia also reported

negative attitudes towards aging particularly in terms of psychosocial loss (Trigg, Watts, Jones, Todd & Elliman, 2012). In contrast, the results in the current study, although based on a very small sample, highlight how some older adults may still hold positive views of ageing in the early stages of a dementia diagnosis. It also compliments previous findings that older adults report positive attitudes towards ageing. Communicating these positive perceptions held by older adults and those living with degenerative conditions, even within small samples, could help to continue to improve the reduction of age stereotypes and negative attitudes often held by younger populations.

Theoretical Implications

The term "dementia worry" has been understood within various models and definitions, including perceived threat to dementia within the health belief model (Shi, Sun, Liu, & Marsiglia, 2018), and health anxiety frameworks (Warwick & Salkovskis, 1990). Within the health anxiety framework prior experience of a disorder, such as knowing someone with dementia, and perceived risk are thought to combine with ruminative beliefs about developing the disease. This causes hypervigilance to possible symptoms, anxiety, and increased help-seeking which maintain the cognitive beliefs (Warwick & Salkovskis, 1990). Within the current systematic review, the presence of dementia worry was found to be highly linked to proximity to dementia and subjective memory performance concerns. These aspects may therefore be more aligned to the cognitive aspects within a health anxiety model understanding of dementia worry. This understanding of dementia worry may also indicate a possible relationship between dementia worry and other mental health difficulties. However, the current literature does not allow us to ascertain whether the behavioural aspects of the health anxiety model are associated with dementia

worry and thus the maintenance of these concerns. Subjective memory performance concerns have shown some links with increased help-seeking; however, although subjective memory concerns are associated with greater dementia worry this does not necessarily infer increased help-seeking would also be found in these populations. This would therefore need further investigation to provide more evidence for the applicability of this model. Furthermore, these findings are only based on one definition of dementia worry and are therefore not fully representative of the wider dementia worry literature.

The results evidenced in the empirical paper, may identify some theoretical implications on the underlying mechanisms involved during the checking task. Rachman (2002) proposed a self-perpetuating cognitive theory of checking based on those with obsessive-compulsive disorders. The repetitive checking compulsions often seen within this disorder are thought to be completed, in part, as a method to prevent themselves or others from potential harm and for reassurance when feeling uncertain as to whether the "threat" has been removed or the task completed (Rachman, 2002). However, it was proposed that repeatedly checking paradoxically causes more uncertainty due to reductions in confidence when trying to recall the checking event. The more checks that are completed, the less confident the person is in the memory of the checking event (Tolin et al., 2001). Therefore, repeated checks are implemented to try and regain confidence and certainty, causing a self-perpetuating mechanism (Rachman, 2002). The reduction in confidence following repeated checking has been theorised to be due to increased familiarity amongst checking events. With increased familiarity, less perceptual details are processed, resulting in each memory lacking in detail and vividness when recalled (van den

Hout & Kindt, 2003a). This theory has been applied to understand the impact found following the current checking paradigm on memory in non-clinical populations.

The current study provides complimentary evidence for the above theory in that checking does lead to increased memory doubt, with participants within the current study also reporting lower confidence and deteriorations in vividness and detail following repeated checking events. However, older adult participants within the current study did not indicate the same degree of change in vividness and detail nor changes in familiarity following checking as would be predicted from this theory. Possible hypotheses to explain these findings will be explored.

The first hypothesis is that a similar process as proposed by Rachman (2002) is occurring during the checking task. However, this may be better understood within a competitive trace theory perspective of memory recall. Competitive trace theory proposes that each time a memory is reactivated the central features of the original memory are remembered and strengthened, however, new overlapping altered aspects of the memory are also stored with less detail (Yassa & Reagh, 2013). Therefore, a re-contextualised memory which is similar but not identical, is encoded. The more a memory is reactivated, the more interference is built by competing memory details. Furthermore, false details could be added into the re-encoding each time the memory is recalled (Yassa & Reagh, 2013). Although this theory is mainly discussed in terms of reactivating a single memory, it could be considered within the checking task due to the similarity of checking events that are repeatedly being encoded. Therefore, within the current task, participants are frequently revisiting the same procedure and encoding similar but not identical memory events. This may strengthen the core details of the checking memory (e.g. the visual of the stove top), but other specific details and the clarity of each event builds in interference.

Therefore, in comparison to the memory of the very first checking trial, the overall detail and clarity of the post-checking trial is reduced, but not perceived as completely negated. This may help to explain the variations seen in reports of vividness and detail ratings, as certain groups or individuals may differ in their susceptibility or interpretation of the familiarity of these central and competing features of each memory. As there are still multiple exposures during the checking task this still creates uncertainty and a lack of confidence in memory, as described by Rachman (2002).

Secondly, as discussed in the main empirical paper, older adults are reported to have lower confidence and trust in their memory compared to younger individuals (Wells & Esopenko, 2008). In addition, they have reported to feel increased uncertainty and doubt with age that they have completed certain tasks (Lovelace & Twohig, 1990). Therefore, the higher rates of "knowing" responses found within the current study during the pre-checking trial, in comparison to studies with younger participants, may be indicative of reduced certainty in their memory already held by older participants. Despite this, only two participants within the healthy older adult group shifted from "remember" to "know" responses following repeated 'relevant checking'. This may again be due to a higher perceived sense of central details retrieved and thus a sense of familiarity, as discussed within the competitive trace theory perspective. This would also be consistent with previous research that indicated older adults tended to report more "remember" responses when exposed to similar but not identical objects due to interpreting familiarity from the overlapping object details (Trelle, Henson, Green & Simons, 2017).

The current study highlights that although the theory of checking proposed by Rachman (2002) and Van den Hout and Kindt (2003a) are still applicable and

consistent with some of the results replicated in the current study, more recent theories of memory, such as the competitive trace theory, may provide a deeper understanding on the processing of similar memory events.

Strengths and Limitations

The systematic review was one of the first to be conducted into the prevalence of dementia worry in the general population. The search strategy, exclusion and inclusion criteria ensured that relevant articles were included. The strength of this thorough and robust process is highlighted in articles published prior to 2011 that were not included in the conceptual review by Kessler et al. (2012) but were picked up within the systematic search conducted in this review. The topic of dementia worry is extremely broad, and therefore the review took a single definition of this term for use in the current review. This could be seen as a limitation. Other studies which have investigated this topic using other models and definitions, or as secondary factors in their study were not included in this review. This may mean that alternative aspects of dementia worry may have been missed. However, as this is the first systematic review in this area, certain parameters to unify a subdivision of the literature were required. This enabled the review to provide some conclusions of the presence and correlates of 'dementia worry', as per the agreed definition, amongst the general population.

