Research Project Portfolio

University of Nottingham

School of Medicine

Mental Health and Clinical Neurosciences

The acceptability and feasibility of a guide for sharing the outcome of a memory assessment.

Short title: Sharing the outcome of a memory assessment.

Annabelle Silvester, BSc (Hons), PGCert

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Statement of Contribution

I. **Journal Paper:**
Annabelle Silvester with supervision from co-author Danielle De Boos

II. **Project design:**
Annabelle Silvester (with supervision from Danielle De Boos and Nima Moghaddam, and advice from clinicians at the hosting service)

III. **Applying for ethical approval:**
Annabelle Silvester (with supervision from Danielle De Boos, Nima Moghaddam and the Innovation and Research Team of the hosting service)

IV. **Recruiting participants:**
Annabelle Silvester arranged with the field supervisor and service managers of the hosting service that MAS administrative staff would disseminate information about the project to patients and companions via letter. Clinicians gained consent for contact details of people who were interested to be shared with Annabelle Silvester. Annabelle Silvester arranged with the field supervisor and the service manager of the hosting service to contact clinicians via a video call about participating in the study.

V. **Data collection:**
Annabelle Silvester with help from Memory Assessment clinicians at the hosting service.

VI. **Transcription:**
University of Nottingham Automated Transcription Service.

VII. **Data analysis:**
Annabelle Silvester (with supervision from Danielle De Boos and Nima Moghaddam)

VIII. **Write up:**
Annabelle Silvester (with supervision from Danielle De Boos and Nima Moghaddam)

Journal paper

Abstract

How outcomes of assessments for dementia are communicated is a challenging task to navigate for clinicians, patients, and their companions. Miscommunication can result in negative consequences for health-related outcomes including reduced self-esteem and loss of meaningful roles. Interventions to support communication specific to the diagnosis of dementia are required. A prototype intervention has been developed aiming to promote good practice in Memory Assessment Services. This mixed methods project assessed the acceptability and feasibility of a trial to evaluate effectiveness of the intervention. Framework analysis was used following interviews with five clinicians to produce themes relating to the constructs identified in the Theoretical Framework of Acceptability (affective attitude, burden, ethicality, intervention coherence, opportunity costs, perceived effectiveness, self-efficacy). Clinicians reported good acceptability of the intervention and willingness to adopt the intervention into their practice. The recruitment strategy was not feasible for patients and companions and therefore acceptability of the intervention was not assessed from their perspective. Explanations for poor recruitment are explored. An alternative study design to investigate the effectiveness of the intervention is required.

Introduction

An estimated 885,000 people are currently living with dementia in the UK, which is predicted to rise to 1.6 million by 2040[1] (Wittenberg et al., 2019). Early diagnosis of dementia has provided several advantages for individuals and those around them (Dubois et al., 2016) including improved management of symptoms, reduced need for institutionalisation, lower anxiety, and improved quality of life (Werner et al., 2013). Growing efforts to increase early identification of dementia exist as a result of the Prime Minister's Challenge on Dementia[2] (Department of Health, 2015); however, the quality of people's experiences of the diagnostic process has been questioned with individuals reporting dissatisfaction with information provided to them about their diagnosis (Low et al., 2019) alongside negative experiences of how diagnoses are

[1] See extended introduction section 1.1 if or details of dementia.
[2] See extended introduction section 1.2.1 for details of the dementia care pathway in the UK.

delivered (British Psychological Society, 2014). The Department of Health (2009) produced guidelines stressing the importance of delivering a diagnosis in a supportive manner but no information on how this could be achieved was included; additionally, there is limited reference to this aspect of care in the National Institute for Health and Care Excellence (NICE) (2018) guidelines. The challenging nature of communicating a diagnosis of dementia is identified by the Division of Clinical Psychology (2016) who highlight the role of psychological input in developing and maintaining a sensitive, person-centred approach to this communication.

Clinicians communicating diagnosis of dementia report finding the process emotionally demanding and have had little access to relevant training and supervision (Bailey et al., 2019). Concerns over stigma, the best interests of service users, and the triadic nature of discussions where family members/carers are included have been highlighted (Phillips et al., 2012). Lecouturier et al., (2008) identified the need to tailor the communication of dementia diagnosis to meet the needs of the person and their companion. However, the expectations of different stakeholders are often different, making triadic discussions harder to navigate for clinicians (Karnieli-Miller et al., 2012). Patient centred communication that gives people clear information about their diagnosis is not being routinely offered in practice (Zaleta & Carpenter, 2010; Low et al., 2019)

Patient and companions often experience high levels of distress, particularly in the lead up to appointments with memory assessment services (Cahill et al., 2008). The diagnostic process is a time of ambivalence and uncertainty for patients (Nielsen and Boenick, 2021) and for companions that can result in feelings of nervousness whilst they are under-going assessments (Gruters et al., 2021). Awareness and appraisal of dementia is thought to have a significant impact on the emotional response to a diagnosis (Aminzadeh et al., 2007), which in turn is impacted on by the social and psychological context in which the person exists (Pratt & Wilkinson, 2003)[3]. Some people experience resistance to new information as a means of coping with the

[3] See extended introduction section 1.3.1 for consideration of adjustment to a diagnoses of dementia.

distress they feel about the potential of having dementia, which in turn impacts their engagement with support post-diagnosis (Bunn et al., 2012).

The consequences of poor communication of a dementia diagnosis can be significant. The point of disclosure is key in the development of feelings of disempowerment experienced by people with dementia (Low et al., 2018). Swaffer (2015) described how poor communication during diagnosis generates feelings of hopelessness, reduced self-esteem, and a loss of previously meaningful roles.

Increased levels of satisfaction with healthcare consultations have been found when there is a match between the expectations and involvement of the individual with those of the clinician during consultations (Campbell et al., 2007). The relationship between positive experiences of consultations with improved health outcomes has been established with several patient groups with physical health diagnoses other than dementia. The role of empathy (Mercer et al., 2004) and instilling a sense of hope and compassion (Fogarty et al., 1999) in consultations is associated with improved health outcomes including reduced anxiety, better treatment compliance, and increased functioning (Kaplan et al., 1989). Zachariae et al., (2003) found clinician attentiveness and empathy were associated with increased satisfaction and self-efficacy as well as reduced emotional distress following consultations. Clinician empathy during consultations has been found to be associated with improved health outcomes (Mercer et al., 2016). The relationship between improved perceptions of empathy and increased enablement suggests a potential mechanism through which health outcomes benefit from improved patient-clinician communication (Mercer et al., 2008)[4].

Protocols and interventions for delivering bad news[5] in other health settings have been developed (Baile et al., 2000; Narayanan et al., 2010). Poyser & Tickle (2019) highlight

[4] See extended introduction section 1.5 for details of patient satisfaction and empathy.
[5] See extended introduction section 1.4 for details of breaking bad news.

the need for evidence-based guidance for clinicians that address the unique requirements of the disclosure of a diagnosis of dementia. Cognitive deficits, and the triadic nature of the communication of dementia diagnosis through inclusion of companions in consultations, means that these interventions are inadequate for communicating a diagnosis of dementia (British Psychological Society, 2014). Bennett et al., (2019) developed a prototype intervention that supports good practice. The intervention is based on clinician, patient, and companion experiences of the important features of an outcome consultation in Memory Assessment Services in the UK and identifies key behaviours of good practice for consideration when communicating a diagnosis of dementia. Initial feedback from service users and their companions suggests this intervention has potential for improving practice. Further work is required to evaluate this intervention in relation to its acceptability for patients, companions, and clinicians and to establish if it is effective in developing good practices. The aim of this study is to conduct preliminary work considering the acceptability of the intervention and the feasibility of further evaluation of its effectiveness.

Table 1 provides an overview of key terms used within this study. Throughout, the intervention being evaluated is referred to as ‘the guide’. This term was selected following consultation with service users during the development of the protocol for this study, who preferred this to the original term ‘tool’ utilised by Bennett et al., (2019).

Table 1. Key Terms

Term	Definition
Memory Assessment Service (MAS)	A service with the purpose of assessing people for signs of cognitive deficits and determining diagnosis of dementia
Patient	Person under-going assessment by a Memory Assessment Service
Companion(s)	A person or people supporting and attending appointments with patients
Clinician	Healthcare professionals working in MAS
Initial Assessment	The first appointment attended by a patient (and companion) where information about the patient is gathered
Outcome Appointment	An appointment where the conclusions of assessments are shared with patients (and companions)
Triad	A term used to refer to the three parties usually involved in outcome appointments (clinician, patient, companion)
Dyad	A term used to refer to the patient and their companion

Method

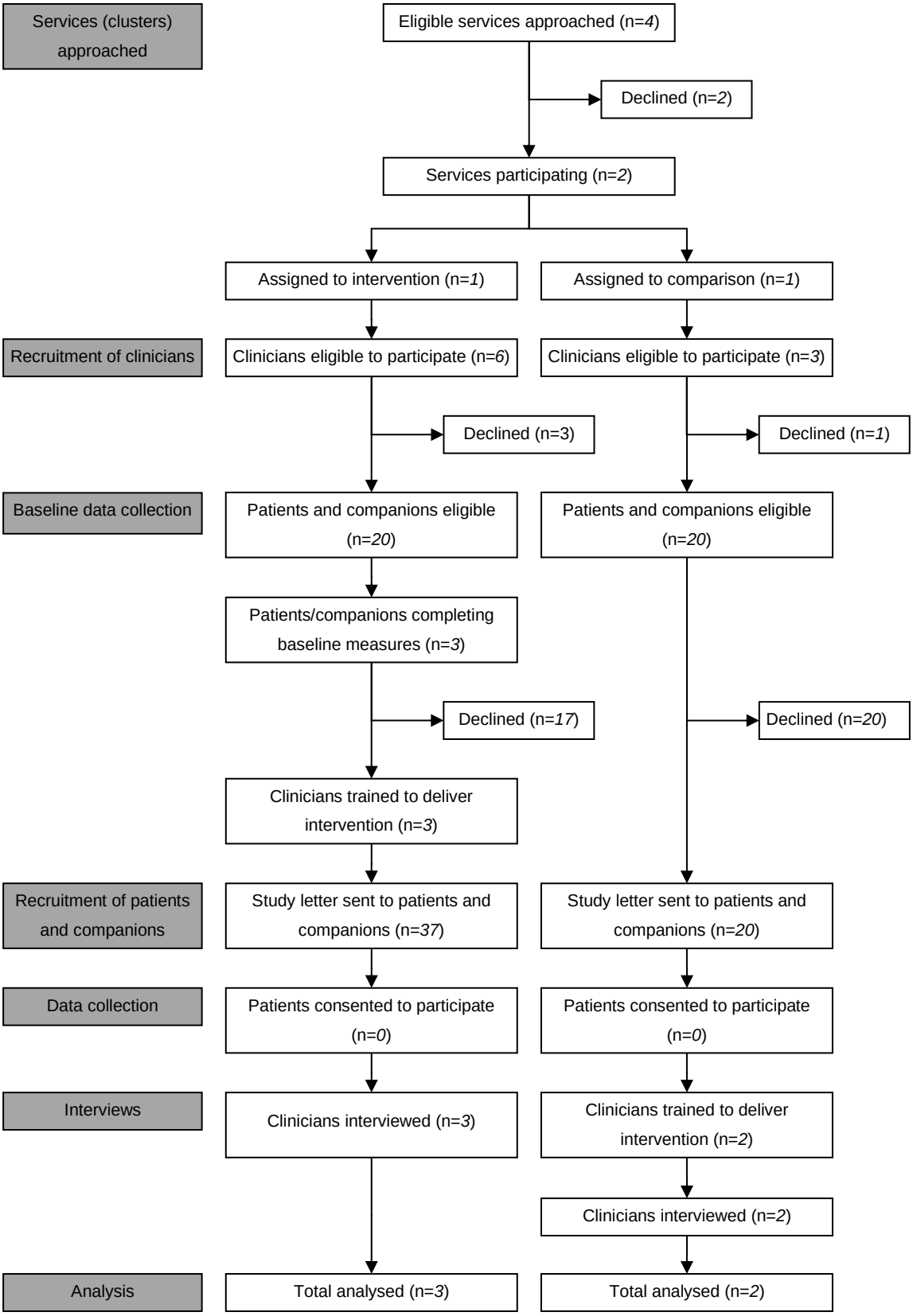
Design

See Figure 1 For Consolidated Standards of Reporting Trails CONSORT diagram of participant flow through the study.