The empirical research study was based upon a frequently used and effective checking paradigm documented within the literature (van den Hout & Kindt, 2003a; van den Hout & Kindt, 2003b, Radomsky et al., 2006; Radomsky et al., 2014). Further to this, the apparatus used within the study was aimed to increase ecological validity to its target populations, by using a replica stove top and dosette box, which

are more commonly used amongst older populations. However, there were several limitations to the study. As highlighted in the recent meta-analysis of the checking paradigm, the procedure based on previous studies, is not fully counterbalanced. Due to limitations in time and the need for a larger sample size for this it was not undertaken in the current study. However, this is the first study to test the effect of checking in a fully powered sample of older adults. Furthermore, other studies using the fully counterbalanced design have shown the same effect as with the original paradigm. A further limitation is whether the checking paradigm used fully engaged participants in the action of "checking". Some participants within the current study reported to remember the numbers assigned to each hob rather than focusing on the perceptual aspects of the task. Replacing the method of indicating which hobs to be manipulated, removing numbers on the dials, and asking participants whether they turned all the hobs off may reinforce and engage them in the action and more cognitive aspects of "checking". These alterations have been undertaken in some previous studies (van den Hout & Kindt, 2003a; Radomsky et al., 2014), although not routinely, and has not been reported to change the outcome of the paradigm effects. Although these alterations may increase participants focus, they may also reduce the ecological validity of the task. A final limitation of the current empirical study was the small sample of participants recruited with a diagnosis of dementia. The difficulties across the literature in recruiting participants to dementia studies has been discussed in the main paper. Despite this, a method of analysis was able to be utilised to provide some evaluation of findings.

Further strengths and limitations of the individual research studies have been discussed within the respective main papers.

Future Research

The papers within this thesis portfolio have built upon knowledge within the current research base, however, there are several areas where further research is needed.

Despite the implementation of the National Dementia Strategy in the U.K. (DoH, 2009) with the aim to increase awareness of dementia and reduce stigma through campaigns; fear or worry about developing dementia is still highly present among the general population. Furthermore, the NHS has developed a long-term plan to implement more integrated health services, expand community health teams, focus on prevention of ill health, and for healthy ageing and dementia to continue being one of the NHS's health priorities (NHS England, 2019). Thus, further research in this area is needed across several aspects.

Firstly, several studies have used qualitative approaches to assess individuals' perceptions, concerns and fears about potentially developing dementia (e.g. Moniz-Cook, Manthorpe, Carr, Gibson, & Vernooij-Dassen, 2006). However, to the authors knowledge, no systematic review on this literature has been undertaken. Although these may also vary in conceptualisation and approach, synthesising the results of these studies would provide an additional view of 'dementia worry'. This along with the current quantitative systematic review may help to identify the correlates of 'dementia worry', common concerns, and what may contribute to the development of 'dementia worry'. These aspects will be important to understand to reduce dementia worry and any linked negative attitudes or stigma, in addition to supporting clinicians and health campaigns to target key populations or address specific concerns.

Secondly, the variation in methods of assessing 'dementia worry', even when a single conceptualisation is used, makes it difficult to draw unified conclusions from the research. It may also highlight that this single definition is still quite broad in how it can be interpreted. Further exploration to gain more cohesion in our understanding of this concept is still required. Particularly, further research should examine more closely how individuals understand the term and interpret the different variations in questions asked. For example, do people consider worry, fear and concern to address the same concept or distinct aspects.

Finally, Kessler et al. (2012), highlighted the lack of research into the consequences of dementia worry. Seven years after their review this continues to be an area under researched within the literature. Considering the hypothesised perpetuating cycle discussed in this portfolio, more understanding of the psychological and behavioural consequences of those who report high dementia worry would be beneficial. Furthermore, there are contradictions within the literature as to whether fear of developing dementia may increase the likelihood of help-seeking behaviours (Tang et al., 2017). Or whether due to the stigma and negative attitudes held about dementia, this would reduce help-seeking behaviours (Werner, Goldstein, Karpas, Chan & Lai, 2014). Further research into the psychological and behavioural aspects following the reporting of dementia worry may be able to provide some clarification. In addition, investigating these aspects may also provide further indications of maintaining factors and what may help to reduce dementia worry in the general population.

In terms of the checking paradigm, further research is needed to explore the paradoxical checking effect in older adults with and without cognitive impairments. Only two studies to date have explored repeated checking within these populations,

which differed in their findings of familiarity, accuracy, vividness and detail. Each of these studies have only been able to recruit a small sample of participants with MCI or dementia and larger samples are needed to assess these disparities further. These studies do, however, indicate a relationship exists.

As discussed previously, it would be interesting to compare variations of the checking task within older populations to see whether these moderate the effects of checking. For example, variations in the number of checking trials undertaken to assess at what point the paradoxical effect occurs, as previously explored in younger participants by Coles et al. (2006); using a perceptual cue to indicate the hobs to be manipulated; or ensuring visual cues of whether the hobs are off are removed. These adaptations may highlight the strategies older adults use alongside checking as a way of supporting their memory within the task, as well as differences in the processing or perception of familiarity of checking events.

Finally, further research is needed more broadly to assess the efficacy of different memory strategies used in the general population and recommended by practitioners. These studies should be designed with more ecological validity and assess the impact these strategies have on quality of life, self-perception as well as objective memory to fully evaluate the generalisability and effectiveness of these strategies.

Self-Reflection

The aim of this research portfolio was to extend the current knowledge on factors pertaining to memory concerns and strategy use in older adults and those with a diagnosis of dementia. One aim of the empirical paper was to discover whether a similar repeated checking effect, as consistently shown in previous

literature within OCD and undergraduate samples, was found in those with a diagnosis of dementia. However, due to difficulties with recruitment, a full sample of participants was not gained to enable more firm conclusions to be drawn. Despite the effort made to meet with various teams around East Anglia, attend team meetings and service groups, most referrals were received from teams where previous links had been built and more frequent visits were able to be undertaken. This process has shown the need to devote sufficient time into recruitment, as well as getting alongside teams and ensuring the process of identifying potential participants is ideally developed to fit easily within current service processes. These are key learning points that I will ensure to take forward when planning future research endeavours.

Although I was disappointed following the large amount of time and effort spent trying to recruit participants to the dementia group, I was pleased to ascertain a small sample of participants. By using a case-control analysis method, I was also able to assess indications of the effect of repeated checking within this group. Furthermore, I was able to recruit a full sample of 'healthy' older adults from local community groups, from which the results have added to the research base. This has provided me with an experience of the reality of conducting research and the inevitability of needing to compromise or amend research plans. Nevertheless, there are many local community groups that take place in East Anglia for individuals with a diagnosis of dementia, such as dementia cafes and post-diagnostic support groups. An amendment to include these types of groups in the recruitment strategy was considered, but it was agreed that this was not feasible due to time limitations. However, the success of using community groups for the 'healthy' older adult group, has highlighted that these may also be a helpful recruitment site for the 'dementia

group' should this research paradigm be taken forward by future trainee clinical psychologists.

The process of the thesis portfolio has involved learning several new skills particularly within different research methods, applications for REC approval, engaging in discussions with ethics committees, liaising with NHS services for recruitment, and consolidating findings into papers fit for publication. Each of these skills will be hugely beneficial in continuing to develop as a clinical psychologist and scientist-practitioner within the NHS.

Overall Conclusion

Both the systematic review and empirical research study findings have added further knowledge to our understanding of memory concerns and memory strategies within older populations. The systematic review evidenced the high rates of 'dementia worry' reported amongst the general population, with certain demographics experiencing higher levels of worry and fear of developing the disease. There remains vast variation in understanding and assessment of the concept, where further research is needed to provide a more cohesive approach. The empirical paper provided further evidence for the paradoxical effect of repeated checking on memory in older adults, in that checking leads to increased memory doubt. Indications of this effect were also found in older adults with a diagnosis of dementia. As noted throughout, the results should be interpreted with caution due to limitations in both papers. However, the clinical impact and potential excessive disability caused by using checking as a memory strategy in older populations was highlighted, and this calls for current practice on recommended strategies to be revisited. Taken together, these two papers highlight a potential perpetuating cycle

of dementia worry, increased strategy use, and subsequent increased memory concern, which warrants further exploration. Dementia remains a global health priority within an ageing population. The clinical and theoretical implications of these research findings, along with the further identified research directions, build on the current understanding of memory concerns and promote knowledge of effective interventions for older populations with and without cognitive impairment.

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Appendix A

Journal of Psychology & Aging Guidelines

Prior to submission, please carefully read and follow the submission guidelines detailed below. Manuscripts that do not conform to the submission guidelines may be returned without review.

Submission

To submit to the Editorial Office of Elizabeth A. L. Stine-Morrow, please submit manuscripts electronically through the Manuscript Submission Portal in Word Document format (.doc).

SUBMIT MANUSCRIPT

Elizabeth A. L. Stine-Morrow
University of Illinois at Urbana–Champaign
General correspondence may be directed to the Editor's Office.
In addition to addresses and phone numbers, please supply email addresses and fax numbers, if available, for potential use by the editorial office and later by the production office.

Psychology and Aging® is now using a software system to screen submitted content for similarity with other published content. The system compares the initial version of each submitted manuscript against a database of 40+ million scholarly documents, as well as content appearing on the open web. This allows APA to check submissions for potential overlap with material previously published in scholarly journals (e.g., lifted or republished material).

Psychology and Aging® publishes original articles that significantly advance knowledge about adult development and aging. The primary focus of the journal is on reports of novel empirical findings that inform theories related to the psychological science of aging and adult development.

Exceptionally strong articles that present theoretical analyses, systematic reviews, methodological critiques or new methodological approaches, or policy recommendations grounded in psychological science are also welcome.
Studies of basic principles of adult development and aging and their application are appropriate, as are studies about psychological phenomena and processes of special relevance during adulthood and old age.

The journal represents the diversity of topical areas in the psychological science of adult development and aging, including but not limited to, biological bases of behavior, clinical psychology, cognition, cultural and social influences on development, educational psychology, emotion, health psychology, human factors, medical psychology, motivation, neuroscience, personality, and self-regulation.
The journal welcomes rigorous studies regardless of methodological approach (e.g., laboratory-based or field experiments, clinical trials, field studies, naturalistic studies, mixed methods, meta-analyses, or secondary analyses of large datasets).

We especially seek submissions in new areas of inquiry and those that address contradictory findings or controversies in the field, as well as the generalizability of developmental principles to new populations.

Psychology and Aging publishes both regular articles and brief reports.

We deeply value the principles of openness and transparency in science and applaud the progress that has been made in recent years. We encourage investigators to share materials and data, and to preregister their studies, which may include the design, hypotheses, and/or plan for statistical analysis prior to conducting the research. At the same time, we recognize that the processes thus far developed for implementing these principles may be, in turn, impracticable or insufficient in aging research, which often involves longitudinal datasets assembled over decades by multiple investigators.

Authors may choose to make available their data, program code used to analyze data, research materials, and other documentation of the research process by using a trusted digital repository that adheres to policies that make data discoverable, accessible, usable, and preserved for the long term (e.g., Open Science Framework, APA Journal Articles: Data and Related Resources). Trusted repositories assign unique and persistent identifiers (Digital Object Identifier; DOI). If data, program code, materials, and/or other documentation are stored in a repository, the DOI (and a clear description of the contents) should be included in the Author Note.
Authors may also choose to pre-register their studies, which may include the design, hypotheses, and/or plan for statistical analysis prior to conducting the research (e.g., ClinicalTrials.gov, Open Science Framework). If any aspect of the study is preregistered, include the registry link in the Author Note.

Manuscript Preparation

Prepare manuscripts according to the *Publication Manual of the American Psychological Association* (6th edition). Manuscripts may be copyedited for bias-free language (see Chapter 3 of the *Publication Manual*).
Review APA's Journal Manuscript Preparation Guidelines before submitting your article.
Double-space all copy. Other formatting instructions, as well as instructions on preparing tables, figures, references, metrics, and abstracts, appear in the *Manual*.
Additional guidance on APA Style is available on the APA Style website.

Length

Articles

Articles do not typically exceed 8,000 words, excluding references, tables, and figures. Shorter manuscripts are equally welcome.
Articles exceeding the 8,000 word limit may be considered if they offer an especially novel theoretical framework, or complex methodology or statistical approach that requires more extensive exposition.

Brief Reports

The Brief Report format is reserved for particularly "crisp," theoretically noteworthy contributions that meet the highest methodological standards.

Brief reports are typically no longer than 3,500 words, excluding references, tables, and figures, and include no more than two tables or figures.
Papers in this format differ in length from regular articles, but not in rigor.
Below are additional instructions regarding the preparation of display equations, computer code, and tables.

Title Page

The first manuscript page is a title page, which includes a title of no more than 12 words, the author byline and institutional affiliation(s) where the work was conducted, a running head with a maximum of 50 characters (including spaces), and the author note.

Abstract and Keywords

All manuscripts must include an abstract typed on a separate page. After the abstract, please supply up to five keywords or brief phrases.
For regular articles, abstracts are no longer than 250 words; for brief reports, no longer than 100 words.

References

List references in alphabetical order. Each listed reference should be cited in text, and each text citation should be listed in the References section.
Examples of basic reference formats:

- **Journal Article:**
  Hughes, G., Desantis, A., & Waszak, F. (2013). Mechanisms of intentional binding and sensory attenuation: The role of temporal prediction, temporal control, identity prediction, and motor prediction. *Psychological Bulletin, 139,* 133–151. http://dx.doi.org/10.1037/a0028566
- **Authored Book:**
  Rogers, T. T., & McClelland, J. L. (2004). *Semantic cognition: A parallel distributed processing approach.* Cambridge, MA: MIT Press.
- **Chapter in an Edited Book:**
  Gill, M. J., & Sypher, B. D. (2009). Workplace incivility and organizational trust. In P. Lutgen-Sandvik & B. D. Sypher (Eds.), *Destructive organizational communication: Processes, consequences, and constructive ways of organizing* (pp. 53–73). New York, NY: Taylor & Francis.

Figures

Graphics files are welcome if supplied as Tiff or EPS files. Multipanel figures (i.e., figures with parts labeled a, b, c, d, etc.) should be assembled into one file.
The minimum line weight for line art is 0.5 point for optimal printing.
For more information about acceptable resolutions, fonts, sizing, and other figure issues, please see the general guidelines.
When possible, please place symbol legends below the figure instead of to the side.
APA offers authors the option to publish their figures online in color without the costs associated with print publication of color figures.
The same caption will appear on both the online (color) and print (black and white) versions. To ensure that the figure can be understood in both formats, authors should add alternative wording (e.g., "the red (dark gray) bars represent") as needed.
For authors who prefer their figures to be published in color both in print and online, original color figures can be printed in color at the editor's and publisher's discretion provided the author agrees to pay:

- $900 for one figure

- An additional $600 for the second figure
- An additional $450 for each subsequent figure

Additional instructions for equations, computer code, and tables follow:

Display Equations

We strongly encourage you to use MathType (third-party software) or Equation Editor 3.0 (built into pre-2007 versions of Word) to construct your equations, rather than the equation support that is built into Word 2007 and Word 2010. Equations composed with the built-in Word 2007/Word 2010 equation support are converted to low-resolution graphics when they enter the production process and must be rekeyed by the typesetter, which may introduce errors.