A qualitative study and evaluation of the process of taking part was carried out in parallel to a feasibility trial. Acceptability of the guide was measured through semi-structured interviews with clinicians who had not been involved in the guide's development. Clinicians in both aspects of the study took part in these interviews. Ethical approval was sought from the Brighton and Sussex Research Ethics Committee (approval number: 21/LO/0214). For copies of the HRA ethics approval letter and Research and Innovation approval letter see appendices A-B. All participants gave written informed consent for their data to be used in the study, including the use of quotations.

Figure 1

CONSORT diagram to show flow of participants through the study



A mixed-methods, non-randomised, controlled, feasibility design trial was used to compare participants in a service using intervention informed practice with a matched service providing usual care.

Participants

Eligibility Criteria

All patients and companions attending an initial assessment appointment with the two participating MAS services during the recruitment period were invited to take part . Full criteria are presented in Table 2.

Table 2

Inclusion and exclusion criteria

Participant	Inclusion Criteria	Exclusion Criteria
Patient	Taking part in an initial assessment appointment with the participating MAS services	Not fluent in English
	Aged 18 years or over (The participating MAS require patients to be 65 years or over to be eligible for referral. There was no upper age limit)	Reason to doubt their capacity to give informed consent under the Mental Capacity Act 2005.
	Able to provide written informed consent	
Companion	Supporting a patient-participant to attend a MAS initial assessment appointment	Not fluent in English
	Aged 18 years or over	Reason to doubt their capacity to give informed consent under the Mental Capacity Act 2005.
	Able to provide written informed consent	
Clinician	Involved in the delivery of MAS outcome appointments	
	Able to provide written informed consent	

Setting

Memory Assessment Service (MAS) clinicians were approached to take part in the study in two of the four service locations in the county where the service is based. New patients referred to MAS in the participating services, who were due to have an appointment with participating clinicians, were also invited to take part, along with their companion(s).

Clinician Recruitment

All clinicians working in the two MAS teams taking part in the study, who conduct outcome assessments communicating the conclusions of patient assessments were invited to participate. An online meeting was held with all team members introducing the study and explaining what involvement would require. Individual clinicians contacted the research team via email to express their interest in participating.

Patient and Companion Recruitment

All patients and companions who were due to be seen for an initial assessment during the recruitment period were invited to attend via letter which included a participant information sheet. Clinicians then discussed their participation during the initial assessment appointment and collected written informed consent. The recruitment procedure was the same for baseline data collection as well as participation in the second stage of the study. Participants in the baseline cohort provided implied consent by returning completed questionnaires.

Allocation

Participants were assigned to the intervention or usual care group using cluster sampling according to the geographical location of the service they work for or to which they were referred. Two geographically distinct teams were chosen to form each arm of the study. The introduction of the intervention in one team reduced the risk of

contamination of changed practice between clinicians working closely together. The intervention arm was in the largest of the two teams to reduce the recruitment burden on individual clinicians.

Intervention

The Guide to Dementia Diagnostic Delivery[6]

The Guide to Dementia Diagnostic Delivery (Bennett et al., 2019) was developed in conjunction with clinicians, patients and companions with experience of MAS. The guide supports clinicians to provide consultations aligned with best practice when sharing the outcomes of dementia assessment. The guide consists of two sections: a section for clinicians conducting memory assessments and sharing the outcomes with patients and companions; the second is for patients who are being assessed for dementia, with a sub-section for their companion. Copies of both sections of the guide are located in Appendices C and D.

Baseline Measurement

The Consultation and Relational Empathy (CARE) questionnaire (Mercer et al., 2004) was used to collect baseline data for the two sites – for a detailed description of the measure, see the 'Outcomes' section. Baseline data was obtained from consenting patients and their companions who were attending initial assessment appointments within a period of six weeks with any participating clinicians. This allowed for a comparison of any score improvements that could be attributed to the intervention. Patients and companions were provided with a stamped addressed envelope to return their questionnaires to the research team. They completed the questionnaire not in the presence of the clinician. Participants were asked to complete the questionnaire as soon after the appointment as possible.

[6] See extended method Section 2.4 for description of the Bennett et al., (2019) guide.

Usual Care Procedure

Clinicians conducted their initial assessment and outcome appointments according to their usual practice which includes assessment of patient's cognitive abilities, daily functioning, and physical health to determine the possibility of them having a dementia. Outcome appointments require clinicians to rely on their professional judgement of the best way for the outcomes of assessments to be communicated to patients and their companions. No standardised guidelines were used within the service for this purpose.

During initial assessment appointments, patients and companions were asked by clinicians if they wanted to take part in the study. Written consent was obtained during the appointment. Participants were asked to complete the CARE questionnaire and return to the research team using a stamped addressed envelope that was provided. Patients were asked to complete the questionnaire as soon as possible after the end of the appointment.

For patients who consented, the outcomes of standardised assessments conducted by MAS clinicians were collected digitally from patient records. A list of standardised assessments used in the participating MAS are outlined in Table 3.

Table 3

Assessments used by MAS service.

Title	Acronym	Description
Addenbrookes Cognitive Assessment III (Hsieh et al., 2013)	ACE III	A brief cognitive test assessing five cognitive domains. Commonly used to screen for cognitive deficits in memory assessment services.
Health of the Nations Outcome Scale 65+ (Burns et al., 1999)	HoNOS 65+	A scale used to rate the mental and social health of older adult mental health service users.
Bristol Activities of Daily Living Scale (Bucks et al., 1996)	BADLS	A questionnaire developed to measure the ability of someone with dementia to carry out their usual daily activities.
Mini Mental State Examination (Folstein et al., 1975)	MMSE	A questionnaire used to measure cognitive impairment. Often used to screen for dementia.

Intervention procedure

The intervention procedure followed the same steps as the usual care procedure with the addition of use of the Bennett et al. (2018) guide for clinicians, patients, and companions. Following baseline data collection, clinicians involved in the intervention arm of the study received training on how to use the guide to inform their approach to consultations with participating patients and companions. Clinicians received copies of the clinician, patient and companion sections of the guide and were asked to spend time looking at the materials. Online training was delivered to each clinician providing an outline of the guide as well as instructions on how to use it with patients and companions and answer questions clinicians had about its use. A 30-minute online training session with the primary researcher allowed discussion on how to use the guide and gave an opportunity for questions to be answered.

A written copy of the patient and companion section of the guide was provided to all patients and companions no less than one week prior to their initial assessment appointment along with a written explanation about the nature of the study. It was explained that spending time prior to the appointment completing the relevant sections of the guide would be required to participate in the study. Clinicians then conducted their initial assessments using the guide to support conversations with consenting participants.

When conducting outcome appointments with those patients and companions who had consented, clinicians used the guide to inform communication. Appointments were carried out in the patients' homes or remotely via video technology. One clinician met with the patient and their companion(s) for each appointment; usually, the same clinician would then conduct the outcome appointment. Audio recordings of a sample of guide facilitated consultations were made to assess clinician fidelity to the intervention. Both sections of the guide were used for comparison against audio recordings to establish if all topics suggested were covered during discussions.

Interviews

Interviews were conducted with all clinicians who had taken part in the first stage of the study. Clinicians who were in the usual care arm of the study were introduced to the guide prior to the interviews. Interviews were conducted via Microsoft Teams and were recorded and transcribed. Interviews ranged between 23 and 47 minutes.

Outcomes

Interviews

An interview topic guide was developed using the Theoretical Framework of Acceptability (TFA) (Sekhon, 2017). The topic guide explored acceptability of the guide for clinicians as well as questions about feasibility of the study design and clinician's experiences of taking part (Appendix E). The TFA was developed in recognition that

acceptability of healthcare interventions is important but there was no theory-based guidance available to inform approaches (Sekhon et al., 2017). The TFA is a multi-construct theoretical framework that provides a systematic means of assessing the acceptability of healthcare interventions; it defines acceptability as “a multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses to the intervention” (Sekhon et al., 2017,p.4). The TFA includes seven component constructs that contribute to the acceptability of interventions (Table 4). Use of these constructs have been found to result in a more detailed assessment of acceptability compared to when being asked general questions about acceptability (Sekhon et al., 2016). The seven constructs were therefore used to inform the *a priori* deductive codes through inclusion in the interview guide.

Table 4

Overview of TFA Domains (adapted from Sekhon et al. 2017)

Component	Definition
Affective Attitude	How an individual feels about the intervention.
Burden	The perceived amount of effort that is required to participate in the intervention.
Ethicality	The extent to which the intervention has good fit with the individual's value system.
Intervention Coherence	The extent to which the participant understands the intervention and how it works.
Opportunity Costs	The extent to which benefits, profits or values must be given up by engaging in the intervention.
Perceived effectiveness	The extent to which the intervention is perceived as likely to achieve its purpose.
Self-efficacy	The participant's confidence that they can perform the behaviour(s) required to participate in the intervention.

Patients and companions were invited to participate in similar interviews to explore acceptability of the guide and their experiences of taking part in the study, including their thoughts on the use of the CARE as a measure with reference to burdensomeness and relevance.