To construct your equations with MathType or Equation Editor 3.0:

- Go to the Text section of the Insert tab and select Object.
- Select MathType or Equation Editor 3.0 in the drop-down menu.

If you have an equation that has already been produced using Microsoft Word 2007 or 2010 and you have access to the full version of MathType 6.5 or later, you can convert this equation to MathType by clicking on MathType Insert Equation. Copy the equation from Microsoft Word and paste it into the MathType box. Verify that your equation is correct, click File, and then click Update. Your equation has now been inserted into your Word file as a MathType Equation.

Use Equation Editor 3.0 or MathType only for equations or for formulas that cannot be produced as Word text using the Times or Symbol font.

Computer Code

Because altering computer code in any way (e.g., indents, line spacing, line breaks, page breaks) during the typesetting process could alter its meaning, we treat computer code differently from the rest of your article in our production process. To that end, we request separate files for computer code.

In Online Supplemental Material

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In the Text of the Article

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Appendix B

Quality Assessment Tool

Quality Assessment Tool

(Adapted tool based on The Newcastle-Ottawa Scale (NOS) for Cohort Studies, and the National Institute for Health Quality Assessment tool for Observational and Cross-Sectional Studies).

Research Question: (Maximum 1 star)

1) Was the research question or objective in this paper clearly stated?
   a) Research question and objective defined or stated. *
   b) Research question and objective not described or ambiguous.

Selection: (Maximum 8 stars)

1) Was the study population clearly specified and defined?
   a) Study population clearly defined or stated. *
   b) Study population not described or poorly described.

2) Were all the subjects selected or recruited from the same or similar populations including the same time period)?
   a) Participants recruited from similar population or same time period. *
   b) Participants recruited from different populations or time period, or unable to ascertain.

3) Representativeness of the sample:
   a) Truly representative of the target population. * (all subjects or random sampling)
   b) Somewhat representative of the target population. * (non-random sampling)
   c) Selected group of users.
   d) No description of the sampling strategy.

4) Sample size:
   a) Justified and satisfactory. *
   b) Satisfactory but not justified*
   c) Not justified or justified but not satisfactory.

5) Was the participation rate of eligible persons at least 50%?
   a) Participation rate above 50%. *
   b) Participation rate below 50% or not possible to establish.

6) Non-respondents:
   a) Comparability between respondents and non-respondents' characteristics is established. *
   b) The comparability between respondents and non-respondents is unsatisfactory.

c) The characteristics of the responders and the non-responders are not described.

7) Ascertainment of the exposure (target factor):
   a) Validated measurement tool. **
   b) Non-validated measurement tool, but the method of assessment is available or described. *
   c) No description of the measure or method of assessment, or the measure is not available.

Comparability: (Maximum 2 stars)

1) The subjects in different groups are comparable, based on the study design or analysis.
   a) The study compares groups on main factor. *
   b) The study assesses comparisons for any additional factors. *

Outcome: (Maximum 1 star)

1) Statistical test:
   a) The statistical test used to analyse the data is clearly described and appropriate, and the measurement of the association is presented including probability level (p value). *
   b) The statistical test is not appropriate, not described or incomplete.

References:

Wells, G. A., Shea, B., O'Connell, D., Peterson, J., Welch, V., Losos, M., & Tugwell, P. (2019). *The Newcastle-Ottawa Scale (NOS) for assessing the quality of nonrandomized studies in meta-analysis.* Accessed on 10/05/19 via: http://www.ohri.ca/programs/clinical_epidemiology/oxford.asp.

National Institute of Health: National Heart, Lung and Blood Institute. (2014). *Study quality assessment tools. Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies.* Accessed on 10/05/19 via: https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools.

Appendix C

Demographic Questionnaire

Demographic Information Sheet

Participant ID: Experiment Date:

Gender: Age: Total years of formal education:

Is English your first language? Yes ☐ No ☐

- Do you have normal or corrected-to-normal vision? Yes ☐ No ☐

  If No, please describe: ……

- Do you have difficulty hearing? Yes ☐ No ☐

  If yes, please describe: ……

- Do you have any learning or developmental difficulties? Yes ☐ No ☐

  If yes, please describe: …….

- Do you have any medical conditions? Yes ☐ No ☐

  If yes, please describe: ……..……

  ……

- Housing arrangements:

Living on own ☐ Living with partner/family ☐ Residential ☐ Other ☐

- Please rate your overall health (circle):

1	2	3	4	5	6	7	8	9	10
Very Poor		Poor		Average		Good		Very good	

- Please rate your overall quality of life (circle):

1	2	3	4	5	6	7	8	9	10
Very Poor		Poor		Average		Good		Very good	

If you have a diagnosis of Dementia please also complete these additional questions.

Additional Questions

- What is your diagnosis: …….....
- When were you given this diagnosis:……
- Do you take any medication? Yes ☐ No ☐

  If yes, please state: ……

……

- Are you currently accessing memory/health services for support?
  Yes ☐ No ☐

  If yes, please describe: …….

……..……..

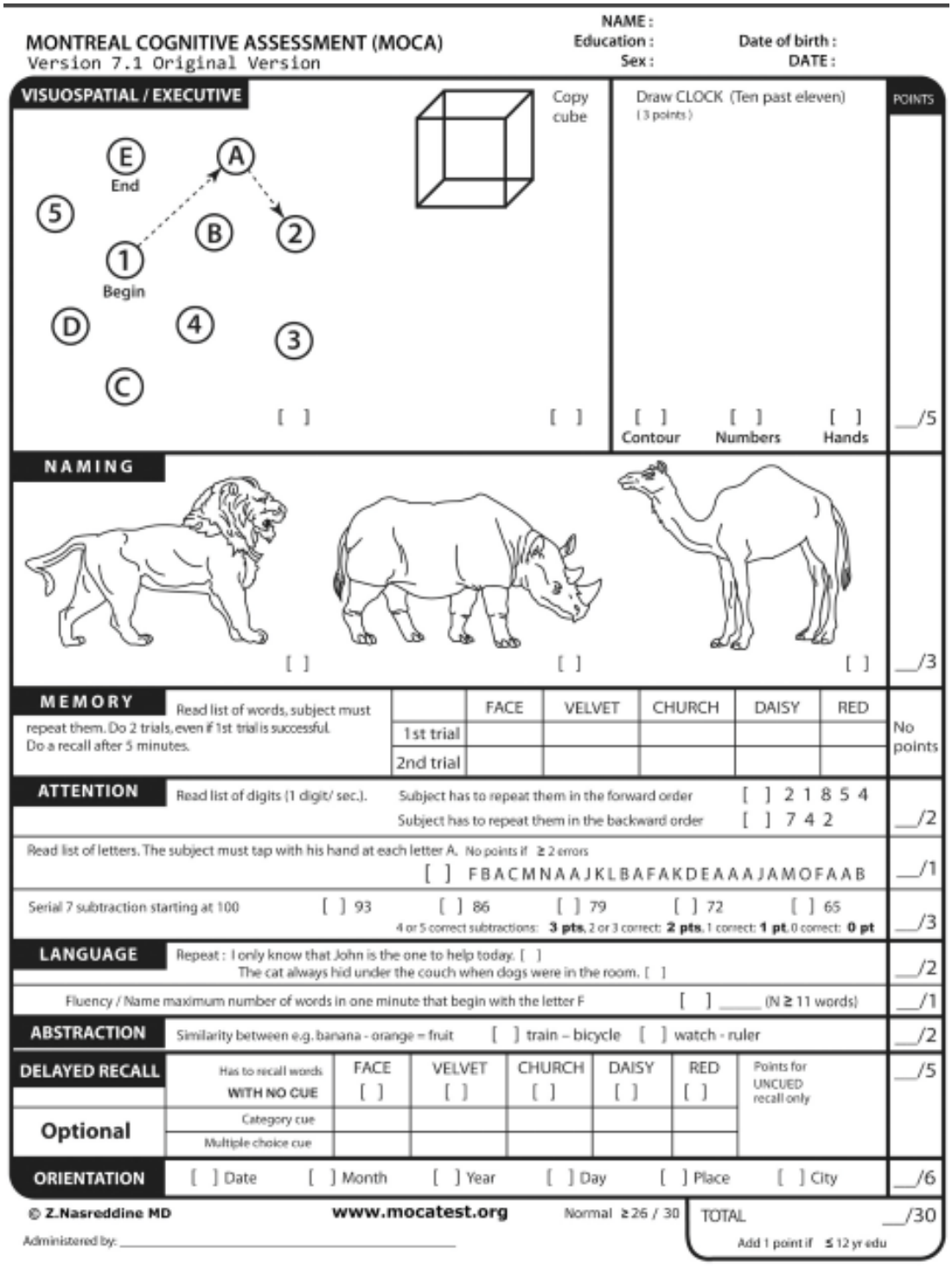
- Do you have social support? (e.g. friends, family) Yes ☐ No ☐

  If yes, please describe: ……...

……..……..

Appendix D

Montreal Cognitive Assessment (MoCA)



MONTREAL COGNITIVE ASSESSMENT (MOCA)
Version 7.1 Original Version

NAME :
Education : Date of birth :
Sex : DATE :

VISUOSPATIAL / EXECUTIVE — POINTS

Copy cube [ ] [ ]

Draw CLOCK (Ten past eleven) (3 points) [ ] Contour [ ] Numbers [ ] Hands __/5

NAMING [ ] [ ] [ ] __/3

MEMORY Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes. — No points

	FACE	VELVET	CHURCH	DAISY	RED
1st trial					
2nd trial					

ATTENTION Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [ ] 2 1 8 5 4
Subject has to repeat them in the backward order [ ] 7 4 2 __/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors
[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B __/1

Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65
4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt** __/3

LANGUAGE Repeat : I only know that John is the one to help today. [ ]
The cat always hid under the couch when dogs were in the room. [ ] __/2

Fluency / Name maximum number of words in one minute that begin with the letter F [ ] _____ (N ≥ 11 words) __/1

ABSTRACTION Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler __/2

DELAYED RECALL

	Has to recall words WITH NO CUE	FACE [ ]	VELVET [ ]	CHURCH [ ]	DAISY [ ]	RED [ ]	Points for UNCUED recall only
Optional	Category cue						
	Multiple choice cue						

__/5

ORIENTATION [ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City __/6

© Z.Nasreddine MD www.mocatest.org Normal ≥ 26 / 30 TOTAL __/30
Add 1 point if ≤ 12 yr edu

Administered by: _____

Appendix E

Five-item Geriatric Depression Scale (GDS)

sagelink.ca
Geriatric eToolkit

5-Item Geriatric Depression Scale [GDS]

5-Item Geriatric Depression Scale [GDS]:		
1. Are you basically satisfied with your life?	**No**	Yes
2. Do you often get bored?	No	**Yes**
3. Do you often feel helpless?	No	**Yes**
4. Do you prefer to stay at home rather than going out and doing new things?	No	**Yes**
5. Do you feel pretty worthless the way you are now?	No	**Yes**
Each bolded answer scores as **1** point. If score is **2** or greater, further evaluation is recommended. ***Score***		

Appendix F

Attitudes to Ageing Questionnaire (AAQ-SF)

University of East Anglia

Norfolk and Suffolk NHS Foundation Trust

NHS Cambridgeshire and Peterborough NHS Foundation Trust

ATTITUDES TO AGEING QUESTIONNAIRE SHORT-FORM (AAQ-SF)

Instructions

This questionnaire asks you how you feel about growing older.

Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in **general**.

For example, thinking how you feel in general, a question might ask:

I dislike growing older

Not at all true	Slightly true	Moderately true	Very true	Extremely true
1	2	3	4	5

You should circle the number that best fits how true the statements are for you. So, you would circle the number 4 if you dislike growing older "Very much", or circle number 1 if you are "Not at all" concerned about growing older. Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

Thank you for your help

The following questions ask **how much you agree** with the following statements. If you agree with the statements an extreme amount circle the number next to "strongly agree". If you do not agree with the statements at all, circle the number next to "Strongly disagree". You should circle one of the numbers in between if you wish to indicate your answer lies somewhere between "Strongly disagree" and "Strongly agree".

1. It is a privilege to grow old.

Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
1	2	3	4	5

2. There are many pleasant things about growing older.

Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
1	2	3	4	5

3. Old age is a depressing time of life.

Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
1	2	3	4	5

The following questions ask **how true** the following statements are for you. If the statement is "Extremely" true for you, circle the number next to "Extremely true". If the statements are not true for you at all, circle the number next to "Not at all true". You should circle one of the numbers in between if you wish to indicate your answer lies somewhere between "Not at all true" and "Extremely true".

4. I don't feel old.

Not at all true	Slightly true	Moderately true	Very true	Extremely true
1	2	3	4	5

5. I see old age mainly as a time of loss.

Not at all true	Slightly true	Moderately true	Very true	Extremely true
1	2	3	4	5

6. I have more energy now than I expected for my age.

Not at all true	Slightly true	Moderately true	Very true	Extremely true
1	2	3	4	5

7. As I get older, I find it more difficult to make new friends.

Not at all true	Slightly true	Moderately true	Very true	Extremely true
1	2	3	4	5

8. It is very important to pass on the benefits of my experiences to younger people.

Not at all true	Slightly true	Moderately true	Very true	Extremely true
1	2	3	4	5

9. I want to give a good example to younger people.

Not at all true	Slightly true	Moderately true	Very true	Extremely true
1	2	3	4	5

10. I feel excluded from things because of my age.

Not at all true	Slightly true	Moderately true	Very true	Extremely true
1	2	3	4	5

11. My health is better than I expected for my age.

Not at all true	Slightly true	Moderately true	Very true	Extremely true
1	2	3	4	5

12. I keep myself as fit and active as possible by exercising.

Not at all true	Slightly true	Moderately true	Very true	Extremely true
1	2	3	4	5

THANK YOU FOR YOUR HELP

Appendix G

Prospective and Retrospective Memory Questionnaire (PRMQ)

REMEMBERING TO DO THINGS

Prospective-Retrospective Memory Questionnaire as described in:

Smith, G., Della Sala, S., Logie, R.H. & Maylor, E.A. (2000). Prospective and Retrospective Memory in Normal Aging and Dementia: A Questionnaire Study. *Memory*, 8, 311-321.

In order to understand why people make memory mistakes, we need to find out about the kinds of mistakes people make, and how often they are made in normal everyday life. We would like you to tell us how often these kind of things happen to you. Please indicate by ticking the appropriate box.

Please make sure you answer all of the questions on both sides of the sheet even if they don't seem entirely applicable to your situation.

Please provide the following details about yourself. Age _____ Male/Female _____

How many year of formal education have you had? _____

Have you suffered from brain or head injury resulting in hospitalisation (Y/N) _____

Please give brief details _____

Please answer all of the questions as accurately as possible.