The CARE questionnaire

The CARE questionnaire (Mercer et al., 2004) was used at baseline and at initial assessment and outcome appointments to provide a measure of empathy in the context of the therapeutic relationship during consultations between clinicians and patients. The CARE is a 10-item questionnaire which has good psychometric properties including high internal reliability (Cronbach's alpha α= .94) and construct validity (r= .70) (Mercer & Murphy, 2008). Scores range from 10 to 50, with higher scores suggesting high levels of clinician empathy. An adapted version for companions was developed for this study changing the language to acknowledge the relationship between the companion and clinician. Please see Appendix F and G for both versions of the CARE used.

Feasibility

Feasibility of recruitment to the study was established by comparing the number of people who were eligible to take part in the study with the number of people who were recruited. This was conducted for patients, companions, and clinicians.

Sample size

All clinicians participating in both the intervention and usual care arms of the study were interviewed to inform understanding about the acceptability of implementing the study procedures. This interview was also be used to explore the acceptability of the intervention from the perspective of MAS clinicians who were not involved in the development of the guide.

The study aimed to collect quantitative data from 12 patients and their corresponding companions who were recruited to each condition of the study. As the feasibility of future research is an aim of this study, it was not possible to recruit enough participants to detect the effect size of the intervention. Julious (2005) suggests a sample

population of 12 is enough to inform the feasibility of trial outcomes and provide sufficient precision for preliminary parameter estimates including an estimate of variance from which future sample size calculations could be made.

Six patients and their corresponding companions took part in semi-structured interviews to gather qualitative data. Braun and Clarke (2013) state for small sized studies, 6-10 participants is recommended as this provides enough data to identify patterns. Guest et al., (2006) identified that broad themes can become apparent after six interviews and by 12 interviews, saturation has been achieved. Thorne (2020) has questioned the convention of identifying saturation after reaching a pre-identified number of interviews prior to the collection of data as it is often used as a defence for concluding data collection, rather than for its original purpose of the development of theories. This suggests that six patients from each condition were sufficient to provide data on the acceptability of the intervention – particularly given the focussed nature of these interviews in addressing narrow acceptability and feasibility questions.

Data analysis

A summary of data analysis is presented in Table 5.

Qualitative data analysis

A framework method, as set out by Ritchie and Spencer (1994), was used to generate themes. This approach provided a systematic approach to thematic analysis that used the development of a coding framework, usually done a priori, based on previous theory of research but also allows for inductive codes to be developed based on the data collected (Barker et al., 2016). The steps outlined by Ritchie and Spencer (1994) were followed: familiarisation, identifying a thematic framework, indexing, charting and mapping and interpretation. A transcription service was used to transcribe interviews. Following familiarisation with the data, each transcript was coded by a researcher (AS). Discussion and consensus on these codes was then reached by the research team and a coding framework was developed both deductively, using the TFA, and

inductively, to identify other themes that emerged regarding acceptability of the guide and feasibility of the study procedure. All transcripts were then indexed using the framework. Codes were grouped to form descriptive themes and following discussion with all researchers these were developed into analytic themes. All participants were given a pseudonym to retain anonymity.

Quantitative data analysis

Each care episode accounted for one case. Therefore, patients and their companions were not considered independent participants; their outcome data contributed to one case. Statistical Package for the Social Sciences (SPSS) was used to manage and analyse quantitative data. To avoid over-representation of care episodes cases, including patient and companion, data had their weighting adjusted to allow for this.

Quantitative analysis was descriptive giving confidence interval estimation. Baseline measures were collected for each location allowing estimates of the variability between the two sites for comparison. Intra Class Correlations (ICCs) were carried out to examine the degree of clustering. Intention to Treat (ITT) analysis was conducted to give a more accurate estimate of effectiveness in clinical practice. Participants data were analysed based on their experimental arm allocation. Viability of recruitment was assessed using eligibility and consent rates for patients and clinicians. The burden of measure completion was assessed through missing data levels as well as interviews with patients and clinicians. Withdrawal rates post consent were calculated by study arm for use in future sample size calculations.

Table 5

Data Analysis Summary.

	Question	Data	Analysis
1	Acceptability of the intervention	Semi-structured interviews with patients/companions and clinicians	Framework Analysis
		Drop-out rate (for each arm)	Frequencies/percentages
2	Feasibility of the study	Semi-structured Interviews	Framework Analysis
	Fidelity to the intervention	Audio recordings of outcome appointments	Fidelity rating against items included in the guide
	Feasibility/burdensomeness of measures	Missing CARE data	Percentage
		Feedback interviews	Framework Analysis
	Feasibility of recruitment	Number of referrals to the service that are eligible during recruitment period	Frequencies/percentages
		Number of people who consented to take part	Frequencies/percentages
		Number of eligible clinicians	Frequencies/percentages
		Number of clinicians who consented to take part	Frequencies/percentages
3	Informing future study-sample size estimates	Variability estimates for CARE scores	Standard deviations, range and inter-quartile range
		Withdrawal rates for each arm of the study	Frequencies/percentages
		ICCs	To be determined based on distribution
4	Preliminary effect size estimate	CARE scores SD, group means	Effect size calculation

Results

Aim 1. Acceptability of the guide to dementia diagnostic delivery

Participants

Clinicians[7]

Clinicians (*n=5)* from both arms of the study consented to take part in the study, usual care (*n*=2) and intervention (*n*=3). Table 9 provides percentage recruitment rates. All consenting clinicians were female and Registered Mental Health Nurses (RMN) who had between 1.5 and 15 years-experience working in dementia assessment services. Those that did not consent to take part included psychiatrists (*n=3)* and RMNs *(n=2)*. Additionally, all clinicians who consented to take part in the study also consented to take part in a semi-structured interview focussing on the acceptability of the intervention and the feasibility of the study procedure.

Patients and companions

No patients or companions were recruited in either arm of the study. It was therefore not possible to collect data regarding acceptability of the intervention or the study procedure from the perspective of the patient or companion.

[7] See section 2.1 for details on attempts to recruit clinicians

Framework Analysis using Sekhon's Theoretical Framework of Acceptability (2017).

Framework analysis identified deductive themes relating to each of the seven constructs included in the TFA[8]. Subthemes identified within each domain were identified inductively. Inductive themes relating to acceptability were also identified. Table 6 summarises deductive themes, with themes analysed inductively relating to acceptability of the guide summarised in table 7.

[8] See Extended Results 2.8 for further information on Framework Analysis

Table 6

Summary of themes and subthemes for acceptability from deductive analysis

Domain and definition	Theme/Subtheme	Findings
Affective attitude *"how an individual feels about the intervention" (prospective)*	**Positive feelings about the guide**	**Positive feelings about the guide** *"As a clinician looking at the guide, I thought it was actually a good tool. A really excellent tool" (Paige).* *"What I liked about it was that it was, um, quite um. Sort of simple, really. I felt it was very user friendly" (Iris).* *"I suppose it was quite reassuring in a way that some of what I was reading was the stuff that we were doing already because you think ah! we're probably doing OK" (Nicole).*
Burden *"the perceived amount of effort that is required to participate in the intervention"*	**The amount of information is too much and might put off patients and companions**	**The amount of information is too much and might put off patients and companions** *"So, you find that reading anything other than the appointment and just knowing that [the nurse] is coming here at 10:30. It's more important to them than any other thing that's put in" (Paige).* *"It's a really hard situation, isn't it? You know when people are living with dementia and you know, possibly*

Domain and definition	Theme/Subtheme	Findings
		struggle with, you know big forms and stuff like this" (Emma). *"I'd rather have you know bullet points. You know, this is what you've got to do, whereas obviously within the guide it was paragraphs and stuff like that, which I did find quite difficult to manage" (Emma).*
Ethicality *"the extent to which the intervention has good fit with an individual's value system"*	**Clinician practice is enhanced**	**Clinician practice is enhanced** *"…the diagnosis is for them and um and it's about sometimes it's about me as a clinician…helping them to make choices that they want to make with their carers or relatives being present cause they might have a different definition of what… mum or dad should or shouldn't be doing" (Iris).* *"Um, yeah I liked that section, giving them ownership of their diagnosis and allowing them to discuss and explore what choices they have to make really and not being made for them" (Iris).* *"It's quite nice that you acknowledge that it is very tiring process, and we are only given an hour for…disclosures" (Paige).* *"I always think to myself if I ever went in thinking oh, she's another person that I've gotta tell, you know, tell*

Domain and definition	Theme/Subtheme	Findings
		them they've got dementia…I wouldn't be, you know, I probably wouldn't be doing the best job" (Nicole).
	Finding a balance between honesty, autonomy and harm	**Finding a balance between honesty, autonomy and harm** *"I worry that you know, if we don't share the outcome with the patient, somebody is going to slip up eventually and tell them. And that's going to be really distressing for them" (Emma).* "*The person not knowing or wanting to know, because that could be a challenge for us..[not wanting to] know the outcome sometimes because of implications around say for example driving, it can make it really, really tricky to actually not give a person their results, but at the same time ensure that they're safe on the road"(Nicole).* *"It gives them some information because information is power, isn't it? You know it's empowering because… they come to the appointment, but they don't really know what they come in to. Whereas if it's laid out for them…this is what the memory assessment will take…this is what happens with the information that we…take. I think would be really good for the patient" (Edie).*

Domain and definition	Theme/Subtheme	Findings
Intervention Coherence *"the extent to which the participant understands the intervention and how it works"*	**Linking the initial assessment and outcome appointments helps clinicians to share the diagnosis of dementia**	**Linking the initial assessment and outcome appointments helps clinicians to share the diagnosis of dementia** *"I suppose I'd only need to read my one to know what it is that the other person…the patient, and the relative have been asked to…you know, consider or think about the information that they have because the one that I had summarised that" (Nicole).* *"…maybe they've highlighted a concern which we could bring back to the diagnosis meeting with an answer or a solution or possible ideas we could throw about. So, I think that you know it could help with our outcome. As I said to talk about it raise questions, you know that were at the beginning, so that sort of so that they feel a bit more that the diagnosis meeting is a bit more, um complete" (Edie).*
Opportunity Costs *"the extent to which benefits, profits or values must be given up to engage in the intervention"*	**The guide is easy for clinicians to use**	**The guide is easy for clinicians to use** *"I can't see that it would be like it's too much paperwork… because it isn't really, it's only it's really, paperwork is really for the patient and the relative" (Edie).* *"It was quite wordy, but I thought once you got to the grasps of it…then it was quite easy to follow and it just… sort of flowed" (Emma).*

Domain and definition	Theme/Subtheme	Findings
Perceived Effectiveness *"the extent to which the intervention is perceived as likely to achieve its purpose*"	**The guide helps to manage expectations of the memory assessment process**	**The guide helps to manage expectations of the memory assessment process** *"When you actually sit down as a family and you read what's going to happen, at your appointment. What tests we do. You know it. It makes it clearer to them. Well before I even come into their house to know that this is what this lady's is coming to do" (Paige).* *"I've worded it in so many different ways for people, but you know a lot of the time it doesn't matter how you word it; it's still got that massive impact on people. And unfortunately, I just don't think the guide can change that" (Emma).*
	The guide's impact on the assessment and outcome sharing process	**The guide's impact on the assessment and outcome sharing process** *"I think it probably would be of benefit because as I said, I do come across, not often, but I do come across people who can't talk in front of their relatives. Who may or may not be able to say something…or not get it over…to the extent how it's impacting because their loved one is sitting there, and they don't want to talk about it" (Edie).* *"it builds up those sort of like barriers as well, because then it's…difficult for the patient…and the carer then*