	Very Often	Quite Often	Sometimes	Rarely	Never
Do you decide to do something in a few minutes' time and then forget to do it?	☐	☐	☐	☐	☐
Do you fail to recognise a place you have visited before?	☐	☐	☐	☐	☐
Do you fail to do something you were supposed to do a few minutes later even though it's there in front of you, like take a pill or turn off the kettle?	☐	☐	☐	☐	☐

	Very Often	Quite Often	Sometimes	Rarely	Never
Do you forget something that you were told a few minutes before?	☐	☐	☐	☐	☐
Do you forget appointments if you are not prompted by someone else or by a reminder such as a calendar or diary?	☐	☐	☐	☐	☐
Do you fail to recognise a character in a radio or television show from scene to scene?	☐	☐	☐	☐	☐
Do you forget to buy something you planned to buy, like a birthday card, even when you see the shop?	☐	☐	☐	☐	☐
Do you fail to recall things that have happened to you in the last few days?	☐	☐	☐	☐	☐
Do you repeat the same story to the same person on different occasions?	☐	☐	☐	☐	☐
Do you intend to take something with you, before leaving a room or going out, but minutes later leave it behind, even though it's there in front of you?	☐	☐	☐	☐	☐
Do you mislay something that you have just put down, like a magazine or glasses?	☐	☐	☐	☐	☐
Do you fail to mention or give something to a visitor that you were asked to pass on?	☐	☐	☐	☐	☐
Do you look at something without realising you have seen it moments before?	☐	☐	☐	☐	☐
If you tried to contact a friend or relative who was out, would you forget to try again later?	☐	☐	☐	☐	☐
Do you forget what you watched on television the previous day?	☐	☐	☐	☐	☐
Do you forget to tell someone something you had meant to mention a few minutes ago?	☐	☐	☐	☐	☐

Appendix H

Checking Task Memory Questionnaire (Version 1.0 24/10/17)

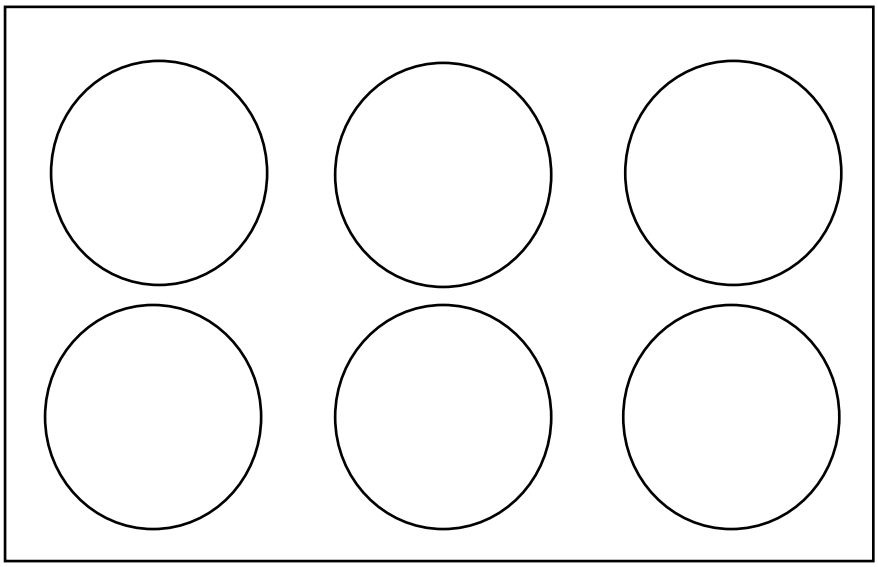
University of East Anglia

NHS Cambridgeshire and Peterborough NHS Foundation Trust

Norfolk and Suffolk NHS Foundation Trust

_____

1. During the last trial please indicate which three hobs you checked and in which order? Please show your answer by writing a '1' on the appropriate hob for the first hob you checked, a '2' for the second hob you checked, and a '3' for the third hob you checked.



2. On a scale of 0-100 where 0 means "not at all" and 100 means "extremely", please rate:

- How confident you are in your answers to question 1? _____
- The vividness of your memory of the last checking trial? _____
  (The intensity or clarity of the memory)
- The detail in your memory of your last checking trial? _____
  (The individual features and visual details of the memory)

3. Please read both definitions below and then tick which one you think best applies to the memory you have of the last checking trial. Please ask if you are unsure about these terms.

☐ ‘Remember’: This means you can directly bring the memory of turning the hobs off to mind and go through the specific details of this memory.

☐ ‘Know’: This means that you do not have a firm memory of the event but have a general sense of knowing that you turned the hobs off.

Appendix I

Participant Information Sheet – Patient Group (Version 3.0 10/07/18)

Participant Information Sheet – Patient Group

Title of Project: Investigating the effects of repeated checking on memory in older adults and those with Dementia.

Name of Lead Investigator: Miss Deborah Green

You are being invited to take part in a research study, which is being completed as part of a degree in Clinical Psychology. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the information carefully and discuss it with others if you wish. Please do ask if you have any questions.

What is the purpose of this study?
This study aims to find out what affect repeated checking has on our memory. Many older adults and those with memory difficulties use checking as a strategy to help remember to do everyday tasks. The results of this study will help us to know whether checking is a helpful or unhelpful strategy to use, especially for those with memory difficulties.

Who is being asked to take part?
We hope to recruit people with and without memory difficulties into the study. One group will be adults aged 60 years and over who have a diagnosis of dementia, either Alzheimer's disease, vascular dementia or mixed dementia. The other group will be adults aged 60 years and over who do not have diagnosed memory problems. Participants must be fluent in English and have no learning difficulties. They should also not have any difficulties with drugs or alcohol or obsessive-compulsive disorder.

What does the study involve?
The study will involve the researcher coming to visit you at home or in a clinic, whichever you prefer. You are welcome to have someone with you during the visit to support you, if you would find that helpful. They will be unable to answer questions for you during the main task, but can be present through the whole session.

During the session, the researcher will firstly go over this information again and give you the opportunity to ask any questions you may have. If you decide to take part you will be asked to complete a consent form and some questionnaires about yourself, your mood, views about ageing, and your memory. Following this, you will be taught how to use the task items, which include a pretend stove top and dosette box. The main task will then involve carrying out a number of checks on either the stove top or dosette box. At certain times in the task you will be asked about your memory for these checks. The whole session should last between one and two hours. We will ensure a break is given, but more breaks can be taken during the session if necessary. You can also stop the session at any time, if you need to do so.

After the study

After the session, you will be asked if you would like to gain feedback on the results of the overall study. You will also be offered the chance to enter into a prize draw to win one of two £25 Marks and Spencer gift vouchers.

Do I have to take part?

Taking part in the study is completely voluntary. If after reading this information, you are still unsure, you can discuss it with others or ask any questions you may have. If you decide to take part, you will be asked to sign a consent form. However, you are still free to change your mind and withdraw from the study at any time, up until data analysis (January 2019), without giving a reason. Deciding not to take part or to withdraw will not affect the care you receive within the NHS.

What are the possible benefits of taking part?

Although there are no direct benefits to taking part in the study, the study will help us learn if checking is a helpful or unhelpful strategy, particularly for those with memory difficulties. This may also help us to reduce any confusion checking may be causing and find more helpful strategies for people to use.

What are the possible disadvantages or risks of taking part?

This study looks at memory, which we know tends to become more difficult as we get older. Some people can find memory difficult to talk about or worry about completing memory tasks. This task has been used before with people with memory problems and no distress or concerns were raised. Therefore, this is unlikely to happen in the current study. However, if you do feel distressed, you can stop the task at any time. We will also ensure that breaks are provided throughout the session. If, following the study, you feel distressed or have any concerns, you can contact the researchers listed at the bottom of this information sheet, your General Practitioner (GP), or your care co-ordinator.

Other support services

Further methods of support are also through local dementia groups, such as:

Alzheimers UK: Support groups, and national helpline offering advice, support and information. Website: https://www.alzheimers.org.uk/. Helpline: 0300 222 11 22.

Dementia UK: The Admiral Nurse Dementia Helpline offers support and advice about dementia. Website: http://www.dementiauk.org/. Telephone: 0800 888 66 78.

Confidentiality

With your agreement we will send a letter to your GP explaining the study and that you have agreed to take part. All information you provide during the study will be kept fully confidential and only accessed by the research team or official regulatory organisations who may be monitoring or auditing the research. However, if during the study there are concerns regarding your safety or the safety of others, this will have to be shared with those involved in your care (e.g. GP), or discussed with the NHS safeguarding team, to help to keep you and others safe.

What will happen to the study results?

The University of East Anglia (UEA) is the sponsor for this study based in the United Kingdom. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The UEA will keep identifiable information about you for 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

The University of East Anglia will collect information from you and your medical records for this research study in accordance with our instructions.

The University of East Anglia will use your name and contact details to contact you about the research study, make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from the UEA and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Cambridge and Peterborough NHS Foundation Trust or Norfolk and Suffolk NHS Foundation Trust will pass these details to UEA along with the information collected from you and your medical records. The only people in the UEA who will have access to information that identifies you will be people who need to contact you to undertake the research or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

All the data collected will be held on a secure password protected device and kept within locked storage facilities. The study will be written up as a thesis project, research paper or presented at conference. It will not identify any specific individuals involved.

You can find out more about how we use your information by contacting Deborah Green on d.green2@uea.ac.uk.

Withdrawal
We would like to emphasize that you can withdraw from the study at any time up until data analysis (January 2019), without explaining why and without your care within the NHS being affected.

Complaints
If you are unhappy with any part of your involvement in the study, please do not hesitate contact one of the researchers at the bottom of this information sheet. We will do our best to address any concerns you have. However, if you would like further advice or to make a formal complaint, you can contact the NHS Patients Advice and Liaison Services. This will not affect any treatment you receive.

Norfolk and Suffolk NHS Foundation Trust contact: PALS Office, Hellesdon Hospital, Drayton High Road, Norwich, Norfolk, NR6 5BE. Telephone: 0800 279 7257. Email: PALS@nsft.nhs.uk

Cambridge and Peterborough NHS Foundation Trust contact: PALS, Elizabeth House, Fulbourn, Cambridge, CB21 5EF. Telephone: 0800 376 0775. Email: PALS@cpft.nhs.uk.

Ethics Committee Approval
All research undertaken in the NHS is checked to ensure participants are kept safe and your rights and well-being are protected. This project has been reviewed by the West Midlands – Black Country Research Ethics Committee.

If you have any questions about the study, please contact a member of the team using the contact details below:

Miss Deborah Green
Clinical Psychologist In-training
Norwich Medical School
University of East Anglia
Norwich
NR4 7TJ
d.green2@uea.ac.uk

Dr Adrian Leddy
Clinical Tutor
Norwich Medical School
University of East Anglia
Norwich
NR4 7TJ
a.leddy@uea.ac.uk

Thank you for your time.

Appendix J

Participant Information Sheet – Control Group (Version 3.0 10/07/18)

Participant Information Sheet – Control Group

Title of Project: Investigating the effects of repeated checking on memory in older adults and those with Dementia.

Name of Lead Investigator: Miss Deborah Green

You are being invited to take part in a research study, which is being completed as part of a degree in Clinical Psychology. Before you decide whether to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please do ask if you have any questions.

What is the purpose of this study?
This study aims to find out what affect repeated checking has on our memory. Many older adults and those with memory difficulties use checking as a strategy to help remember to do everyday tasks. The results of this study will help us to know whether checking is a helpful or unhelpful strategy to use, especially for those with memory difficulties.

Who is being asked to take part?
We hope to recruit people with and without memory difficulties into the study. One group will be adults aged 60 years and over who have a diagnosis of dementia, either Alzheimer's disease, vascular dementia or mixed dementia. The other group will be adults aged 60 years and over who do not have diagnosed memory problems. Participants must be fluent in English and have no learning difficulties. They should also not have any difficulties with drugs or alcohol or obsessive-compulsive disorder.

What does the study involve?
The study will involve the researcher coming to visit you at home or in a clinic, whichever you prefer. You are welcome to have someone with you during the visit to support you, if you would find that helpful. They will be unable to answer questions for you during the main task but can be present through the whole session.

During the session, the researcher will firstly go over this information again and give you the opportunity to ask any questions you may have. If you decide to take part you will be asked to complete a consent form and some questionnaires about yourself, your mood, views about ageing, and your memory. Following this, you will be taught how to use the task items, which include a pretend stove top and dosette box. The main task will then involve carrying out a number of checks on either the stove top or dosette box. At certain times in the task you will be asked about your memory for these checks. The whole session should last between one and two hours. We will ensure a break is given, but more breaks can be taken during the session if necessary. You can also stop the session at any time, should you need to do so.

After the study

After the session, you will be asked if you would like to gain feedback on the results of the overall study. You will also be offered the chance to enter into a prize draw to win one of two £25 Marks and Spencer gift vouchers.

Do I have to take part?

Taking part in the study is completely voluntary. If after reading this information, you are still unsure, you can discuss it with others or ask any questions you may have. If you decide to take part, you will be asked to sign a consent form. However, you are still free to change your mind and withdraw from the study at any time, up until data analysis (January 2019), without giving a reason.

What are the possible benefits of taking part?

Although there are no direct benefits to taking part in the study, the study will help us learn if checking is a helpful or unhelpful strategy, particularly for those with memory difficulties. This may also help us to reduce any confusion checking may be causing and find more helpful strategies for people to use.

What are the possible disadvantages or risks of taking part?

This study looks at memory, which we know tends to become more difficult as we get older. Some people can find memory difficult to talk about or worry about completing memory tasks. This task has been used before with people with memory problems and no distress or concerns were raised. Therefore, this is unlikely to happen in the current study. However, if you do feel distressed, you can stop the task at any time. We will also ensure that breaks are provided throughout the session. If, following the study, you feel distressed or have any concerns, you can contact the researchers listed at the bottom of this information sheet, or your General Practitioner (GP).

Confidentiality

All information you provide during the study will be kept fully confidential and only accessed by the research team or official regulatory organisations who

may be monitoring or auditing the research. However, if during the study there are concerns regarding your safety or the safety of others, this will have to be shared with those involved in your care (e.g. GP), to help keep you and others safe.