Domain and definition	Theme/Subtheme	Findings
		to…like see eye to eye and you don't want to make any relationship difficult and I think that's what the guide also helped" (Emma) *"I think it's about turn turning it, like turning it round, and so they're bringing to you. They're bringing you the… information that's important to them" (Nicole).* *"I do think it's beneficial to get a more holistic sense of a person. Um, because some people… some people might be a bit reluctant to be honest with you face to face, but actually might be honest with you on paper" (Emma).* *"the guide really allows the person and their relative to bring forward the things that they want me to know" (Nicole).*
	The guide provides a standard for practice	**The guide provides a standard for practice** *"It doesn't matter if they see a nurse or a doctor. You know everybody is getting treated the same…you know everybody is going to have… the same experience" (Emma).*
Self-Efficacy "*the participant's confidence that they can perform the*	**Clinicians can see how the guide could be used in practice**	**Clinicians can see how the guide could be used in practice**

Domain and definition	Theme/Subtheme	Findings
behaviour(s) required to participate in the intervention"		*"I think…quite a lot that was being asked of us, like I said, was being was being done anyway, so I think…It's not that much different, so actually adopting the changes wouldn't be that much of an effort" (Emma).* *"It's something that I would probably print out and keep with me all the time. I feel quite capable of using it and keeping the guide with me. It's only a few pages and it's quite bulleted in nicely" (Paige).* *"I think it would take more than our sort of an hour and a half that we allocate for each assessment at the moment…whether the Trust would take that on board because in the past they've tried to ask us to do more assessments and gather information over the telephone with carers and with patients rather than on a face-to-face basis" (Iris).*

Affective Attitude

Affective Attitude domain: positive feelings about the guide. Clinicians expressed positive opinions about the prospect of using the guide during both initial assessments and outcome appointments. Clinicians spoke about finding the guide a helpful resource as the information included in it was useful to their practice. The guide's simplicity was identified as something particularly appealing to clinicians. Some clinicians outlined their plan to adopt the guide into their practice. The guide prompted clinicians to reflect on their practice and whether they were meeting the expected standards. Clinicians noted that the guide impacted their confidence in their own practice and the existing way they assess for dementia and communicate the outcomes of memory assessments.

Burden

One subtheme was identified for the burden domain: the amount of information is too much and might put off patients and companions. Clinicians discussed this in relation to their own practice and the impact on patients and their companions. The amount of information patients and companions are required to read when using the guide was considered too much and clinicians felt reducing its length would make it more accessible to patients and companions. One clinician spoke about finding the amount of reading required overwhelming. Clinicians felt there was a risk that people would feel overwhelmed by the amount of information and would therefore be put off reading the guide. Clinicians felt that when patients receive written information about their initial assessment appointment, the most important part is when they will be seen by a clinician, and they do not pay much attention to other information sent out with an appointment letter. There was recognition that many people referred for a MAS assessment were in the early stages of dementia and experiencing disruption in the cognitive abilities required to read and absorb large amounts of written information, meaning they did not use the guide.

Ethicality

Ethicality was separated into two subthemes: clinician practice is enhanced, finding a balance between honesty, autonomy and harm. The guide was seen as promoting person centred practice which helped clinicians better understand and meet individual needs of patients and companions. The triadic nature of dementia assessment between the clinician, patient and companion is something clinicians discussed. The guide was seen as a means of managing conflicting opinions from patients and their companions, which reduced the detrimental effect on their relationship but still allowed both parties' opinions to be captured. Clinicians liked that the guide encouraged patients and companions to take an active role in assessment and felt the guide allowed them to be responsive to the needs of both stakeholders.

Moreover, the guide prompts clinicians to recognise the emotional impact sharing dementia diagnoses with people can have on them. The need for clinicians to recognise this, and take action to look after their own needs, potentially reduces burn out and maintains clinician empathy. The potential for the guide to prevent complacency in practice was discussed by two clinicians. They felt that whilst much of the guidance is aligned with their existing practice, the guide is a reminder for what best practice entails and encourages clinicians to remain empathic.

Opinions on what information should be shared with the patient and companion during the assessment were given by clinicians and formed the second subtheme. Opinions included that it feels difficult not to share the outcome of an assessment for dementia, even if the person being assessed has expressed a preference for not knowing. Issues such as informed consent and worries about causing distress by using the word 'dementia' in the initial assessment were discussed as well as being worried about further distress being caused if someone is told by accident by another healthcare professional. There is a dilemma between wanting to respect the autonomy of the person but also the practical and ethical aspects of them not knowing they are living with dementia, such as gaining informed consent for medication and informing the DVLA about their diagnosis. One clinician felt that being open about the purpose of

assessments is positive as it allows patients and their companions to be fully understanding of what they are taking part in, including the potential outcomes and prepares them for what they can expect.

Intervention coherence

One subtheme was identified for this domain: linking the initial assessment and outcome appointments helps clinicians to share the diagnosis of dementia. Clinicians recognised how the clinician version of the guide complements the patient and companion version as they both contain summaries of the information contained in it. Clinicians thought this awareness of patient and companion requirements helped them adjust their delivery of appointments accordingly. By linking the assessment and outcomes appointments, clinicians felt the guide made the process of memory assessment more coherent, helping them structure outcome appointments. By raising issues that were important to the patient and companion during the initial assessment, the guide linked the two appointments providing greater continuity.

Opportunity Costs

One subtheme was identified for the opportunity costs domain: The guide is easy for clinicians to use. Clinicians felt the guide could be adopted into practice with similarities with how they already practise. All the clinicians gave the opinion that because of how much the guide is aligned with existing practice, it would not require them to make other sacrifices to implement its use, such as reducing time spent on other tasks. Contrastingly, one clinician felt the way information was presented and the amount of prose that required reading was overwhelming but once they had familiarised themselves with the guide, it would fit well with their existing practice.

Perceived effectiveness

Perceived effectiveness was divided into three subthemes: the guide helps to manage expectations of the memory assessment process, the guide's impact on the assessment and outcome sharing process, the guide provides a standard for practice. The guide was thought to provide an outline of what patients should expect from the assessment and diagnosis process. Clinicians expressed that this could help people identify their goals from the process. One clinician felt the way people are told about their diagnosis does not significantly impact stakeholders emotionally, and that factors outside of the interaction between clinicians and patients have greater influence, suggesting the guide is unlikely to be effective in reducing distress.

Information gathering was thought to be improved through use of the guide as there is an explicit mechanism through which both the patient and the companion can put across their opinions. Clinicians spoke about finding it difficult if there is discord between patients and companions and fear the impact they may have on relationships and the guide would help them navigate this. The function of the guide that allows both patients and their companions to discuss topics separately was thought to be beneficial for this purpose.

Clinicians also felt the guide would help gather information in a more person-centred way meaning the quality of information would be improved and allow a more accurate understanding of the patient and their needs, thereby helping patients and companions to feel better understood. Several clinicians spoke about the guide providing a standard for practice to reduce variability between clinicians which would mean patients and companions are guaranteed the same features of appointments. By standardising practice, clinicians felt the quality of appointments would be improved by using the guide which in turn made them motivated to use it.

Self-efficacy

Clinicians could see how they would use the guide and felt it would not take a huge amount of change to use the guide. Clinicians spoke about feeling confident that they would be able to use the guide and spoke about having already incorporated aspects of it into practice. One clinician felt the change to using the guide might require a process of adjustment for both the clinicians and the patients but thought this was possible. Another clinician felt extra time would be needed for assessments and because of this, it would be difficult to get the NHS trust to adopt it into practice.

Table 7

Summary of inductive themes and subthemes for acceptability

Theme	Subtheme	Findings
Comparisons with usual care	**The guide contains information that aligns with clinician's existing knowledge**	**The guide contains information that aligns with clinician's existing knowledge** *"I don't think the guide's a lot different to what we do currently. I think it gives you more to think about because there's more written down there, rather than the scant questions that the BADLS offers you" (Iris).*
	The guide is a potential training aid	**The guide is a potential training aid** *"Before I joined [the] memory team I'd never worked in a position where we broke difficult or bad news in that way, and I know that in certain services where they are doing that, for example, cancer services, they…do have training in that" (Nicole).* *"I guess you know it's something that can be incorporated in our peer supervision as a MAS group into just talking about what makes a good delivery" (Paige).*

Comparisons with usual care

Clinicians made comparisons between how they currently practice, and the impact of using the guide to inform appointments. They identified potential benefits to using the guide that would motivate them to adopt it into practice. Two additional subthemes were identified: *The guide contains information that aligns with clinician's existing knowledge; The guide is a potential training aid.*

Subtheme: The guide contains information that aligns with clinician's existing knowledge

All clinicians spoke about the guide containing much of the information that they were already aware of and already guided their practice. This was viewed as positive as they felt it validated their existing practice and made them feel that it would be easier to adopt into their practice as it didn't clash with their existing knowledge. Comparisons with an existing standardised measure of the ability of people with dementia to carry out daily activities, called the Bristol Activities of Daily Living (BADLS) were made, with the guide perceived as superior to this.

Subtheme: The guide is a potential training aid

A lack of standardised training for nurses who are new to memory assessment was discussed as a current short coming of services, meaning that they are undertaking a sensitive task where they are required to share bad news without formal training to do so. The guide was thought to have the potential to provide new members of staff with a resource to help them to learn how to break bad news with patients and companions, something that is currently lacking in the service. There is evidence to suggest that this is something that is also representative of other services (Lecouturier et al., 2008b). Similarly, the guide was seen as a potential resource for skills development for existing clinicians.

Aim 2. Feasibility

Framework Analysis- Feasibility of the Study procedure.

Themes relating to feasibility of the study procedure separated from those relating to acceptability and are presented in table 8.

Table 8

Themes relating to feasibility of the study procedure

Theme	Subtheme	Findings
Clinician's views on feasibility of the study procedure	**Clinician's experiences of the procedure**	**Clinician's experiences of the procedure** *"I think the way we…our understanding…was kind of…facilitated…that was great. No problems at all. We knew exactly what we were doing and how we needed to do it" (Nicole).* *"so it wasn't that it's a burden because I'm already there. You're not asking me to go out on a separate visit then that, that would have been a burden. I would have said I can't do it because. No. [But] because I'm already there, it's not anything extra, it's part of the conversation that I'm also having with them" (Paige).*
	Reasons why patients and companions may not have taken part in the study	**Reasons why patients and companions may not have taken part in the study** *"They'd put that somewhere and they didn't know where they'd put it…they've put the appointment letter on a like the Cork board, but the other information is nowhere to be seen" (Emma).* *"We thought perhaps people just take a glance and pop it in the bin. Or perhaps don't even realise what it's for. They might just assume that it's the kind of the leaflets that you get alongside an appointment letter" (Nicole).* *"The relatives were really very stressed and juggling lots of things trying to keep you know mum or dad head above water and their own and it just wasn't on their agenda at all really" (Nicole).*

Theme	Subtheme	Findings
	Recruitment of patients and companions could be aided by increased time and support	**Recruitment of patients and companions could be aided by increased time and support** *"maybe liaise with family if they really, if the patient's really struggling with filling it out and ask the family member to help them" (Emma).* *"It would benefit, especially people who are about to be seen if we send them out, week or two before they actually received their appointments in the next two or three weeks so that they have some information to read and they concentrate on that. …by the time the letter then comes out for [the] appointment then…would have completed it because they are only focusing on one thing at a time" (Edie).*

Three inductive subthemes regarding the feasibility of the procedure from the perspective of clinician participants were identified: *Clinicians' experiences of the procedure; Reasons why patients and companions didn't take part in the study; Recruitment of patients and companions could be aided by increased time and support.*

Subtheme: Clinician's experiences of the procedure

All but one clinician reported the study procedure was not burdensome as it was straightforward to follow, and they knew what was expected of them. Information given to them prior to taking part was sufficient for them to understand the study. One clinician felt that it had been difficult to retain information about what they were required to do due to information being shared through online meetings and in emails. They felt a face-to-face meeting would have helped them retain the information more effectively. Clinicians felt the procedure placed little burden on their time and fitted in well with their existing procedure for appointments.

Subtheme: Reasons why patients and companions didn't take part in the study

Clinicians provided several explanations as to why recruitment of patients and companions to the study was not possible based on their responses when they outlined the study during the initial assessment. Most clinicians reported that when they asked people about taking part in the study, they denied knowledge of it or did not know where the relevant paperwork was. Clinicians speculated this was because the study materials and guide required a lot of reading which was not a priority for them so they put it physically away somewhere.

Clinicians also noticed an increase in distress levels in patients and companions since the coronavirus pandemic. Waiting times for initial appointments were longer than pre-pandemic. Clinicians felt one result of this was that people they

were seeing for initial appointments were more cognitively impaired than before the pandemic. One clinician estimated around 50% of people they saw for initial assessment lacked capacity to consent to take part in the study due to cognitive impairment – this had changed since prior to the pandemic. Consequently, patients and their companions were experiencing higher levels of stress and distress and were more focussed on getting the support they needed from the assessment process [9].

Subtheme: recruitment of patients and companions could be aided by increased time and support.

Clinicians suggested steps that could be taken to promote participation in the study and overcome some of the barriers to recruitment that were faced. Making direct contact with patients and companions prior to their initial appointment to discuss the study was thought to be something that would provide people with a reminder about the study and give them an opportunity to discuss it with someone prior to their initial appointment. Other suggestions included referring to the study in the main appointment letter sent by the service, and sending the study information separately to the initial assessment letter.

Fidelity to the intervention

It was not possible to rate audio recordings of clinicians using the guide in appointments with patients as no patients were recruited to the study.

Feasibility and burdensomeness of measures

Of the three baseline measures, all were fully completed with no missing items. Only one complete dyad returned completed measures. The other completed

[9] See Extended Results section 0 for further information on contextual Covid-19 data

measure was from a companion with no measure from the patient who they supported in the appointment.

Recruitment

Baseline

Baseline measures were initially distributed over a four-week period (2021, September 1-29). For each arm of the trial, questionnaires (*n*=20) were distributed to patients and companions. During this time, CARE questionnaires were returned in the intervention arm (*n=1)*; therefore, ethical approval for a two-week extension to the recruitment period was applied for (2021, September 29-October 13) as this was thought to be a long enough period to establish if the recruitment process for baseline measures was feasible. During this period, CARE questionnaires were returned in the intervention arm (*n=2)*. The overall return rate was therefore 7.5%. Table 10 outlines baseline recruitment frequencies and percentages. A further questionnaire was returned that had not been completed but included a letter addressed to the clinician who had conducted the appointment. Table 9 shows baseline CARE scores. Scores range from 10 to 50, with higher scores suggesting higher levels of clinician empathy. The baseline scores obtained suggested high ratings of clinician empathy. No comparison between the two sites was possible due to low return numbers.

Table 9

Returned Baseline CARE Scores.

Study Arm	**CARE Score**	
Intervention	Patient	-
	Companion	40
Intervention	Patient	48
	Companion	50

Table 10

Baseline Recruitment Frequency and Percentage for Each Arm of the Study.

Arm	Frequency	Percentage %
Usual Care		
Patient	0	0
Companion	0	0
Intervention		
Patient	1	5
Companion	2	10

Second stage

Invitations to participate in the study were sent to patients with appointment letters for initial appointments with participating clinicians for usual care (*n*=20) and intervention (*n*=37) arms, between November 2021 and February 2022. Table 11 shows the recruitment frequency and percentages for each arm of the study. No patients or companions were recruited to either arm of the study.

Table 11

Recruitment Frequency and Percentage for Each Arm of the Study.

Arm	Frequency	Percentage %
Usual Care		
Clinician	2	75
Patient	0	0
Companion	0	0
Intervention		
Clinician	3	50
Patient	0	0
Companion	0	0

Attrition

No participants who consented to take part dropped out of the study. All five clinician participants completed the interview and study in full.

Discussion

The aims of the study were two-fold: firstly, to establish the acceptability of a guide supported consultation with clinicians, patients, and their companions and secondly, to determine the feasibility of the study design to further establish its effectiveness.

It was not possible to establish the acceptability of the guide with patients and companions due to lack of recruitment. The clinician's section of the guide was found to be acceptable to clinicians working in a MAS as it could be easily adopted into practice and was thought to enhance the quality of the memory assessment process. However, because of the lack of recruitment of patients and companions, it is not possible to establish acceptability of the full intervention with clinicians as they had no experience of using the guide with patients and companions.

The results suggest that a trial to investigate effectiveness of the guide using the current study design is not feasible. Whilst uptake to the study with MAS clinicians was feasible, recruitment of patients and companions was not sufficient and, therefore, a definitive trial examining the effectiveness of a guide-supported assessment using this study design was not feasible.

Clinicians spoke about the acknowledgment of the emotional impact of their work on themselves as something that was helpful about the guide. Previous literature has highlighted the emotional demands of communicating a diagnosis of

dementia, citing the lack of training in how to manage the process as a potential causal factor (Bailey et al., 2019). The finding that clinicians felt reassured about the standard of their practice after being introduced to the guide, suggests it has the potential to aid feelings of uncertainty in clinicians who lack clear guidance on how to share a diagnosis of dementia.

The triadic nature of dementia assessment has been highlighted as the reason existing protocols for breaking bad news are not suited to disclosure of a dementia diagnosis (British Psychological Society, 2014) and is something also found to be pertinent in previous studies of clinician experiences of disclosure of a dementia diagnosis (Karnieli-Miller et al., 2012; Phillips et al., 2012). The need for diagnoses to be communicated in a person-centred way has been identified as key in best practice (Lecouturier et al., 2008b). This becomes more difficult as in practice there are two people who often have different expectations of the purpose of the meetings (Karnieli-Miller et al., 2012). Person centred care has been described as “an approach to practice established through the formation and fostering of therapeutic relationships between all care providers, patients and other individuals significant to them in their lives” (McCormack et al., 2010). It is, therefore, important to include the views of companions in assessment and diagnostic discussions. Clinicians felt tailoring discussions to meet the needs of patients and companions was aided by the guide. Both opinions are explicitly sought and the guide offers a means by which differing opinions can be considered separately. This was identified as particularly helpful to clinicians in meeting the needs of both the patient and their companion – a task that has previously been identified as difficult for clinicians (Robinson et al., 2005).

By providing patients and companions with information about what they can expect from the memory assessment process, clinicians felt their expectations were managed, something which would be helpful to both patients and companions. Previous research has identified the lead up to appointments for memory assessments as when the most distress is experienced by patients and

companions (Cahill et al., 2008). By providing a clear outline of what people can expect from the assessment process, the guide potentially helps relieve some of the uncertainty and consequent nervousness experienced by patients and companions (Gruters et al., 2021). Managing expectations may also contribute to increased levels of satisfaction with the consultation (Campbell et al., 2007). It is important to note that whilst clinicians felt this would be helpful, the lack of data from patients and companions themselves means this is speculative.

Whilst it was not possible to establish the acceptability of the guide with patients and companions, it was the opinion of some MAS clinicians that the guide places more burden on patients and companions prior to their initial appointment than current practice. Pratt and Wilkinson (2003) propose distress is experienced because of an interaction between the social context and the ability or willingness to be aware of their diagnosis. The social context of the COVID-19 outbreaks and subsequent restrictions in place around the recruitment stage of the study resulted in difficulties with accessing support, and longer than usual waiting times to be seen by memory assessment services[11]. It is possible that this context, coupled with the tendency for distress to increase around appointments (Cahill et al., 2008), meant that patients and companions were less able to engage with the guide as a new source of information (Bunn et al., 2012).

Previous research suggests 10% of people are willing to, and eligible, to take part in dementia intervention studies (Cooper et al., 2014), a view not supported by the findings of this study. There are several factors that could have contributed to the difficulties with recruitment encountered. The cohort of people who access MAS are older adults over the age of 65. Difficulties in recruiting older adults to research are well established, with a range of barriers including complex physical health problems and cultural and social factors (Mody et al., 2008; Provencher et al., 2014). People with dementia, and their companions, face particular barriers

[11] See Extended Discussion section 4.8.1 for theoretical understandings of recruitment and consideration of the impact of COVID-19.

to taking part in research, which leads to recruitment difficulties when conducting research with this population (Beattie et al., 2018). People in the early stages of dementia, and those who do not yet have a formal diagnosis, are less likely to participate in research studies because the mildness of their symptoms means they feel less compelled to share their experiences (Langbaum et al., 2023).

The recruitment period of this study was towards the end of the COVID-19 pandemic, which was been believed to have had a negative impact on recruitment (Baker et al., 2023). Time constraints on companions of people with dementia have also been found to be a barrier to recruitment and this was exacerbated by the COVID-19 pandemic (Joshi et al., 2023). Many media narratives during the pandemic were frightening to older people who were deemed as more at risk (Derrer-Merk et al., 2023). This, coupled with a desire not to further burden an overstretched health service, may have resulted in people delaying accessing the MAS service, consequently making them more distressed by the time they sought support.

The need for evidence-based interventions to guide the process of sharing the outcomes of assessments for dementia has been highlighted (Poyser & Tickle, 2019). The guide used in this study is one such attempt at developing an evidence-based intervention that aims to support good practice in dementia assessment (Bennett et al., 2018). The findings of this study suggest the guide is somewhat acceptable to clinicians working in memory assessment and that they have the desire to use it in their practice, but changes to the format for patients and companions might be indicated. Furthermore, it is likely to encourage and build upon good practice; it contributes to the knowledge around good practice guidelines, which are needed for the development of high-quality dementia assessments.