What will happen to the study results?
The University of East Anglia (UEA) is the sponsor for this study based in the UK. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The UEA will keep identifiable information about you for 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

The University of East Anglia will collect information from you for this research study in accordance with our instructions. The UEA will make sure that relevant information about the study is recorded for your care and oversee the quality of the study. Individuals from the UEA and regulatory organisations may look at your research records to check the accuracy of the research. The only people in the UEA who will have access to information that identifies you will be people who need to contact you to undertake the research or audit the data collection process. All the data collected will be held on a secure password protected device and kept within locked storage facilities. The study will be written up as a thesis project, research paper or presented at conference. It will not identify any specific individuals involved.

You can find out more about how we use your information by contacting Deborah Green on d.green2@uea.ac.uk.

Withdrawal
We would like to emphasize that you can withdraw from the study at any time, up until data analysis (January 2019), without giving a reason.

Complaints
If you are unhappy with any part of your involvement in the study, please do not hesitate to contact Deborah Green at the bottom of this information sheet. We will do our best to address any concerns you have. If you feel your complaint was not resolved or was not handled correctly, please contact Dr Adrian Leddy who can explain how to make a formal complaint through the university.

Ethics Committee Approval

All research is checked to ensure participants are kept safe and your rights and well-being are protected. This project has been reviewed by the West Midlands – Black Country Research Ethics Committee.

If you have any further questions about the study, please contact either myself or my supervisor using the contact details below:

Miss Deborah Green
Clinical Psychologist In-training
Norwich Medical School
University of East Anglia
Norwich
NR4 7TJ
d.green2@uea.ac.uk

Dr Adrian Leddy
Clinical Tutor
Norwich Medical School
University of East Anglia
Norwich
NR4 7TJ
a.leddy@uea.ac.uk

Thank you for your time.

Appendix K

Consent Form – Patient Group (Version 3.0 22/06/18)

Participant Consent Form – Patient Group

Title: Investigating the effects of repeated checking on memory in older adults and those with a diagnosis of Dementia.

Researcher: Miss Deborah Green

Thank you for taking time to consider participating in this study. Our research depends entirely on the goodwill of volunteers such as yourself. If you have any questions, please do ask and we will be happy to provide these answers.

If you are happy to participate in the current study, please read through the following statements. If you agree with each statement, please write your initials in the box.

1. I confirm that I have read the participant information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time up until data analysis (January 2019), without giving any reason, and without my medical care or legal rights being affected. ☐
3. I understand that all personal information and data gathered during the study will be treated as confidential, kept securely and only accessed by the research team. ☐
4. I understand that relevant sections of my notes and data collected during the study, may be looked at by individuals from UEA, regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
5. I give permission for my GP to be informed of my participation in the study. ☐
6. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Researcher	Date	Signature

Appendix L

Consent Form – Control Group (Version 3.0 22/06/18)

Participant Consent Form – Control Group

Title: Investigating the effects of repeated checking on memory in older adults and those with Dementia.

Researcher: Miss Deborah Green

Thank you for taking time to consider participating in this study. Our research depends entirely on the goodwill of volunteers such as yourself. If you have any questions, please do ask and we will be happy to provide these answers.

If you are happy to participate in the current study, please read through the following statements. If you agree with each statement, please write your initials in the box.

1. I confirm that I have read the participant information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time up until data analysis (January 2019), without giving any reason and without my medical care or legal rights being affected. ☐
3. I understand that all personal information and data gathered during the study will be treated as confidential, kept securely and only accessed by the research team. ☐
4. I understand that relevant sections of my notes and data collected during the study, may be looked at by individuals from UEA, regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
5. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Researcher	Date	Signature

Appendix M

Ethical Approval Letter

NHS
Health Research Authority

West Midlands - Black Country Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

06 July 2018

Miss Deborah A E Green
Cambridge and Peterborough NHS Foundation Trust/ University of East Anglia
University of East Anglia
University Drive
Norwich
NR4 7TJ

Dear Miss Green,

Study title:	**Investigating the effects of repeated checking on memory in older adults and those with a diagnosis of Dementia.**
REC reference:	**18/WM/0152**
Protocol number:	**N/A**
IRAS project ID:	**229987**

Thank you for your letter of 22 June 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will

be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Study advertisement]	2	08 June 2018
Copies of advertisement materials for research participants [Twitter advertisement]	2	22 June 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance and Indemnity Letter]	1	08 March 2018
GP/consultant information sheets or letters [GP Letter]	1	24 October 2017
IRAS Application Form [IRAS_Form_04052018]		04 May 2018
Letter from sponsor [Insurance and Indemnity Letter]	1	08 March 2018
Non-validated questionnaire [Demographic Questionnaire]	1	24 October 2017
Non-validated questionnaire [Checking task memory questionnaire]	1	24 October 2017
Other [Summary of results and Prize draw form]	1	24 October 2017
Other [Cover Letter for REC]	1	22 June 2018
Participant consent form [Consent to Contact Form]	1	24 October 2017
Participant consent form [Consent form - Control Group]	3	22 June 2018
Participant consent form [Consent form - Patient Group]	3	22 June 2018
Participant information sheet (PIS) [Participant Information Sheet - Control Group]	2	22 June 2018
Participant information sheet (PIS) [Information Sheet - Control Group (tracked changes)]	2	22 June 2018
Participant information sheet (PIS) [Participant Information Sheet - Patient Group]	2	22 June 2018
Participant information sheet (PIS) [Information Sheet - Patient group (tracked changes)]	2	22 June 2018
Referee's report or other scientific critique report [Research Proposal Feedback]	1	30 June 2017
Referee's report or other scientific critique report [Research Proposal Amendment Letter]	1	03 November 2017
Research protocol or project proposal [Research Protocol]	3	15 June 2018
Summary CV for Chief Investigator (CI) [Research CV - Deborah Green]	1	24 October 2017

Summary CV for student [Research CV - Deborah Green]	1	24 October 2017
Summary CV for supervisor (student research) [Research CV - Prof Ken Laidlaw]	1	21 June 2014
Summary CV for supervisor (student research) [Research CV - Dr Adrian Leddy]	1	24 October 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Flowchart of procedure]	1	03 November 2017
Validated questionnaire [Geriatric Anxiety Inventory]	1	24 October 2017
Validated questionnaire [Geriatric Depression Scale]	1	24 October 2017
Validated questionnaire [Montreal Cognitive Assessment]	1	24 October 2017
Validated questionnaire [Prospective and Retrospective Memory Questionnaire]	1	24 October 2017
Validated questionnaire [Attitudes to Ageing Questionnaire Short Form]	1	24 October 2017

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

18/WM/0152	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely,

Dr Hilary Paniagua
Chair

Email:nrescommittee.westmidlands-blackcountry@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Ms Sarah Ruthven*
Mr Jim Leadbetter, Cambridge and Peterborough NHS Foundation Trust

Appendix N

Consent to Contact Form (version 1.0 24/10/17)

Norfolk and Suffolk NHS Foundation Trust

University of East Anglia

NHS Cambridgeshire and Peterborough NHS Foundation Trust

Consent to Contact Form

Study Title: Investigating the effects of repeated checking on memory in older adults and those with Dementia.

Researcher: Miss Deborah Green

I confirm I am potentially interested in taking part in the above study and give consent for the researcher to contact me on the details below regarding the study. ☐

Participant Name: _____

Please tick which method of contact you would prefer and the contact details below.

☐ Telephone: _____

☐ Email: _____

Signature: _____

Date: _____

……

For Clinician Use Only

	Yes	No
Is the patient safe to visit at home?	☐	☐
Is the patient safe to be visited by a single clinician?	☐	☐
Do you believe the patient has capacity to agree to take part?	☐	☐