Strengths and limitations

The main limitation of this study was the lack of recruitment of patients and companions. This means conclusions about the acceptability of the guide could only be explored from clinicians' perspectives meaning the opinions of people targeted by the intervention are missing from the findings. The sample of clinicians is limited to one discipline. Whilst clinicians from the medical discipline were invited to participate, none were recruited. This could be an indication that the concept of an intervention targeting the diagnostic process for dementia is not acceptable to medics and therefore they did not wish to participate in the study. The findings of this study may not be generalisable to health professionals from other disciplines[12]. However, the mixed methods design of the study allowed a better understanding of the reasons for lack of recruitment than a purely quantitative approach would have produced[13].

Conclusion

The clinician version of the guide was acceptable to MAS clinicians; findings suggest they would be willing to adopt it in their practice. Further investigation of acceptability of the intervention with clinicians from other disciplines is required. The current study design is not feasible for a full trial to determine the guide's effectiveness. The inability to recruit patients and companions to the study may be explained by high levels of distress experienced around the process of assessment for dementia, a lack of awareness of symptoms and barriers presented by the COVID-19 pandemic. The acceptability of the guide for patients and companions, as well as a feasible study design to establish effectiveness of the guide, remain outstanding and are areas for further development[14].

[12] See section 4.11 for further discussion of lack of recruitment of medics
[13] See section 4.10 and 4.11 for further discussion of strengths and limitations
[14] See section 4.13 for discussion of further research.

Word Count:7436

For intended journal article submission please see Appendix H

References

Agnew, S. K., & Morris, R. G. (1998). The heterogeneity of anosognosia for memory impairment in Alzheimer's disease: A review of the literature and a proposed model. *Aging and Mental Health*, *2*(1), 7–19. https://doi.org/10.1080/13607869856876

Alzheimer's Society. (2022a). *People with dementia face up to a two year wait for diagnosis*. https://www.alzheimers.org.uk/news/2022-09-23/people-dementia-face-two-year-wait-diagnosis#:~:text=The%20National%20Audit%20of%20Memory,from%2013%20weeks%20in%202019%3B

Alzheimer's Society. (2022b, August 3). *What is dementia? Symptoms, causes and treatments*. alzheimers.org.uk/about-dementia/types-dementia/what-is-dementia

Aminzadeh, F., Byszewski, A., Molnar, F. J., & Eisner, M. (2007). Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. *Aging and Mental Health*, *11*(3), 281–290. https://doi.org/10.1080/13607860600963695

Aring, C. D. (1958). Sympathy and empathy. *Journal of the American Medical Association*, *167*(4), 448–452. https://doi.org/10.1001/JAMA.1958.02990210034008

Baddeley, A. (1992). Working Memory. *New Series*, *255*(5044), 556–559.

Baddeley, A. (2000). The episodic buffer: a new component of working memory? *Trends in Cognitive Sciences*, *4*(11), 417–423. https://doi.org/10.1016/S1364-6613(00)01538-2

Baddeley, A. D. (1986). *Working memory* [Book]. Clarendon.

Baddeley, A. D., & Hitch, G. (1974). Working Memory. *Psychology of Learning and Motivation - Advances in Research and Theory*, *8*(C), 47–89. https://doi.org/10.1016/S0079-7421(08)60452-1

Baile, W. F., Buckman, R., Lenzi, R., Glober, G., Beale, E. A., & Kudelka, A. P. (2000). SPIKES—A six-step protocol for delivering bad news: application to the patient with cancer. *The Oncologist*, *5*(4), 302–311. https://doi.org/10.1634/THEONCOLOGIST.5-4-302

Bailey, C., Dooley, J., & McCabe, R. (2019). 'How do they want to know?' Doctors' perspectives on making and communicating a diagnosis of dementia. *Dementia*, *18*(7–8), 3004–3022. https://doi.org/10.1177/1471301218763904

Baker, F. A., Blauth, L., Bloska, J., Bukowska, A. A., Flynn, L., Hsu, M.-H., Janus, E., Johansson, K., Odell-Miller, H., Miller, H., Petrowitz, C., Pool, J., Stensæth, K., Tamplin, J., Teggelove, K., Wosch, T., & Sousa, T. V. (2023). Recruitment approaches and profiles of consenting family caregivers and people living with dementia: A recruitment study within a trial [Article]. *Contemporary Clinical Trials Communications*, *32*, 101079–101079. https://doi.org/10.1016/j.conctc.2023.101079

Bamford, C., Lamont, S., Eccles, M., Robinson, L., May, C., & Bond, J. (2004). Disclosing a diagnosis of dementia: a systematic review [Article]. *International Journal of Geriatric Psychiatry*, *19*(2), 151–169. https://doi.org/10.1002/gps.1050

Barker, C., Pistrang, N., & Elliot, R. (2016). *Research methods in clinical psychology: an introduction for students and practitioners* (N. Pistrang & R. Elliott, Eds.; 3rd ed.) [Book]. Wiley Blackwell.

Barnes, T. R. E., Banerjee, S., Collins, N., Treloar, A., McIntyre, S. M., & Paton, C. (2012). Antipsychotics in dementia: prevalence and quality of antipsychotic drug prescribing in UK mental health services [Article]. *British Journal of Psychiatry*, *201*(3), 221–226. https://doi.org/10.1192/bjp.bp.111.107631

Beattie, E., Fielding, E., O'Reilly, M., Brooks, D., MacAndrew, M., & McCrow, J. (2018). Recruitment of individuals with dementia and their carers for social research: lessons learned from nine studies [Article]. *Research in Gerontological Nursing*, *11*(3), 119–128. https://doi.org/10.3928/19404921-20180308-01

Bennett, C. E., De Boos, D., & Moghaddam, N. G. (2018). Developing a tool to support diagnostic delivery of dementia. *Dementia*, *18*(7–8), 2505–2525. https://doi.org/10.1177/1471301217750936

Berger, J. T., & Ribeiro Miller, D. (2022). Physicians Should Stop Breaking Bad News [Article]. *Journal of General Internal Medicine : JGIM*, *37*(13), 3475–3476. https://doi.org/10.1007/s11606-022-07566-6

Borschmann, R., Patterson, S., Poovendran, D., Wilson, D., & Weaver, T. (2014). *Influences on recruitment to randomised controlled trials in mental health settings in England: a national cross-sectional survey of researchers working for the Mental Health Research Network*. https://doi.org/10.1186/1471-2288-14-23

Braak, H., & Braak, E. (1997). Frequency of Stages of Alzheimer-Related Lesions in Different Age Categories [Article]. *Neurobiology of Aging*, *18*(4), 351–357. https://doi.org/10.1016/S0197-4580(97)00056-0

Braun, V., & Clarke, V. (2013). *Successful qualitative research: a practical guide for beginners* (V. Clarke, Ed.) [Book]. SAGE.

British Psychological Society. (2014). *Clinical Psychology in the Early Stage Dementia Care Pathway*.

British Psychological Society. (2021). *BPS code of human research ethics.* https://www.bps.org.uk/guideline/bps-code-human-research-ethics

Brooke, J. (2019). Equity of people with dementia in research, why does this issue remain? [Article]. *Journal of Clinical Nursing*, *28*(21–22), 3723–3724. https://doi.org/10.1111/jocn.14957

Browne, K., Roseman, D., Shaller, D., & Edgman-Levitan, S. (2010). analysis & commentary Measuring Patient Experience As A Strategy For Improving Primary Care [Article]. *Health Affairs*, *29*(5), 921–925. https://doi.org/10.1377/hlthaff.2010.0238

Buckman, R. (1992). How to break bad news [Book]. In *How to break bad news* (1st ed.). University of Toronto Press. https://doi.org/10.3138/9781487596989

Bucks, R. S., Ashworth, D. L., Wilcock, G. K., & Siegfried, K. (1996). Assessment of activities of daily living in dementia: development of the Bristol Activities of Daily Living Scale. *Age and Ageing*, *25*(2), 113–120. https://doi.org/10.1093/AGEING/25.2.113

Bunn, F., Goodman, C., Sworn, K., Rait, G., Brayne, C., Robinson, L., McNeilly, E., & Iliffe, S. (2012). Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies [Article]. *PLoS Medicine*, *9*(10), e1001331–e1001331. https://doi.org/10.1371/journal.pmed.1001331

Burnham, S. C., Bourgeat, P., Doré, V., Savage, G., Brown, B., Laws, S., Maruff, P., Salvado, O., Ames, D., Martins, R. N., Masters, C. L., Rowe, C. C., & Villemagne, V. L. (2016). Clinical and cognitive trajectories in cognitively healthy elderly individuals with suspected non-Alzheimer's disease pathophysiology (SNAP) or Alzheimer's disease pathology: a longitudinal study [Article]. *Lancet Neurology*, *15*(10), 1044–1053. https://doi.org/10.1016/S1474-4422(16)30125-9

Burns, A., Beevor, A., Lelliott, P., Wing, J., Blakey, A., Orrell, M., Mulinga, J., & Hadden, S. (1999). Health of the Nation Outcome Scales for elderly people (HoNOS 65+). *The British Journal of Psychiatry : The Journal of Mental Science*, *174*(MAY), 424–427. https://doi.org/10.1192/BJP.174.5.424

Byszewski, A. M., Molnar, F. J., Aminzadeh, F., Eisner, M., Gardezi, F., & Bassett, R. (2007). Dementia diagnosis disclosure : A study of patient and caregiver perspectives [Article]. *Alzheimer Disease and Associated*

Disorders, *21*(2), 107–114. https://doi.org/10.1097/WAD.0b013e318065c481

Cahill, S. M., Gibb, M., Bruce, I., Headon, M., & Drury, M. (2008). I was worried coming in because I don't really know why it was arranged' [Article]. *Dementia*, *7*(2), 175–189. https://doi.org/10.1177/1471301208091157

Calvo, M. G., & Eysenck, M. W. (1992). Anxiety and Performance: The Processing Efficiency Theory. *Cognition and Emotion*, *6*(6), 409–434. https://doi.org/10.1080/02699939208409696

Campbell, T. A., Auerbach, S. M., & Kiesler, D. J. (2007). Relationship of interpersonal behaviors and health-related control appraisals to patient satisfaction and compliance in a university health center. *Journal of American College Health*, *55*(6), 333–340. https://doi.org/10.3200/JACH.55.6.333-340

Care Quality Commission. (2021). *State of Care*.

Cheston, R., Dodd, E., Christopher, G., Jones, C., Wildschut, T., & Sedikides, C. (2018). Selective forgetting of self-threatening statements: Mnemic neglect for dementia information in people with mild dementia [Article]. *International Journal of Geriatric Psychiatry*, *33*(8), 1065–1073. https://doi.org/10.1002/gps.4894

Cheston, R., Dodd, E., Christopher, G., White, P., Wildschut, T., & Sedikides, C. (2022). The Development and Validation of the Threat of Dementia Scale. *International Journal of Aging and Human Development*, *94*(4), 496–514. https://doi.org/10.1177/0091415020957388

Clare, L. (2002). Developing Awareness about Awareness in Early-Stage Dementia [Article]. *Dementia (London, England)*, *1*(3), 295–312. https://doi.org/10.1177/147130120200100303

Clare, L. (2003). Managing threats to self: awareness in early stage Alzheimer's disease [Article]. *Social Science & Medicine (1982)*, *57*(6), 1017–1029. https://doi.org/10.1016/S0277-9536(02)00476-8

Clare, L., Quinn, C., Jones, I. R., & Woods, R. (2016). “I Don’t Think Of It As An Illness”: Illness representations in mild and moderate dementia. *Journal of Alzheimer’s Disease*, *51*(1), 139–150.

Cohen, D., Kennedy, G., & Eisdorfer, C. (1984). Phases of Change in the Patient with Alzheimer’s Dementia: A Conceptual Dimension for Defining Health Care Management. *Journal of the American Geriatrics Society*, *32*(1), 11–15. https://doi.org/10.1111/J.1532-5415.1984.TB05143.X

Conway, M. A. (2005). Memory and the self [Article]. *Journal of Memory and Language*, *53*(4), 594–628. https://doi.org/10.1016/j.jml.2005.08.005

Conway, M. A., & Pleydell-Pearce, C. W. (2000). The Construction of Autobiographical Memories in the Self-Memory System [Article]. *Psychological Review*, *107*(2), 261–288. https://doi.org/10.1037/0033-295X.107.2.261

Conway, M. A., Singer, J. A., & Tagini, A. (2004). The Self and Autobiographical Memory: Correspondence and Coherence [Article]. *Social Cognition*, *22*(5), 491–529. https://doi.org/10.1521/soco.22.5.491.50768

Cooper, C., Ketley, D., & Livingston, G. (2014). Systematic review and meta-analysis to estimate potential recruitment to dementia intervention studies [Article]. *International Journal of Geriatric Psychiatry*, *29*(5), 515–525. https://doi.org/10.1002/gps.4034

Darbyshire, J., Sitzia, J., Morgan, C., Riley, A., Rosser, M., Kotting, P., McKeith, I., Smye, S., Gower, J., Brown, V., Smyth, R., Poustie, V., Cameron, D., Van’t Hoff, W., Wallace, P., Ellis, T., Wykes, T., Burns, S., Rosenberg, W., … Chaturvedi, N. (2011). Extending the clinical research network approach to all of healthcare [Article]. *Annals of Oncology*, *22*, vii36–vii43. https://doi.org/10.1093/annonc/mdr424

Dementia UK. (2023a). *Young onset dementia: facts and figures*. https://www.dementiauk.org/information-and-support/young-onset-dementia/young-onset-dementia-facts-and-figures/

Dementia UK. (2023b, March). *What is dementia?* dementiauk.org/information-and-support/about-dementia/what-is-dementia/

Department of Health. (2010). *Equity and Excellence: Liberating the NHS*.

Department of Health. (2015). *Prime Minister's challenge on dementia 2020*.

Derksen, E., Vernooij-Dassen, M., Scheltens, P., & Olde-Rikkert, M. (2006). A model for disclosure of the diagnosis of dementia [Article]. *Dementia (London, England)*, *5*(3), 462–468. https://doi.org/10.1177/147130120600500313

Derrer-Merk, E., Reyes-Rodriguez, M.-F., Soulsby, L. K., Roper, L., & Bennett, K. M. (2023). Older adults' experiences during the COVID-19 pandemic: a qualitative systematic literature review [Article]. *BMC Geriatrics*, *23*(1), 1–580. https://doi.org/10.1186/s12877-023-04282-6

Di Blasi, Z., Harkness, E., Ernst, E., Georgiou, A., & Kleijnen, J. (2001). Influence of context effects on health outcomes: A systematic review. *Lancet*, *357*(9258), 757–762. https://doi.org/10.1016/S0140-6736(00)04169-6

Division of Clinical Psychology. (2016). *Communicating a diagnosis of dementia*.

Doyle, C., Lennox, L., & Bell, D. (2013). *A systematic review of evidence on the links between patient experience and clinical safety and effectiveness*. *3*, 1570. https://doi.org/10.1136/bmjopen-2012

Dubois, B., Padovani, A., Scheltens, P., Rossi, A., & Dell'agnello, G. (2016). Timely Diagnosis for Alzheimer's Disease: A Literature Review on Benefits and Challenges. *Journal of Alzheimer's Disease*, *49*(3), 617–631. https://doi.org/10.3233/JAD-150692

Dziobek, I., Kimberley, A. E., Ae, R., Fleck, S., Markus, A. E., Ae, B., Heekeren, H. R., Oliver, A. E., & Ae, T. W. (2007). *Dissociation of Cognitive and Emotional Empathy in Adults with Asperger Syndrome Using the Multifaceted Empathy Test (MET)*. https://doi.org/10.1007/s10803-007-0486-x

Eccles, M. P., Francis, J., Foy, R., Johnston, M., Bamford, C., Grimshaw, J. M., Hughes, J., Lecouturier, J., Steen, N., & Whitty, P. M. (2009). Improving Professional Practice in the Disclosure of a Diagnosis of Dementia: A Modeling Experiment to Evaluate a Theory-Based Intervention [Article]. *International Journal of Behavioral Medicine*, *16*(4), 377–387. https://doi.org/10.1007/s12529-008-9023-3

Eldridge, S. M., Chan, C. L., Campbell, M. J., Bond, C. M., Hopewell, S., Thabane, L., & Lancaster, G. A. (2016). CONSORT 2010 statement: extension to randomised pilot and feasibility trials. *BMJ*, *355*(i5239). https://doi.org/10.1136/bmj.i5239

Emmady, P. D., Schoo, C., & Tadi, P. (2022). Major Neurocognitive Disorder (Dementia). *StatPearls*. https://www.ncbi.nlm.nih.gov/books/NBK557444/

Fallowfield, L., & Jenkins, V. (2004). Communicating sad, bad, and difficult news in medicine. *Lancet*, *363*(9405), 312–319. https://doi.org/10.1016/S0140-6736(03)15392-5

Field, B., Mountain, G., Burgess, J., Di Bona, L., Kelleher, D., Mundy, J., & Wenborn, J. (2019). Recruiting hard to reach populations to studies: breaking the silence: an example from a study that recruited people with dementia [Article]. *BMJ Open*, *9*(11), e030829–e030829. https://doi.org/10.1136/bmjopen-2019-030829

Fields, S. K., Mahan, P., Tillman, P., Harris, J., Maxwell, K., & Hojat, M. (2011). Measuring empathy in healthcare profession students using the Jefferson Scale of Physician Empathy: Health provider-student version. *Journal of Interprofessional Care*, *25*(4), 287–293. https://doi.org/10.3109/13561820.2011.566648

Fogarty, L. A., Curbow, B. A., Wingard, J. R., Mcdonnell, K., & Somerfield, M. R. (1999). Can 40 seconds of compassion reduce patient anxiety? [Article]. *Journal of Clinical Oncology*, *17*(1), 371–379. https://doi.org/10.1200/JCO.1999.17.1.371

Folstein, M. F., Folstein, S. E., & Mchugh, P. R. (1975). “Mini-Mental State” a practical method for grading the cognitive state of patients for the clinician. *J. Gsychiaf. Res*, *12*, 189–198.

Foy, R., Francis, J., Johnston, M., Eccles, M., Lecouturier, J., Bamford, C., & Grimshaw, J. (2007). *The development of a theory-based intervention to promote appropriate disclosure of a diagnosis of dementia* [Article]. https://doi.org/10.1186/1472-6963-7-207

Francis, L., & Robertson, N. (2023). Healthcare practitioners’ experiences of breaking bad news: A critical interpretative meta synthesis. *Patient Education and Counseling*, *107*, 107574. https://doi.org/10.1016/j.pec.2022.107574

Gagliardi, G., & Vannini, P. (2022). Episodic Memory Impairment Mediates the Loss of Awareness in Mild Cognitive Impairment [Article]. *Frontiers in Aging Neuroscience*, *13*, 802501–802501. https://doi.org/10.3389/fnagi.2021.802501

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research [Article]. *BMC Medical Research Methodology*, *13*(1), 117–117. https://doi.org/10.1186/1471-2288-13-117

Gasper, K., & Clore, G. L. (2002). Attending to the Big Picture: Mood and Global versus Local Processing of Visual Information [Article]. *Psychological Science*, *13*(1), 34–40. https://doi.org/10.1111/1467-9280.00406

Goldkuhl, G. (2012). Pragmatism vs interpretivism in qualitative information systems research. *European Journal of Information Systems*, *21*(2), 135–146. https://doi.org/10.1057/EJIS.2011.54

Goldsmith, L. (2021). Using Framework Analysis in Applied Qualitative Research [Article]. *Qualitative Report*, *26*(6), 2061–2076. https://doi.org/10.46743/2160-3715/2021.5011

Green, J., Goldstein, F. C., Sirockman, B. E., & Green, R. C. (1993). Variable awareness of deficits in Alzheimer's disease [Article]. *Neuropsychiatry, Neuropsychology, and Behavioral Neurology*, *6*(3), 159–165.

Gruters, A. A. A., Christie, H. L., Ramakers, I. H. G. B., Verhey, F. R. J., Kessels, R. P. C., & de Vugt, M. E. (2021). Neuropsychological assessment and diagnostic disclosure at a memory clinic: A qualitative study of the experiences of patients and their family members [Article]. *Clinical Neuropsychologist*, *35*(8), 1398–1414. https://doi.org/10.1080/13854046.2020.1749936

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? [Article]. *Field Methods*, *18*(1), 59–82. https://doi.org/10.1177/1525822X05279903

Hare, P. (2023). *Dementia and Hope: Our vision for dismantling the barriers which disable a million people in the UK.* One Dementia Voice http://www.innovationsindementia.org.uk/wpcontent/uploads/2023/01/Dementia-and-Hope-2023.pdf

Harman, G. (2004). *The impact of information on illness representations and coping in early dementia from the perspective of the person with dementia - A phenomenological approach*. University of London.

Healthcare Quality Improvement Partnership. (2022). *National Audit of Dementia: Memory Assessment Services Spotlight Audit 2021*. https://www.hqip.org.uk/wp-content/uploads/2022/08/Ref-317-NAD-Memory-Assessment-Services-Spotlight-Audit-2021_FINAL.pdf

Hill, N., Mogle, J., Kitko, L., Gilmore-Bykovskyi, A., Wion, R., Kitt-Lewis, E., & Kolanowski, A. (2017). *Aging & Mental Health Incongruence of subjective memory impairment ratings and the experience of memory problems in older adults without dementia: a mixed methods study Incongruence of subjective memory impairment ratings and the experience of memory problems in older adults without dementia: a mixed methods study*. https://doi.org/10.1080/13607863.2017.1337715

Hojat, M. (2009). Ten Approaches for Enhancing Empathy in Health and Human Services Cultures [Article]. *Journal of Health and Human Services Administration*, *31*(4), 412–450.

Horvarth, A., & Luborsky, L. (1993). The Role of the Therapeutic Alliance in Psychotherapy. *Journal of Consulting and Clinical Psychology*, *61*(4), 561–573. https://oce.ovid.com/article/00004730-199308000-00004/HTML

Hsieh, S., Schubert, S., Hoon, C., Mioshi, E., & Hodges, J. R. (2013). Validation of the Addenbrooke's Cognitive Examination III in Frontotemporal Dementia and Alzheimer's Disease [Article]. *Dementia and Geriatric Cognitive Disorders*, *36*(3–4), 242–250. https://doi.org/10.1159/000351671

Johnson, J., & Panagioti, M. (2018). Interventions to Improve the Breaking of Bad or Difficult News by Physicians, Medical Students, and Interns/Residents: A Systematic Review and Meta-Analysis [Article]. *Academic Medicine*, *93*(9), 1400–1412. https://doi.org/10.1097/ACM.0000000000002308

Joshi, S., Park, T., Brody, L., Cruz, K., Mukhi, P., Reid, M. C., Herr, K., Pillemer, K., & Riffin, C. (2023). Recruitment of family caregivers of persons with dementia: Lessons learned from a pilot randomized controlled trial [Article]. *Frontiers in Pain Research*, *4*, 1125914–1125914. https://doi.org/10.3389/fpain.2023.1125914

Kaplan, S. H., Greenfield, S., & Ware, J. E. (1989). Assessing the Effects of Physician-Patient Interactions on the Outcomes of Chronic Disease [Article]. *Medical Care*, *27*(3), S110–S127. https://doi.org/10.1097/00005650-198903001-00010

Karnieli-Miller, O., Werner, P., Aharon-Peretz, J., & Eidelman, S. (2007). Dilemmas in the (un)veiling of the diagnosis of Alzheimer's disease: Walking an ethical and professional tight rope [Article]. *Patient Education and Counseling*, *67*(3), 307–314. https://doi.org/10.1016/j.pec.2007.03.014

Karnieli-Miller, O., Werner, P., Aharon-Peretz, J., Sinoff, G., & Eidelman, S. (2012). Expectations, experiences, and tensions in the memory clinic: the

process of diagnosis disclosure of dementia within a triad. *International Psychogeriatrics*, *24*(11). https://doi.org/10.1017/S1041610212000841

Keady, J., & Nolan, M. (1995a). IMMEL 2: working to augment coping responses in early dementia [Article]. *British Journal of Nursing (Mark Allen Publishing)*, *4*(7), 377–380. https://doi.org/10.12968/bjon.1995.4.7.377

Keady, J., & Nolan, M. (1995b). IMMEL: assessing coping responses in the early stages of dementia [Article]. *British Journal of Nursing (Mark Allen Publishing)*, *4*(6), 309–314. https://doi.org/10.12968/bjon.1995.4.6.309

Kitwood, T. (1990). The Dialectics of Dementia: With Particular Reference to Alzheimer's Disease [Article]. *Ageing and Society*, *10*(2), 177–196. https://doi.org/10.1017/S0144686X00008060

Kotting, P., Smith, A., O'Hare, M. B., Giebel, C., Mendis, L., Shaw, C., Shillito, I., & Rossor, M. N. (2021). A national open-access research registry to improve recruitment to clinical studies [Article]. *Alzheimer's & Dementia : Translational Research & Clinical Interventions*, *7*(1), e12221-n/a. https://doi.org/10.1002/trc2.12221

KuÌbler-Ross, E. (1973). *On death and dying* [Book]. Routledge.

Lancaster, G. A., & Thabane, L. (2019). Guidelines for reporting non-randomised pilot and feasibility studies. In *Pilot and Feasibility Studies* (Vol. 5, Issue 1). BioMed Central Ltd. https://doi.org/10.1186/s40814-019-0499-1

Langbaum, J. B., Zissimopoulos, J., Au, R., Bose, N., Edgar, C. J., Ehrenberg, E., Fillit, H., Hill, C. V., Hughes, L., Irizarry, M., Kremen, S., Lakdawalla, D., Lynn, N., Malzbender, K., Maruyama, T., Massett, H. A., Patel, D., Peneva, D., Reiman, E. M., … Aisen, P. S. (2023). Recommendations to address key recruitment challenges of Alzheimer's disease clinical trials [Article]. *Alzheimer's & Dementia*, *19*(2), 696–707. https://doi.org/10.1002/alz.12737

Lecouturier, J., Bamford, C., Hughes, J. C., Francis, J. J., Foy, R., Johnston, M., & Eccles, M. P. (2008a). Appropriate disclosure of a diagnosis of dementia:

identifying the key behaviours of “best practice.” *BMC Health Services Research*. https://doi.org/10.1186/1472-6963-8-95

Lecouturier, J., Bamford, C., Hughes, J. C., Francis, J. J., Foy, R., Johnston, M., & Eccles, M. P. (2008b). Appropriate disclosure of a diagnosis of dementia: identifying the key behaviours of “best practice.” *BMC Health Services Research*, *8*, 95. https://doi.org/10.1186/1472-6963-8-95

Lee, S. M., Roen, K., & Thornton, A. (2014). The psychological impact of a diagnosis of Alzheimer’s disease [Article]. *Dementia (London, England)*, *13*(3), 289–305. https://doi.org/10.1177/1471301213497080

Low, L., McGrath, M., Swaffer, K., & Brodaty, H. (2019). Communicating a diagnosis of dementia: A systematic mixed studies review of attitudes and practices of health practitioners. *Dementia*, *18*(7–8), 2856–2905. https://doi.org/10.1177/1471301218761911

Low, L.-F., Swaffer, K., Mcgrath, M., & Brodaty, H. (2018). Do people with early stage dementia experience Prescribed Disengagement ®? A systematic review of qualitative studies. *International Psychogeriatrics*, *30*(6). https://doi.org/10.1017/S1041610217001545

Lowery, D. P., Warner, J., Cerga-Pashoja, A., Thuné-Boyle, I., & Iliffe, S. (2011). Clinicians as recruiters to dementia trials: lessons from the EVIDEM-E project [Article]. *International Journal of Geriatric Psychiatry*, *26*(7), 767–769. https://doi.org/10.1002/gps.2671

Luborsky, L. (1971). Factors influencing the outcome of psychotherapy: A review of quantitative research [Article]. *Psychological Bulletin*, *75*(3), 145–185. https://doi.org/10.1037/h0030480

Luz, R., George, A., Spitz, E., & Vieux, R. (2017). Breaking bad news in prenatal medicine: a literature review [Article]. *Journal of Reproductive and Infant Psychology*, *35*(1), 14–31. https://doi.org/10.1080/02646838.2016.1253052

Mastwyk, M., Ames, D., Ellis, K. A., Chiu, E., & Dow, B. (2014). Disclosing a dementia diagnosis: what do patients and family consider important?

[Article]. *International Psychogeriatrics*, *26*(8), 1263–1272. https://doi.org/10.1017/S1041610214000751

McCormack, B., Dewing, J., Breslin, L., Coyne-Nevin, A., Kennedy, K., Manning, M., Peelo-Kilroe, L., Tobin, C., & Slater, P. (2010). Developing person-centred practice: nursing outcomes arising from changes to the care environment in residential settings for older people [Article]. *International Journal of Older People Nursing*, *5*(2), 93–107. https://doi.org/10.1111/j.1748-3743.2010.00216.x

McPhillips, M. V., Petrovsky, D. V., Brewster, G. S., Li, J., Gooneratne, N. S., Hodgson, N. A., & Sefcik, J. S. (2022). Recruiting Persons with Dementia and Caregivers in a Clinical Trial: Dyads Perceptions [Article]. *Western Journal of Nursing Research*, *44*(6), 557–566. https://doi.org/10.1177/01939459211008563

Mercer, S. W., Higgins, M., Bikker, A. M., Fitzpatrick, B., McConnachie, A., Lloyd, S. M., Little, P., & Watt, G. C. M. (2016). General Practitioners' empathy and health outcomes: A prospective observational study of consultations in areas of high and low deprivation [Article]. *Annals of Family Medicine*, *14*(2), 117–124. https://doi.org/10.1370/afm.1910

Mercer, S. W., Maxwell, M., Heaney, D., & Watt Mercer SW, G. C. (2004). The consultation and relational empathy (CARE) measure: development and preliminary validation and reliability of an empathy-based consultation process measure. *Family Practice*, *21*(6). https://doi.org/10.1093/fampra/cmh621

Mercer, S. W., & Murphy, D. J. (2008). Validity and reliability of the CARE Measure in secondary care. *Clinical Governance: An International Journal*, *13*(4), 269–283. https://doi.org/10.1108/14777270810912969

Mercer, S. W., Neumann, M., Wirtz, M., Fitzpatrick, B., & Vojt, G. (2008). General practitioner empathy, patient enablement, and patient-reported outcomes in primary care in an area of high socio-economic deprivation in Scotland—A pilot prospective study using structural equation modelling. *Patient*

Education and Counselling, *73*(2), 240–245. https://doi.org/10.1016/J.PEC.2008.07.022

Merl, H., Veronica Doherty, K., Alty, J., & Salmon, K. (2022). Truth, hope and the disclosure of a dementia diagnosis: A scoping review of the ethical considerations from the perspective of the person, carer and clinician. *Dementia*, *21*(3), 1050–1068. https://doi.org/10.1177/14713012211067882/ASSET/IMAGES/LARGE/10.1177_14713012211067882-FIG1.JPEG

Milby, E., Murphy, G., & Winthrop, A. (2017). Diagnosis disclosure in dementia: Understanding the experiences of clinicians and patients who have recently given or received a diagnosis. *Dementia*, *16*(5), 611–628. https://doi.org/10.1177/1471301215612676/FORMAT/EPUB

Mitchell, G., McCollum, P., & Monaghan, C. (2013). The personal impact of disclosure of a dementia diagnosis: a thematic review of the literature [Article]. *British Journal of Neuroscience Nursing*, *9*(5), 223–228. https://doi.org/10.12968/bjnn.2013.9.5.223

Mody, L., Douglas Miller, Ã. K., McGloin, J. M., Div, M., Freeman, M., Marcantonio, E. R., Ã Jay Magaziner, Ã., & Studenski, S. (2008). Recruitment and Retention of Older Adults in Aging Research. *Journal of American Geriatric Society*, *56*, 2340–2348. https://doi.org/10.1111/j.1532-5415.2008.02015.x

Mograbi, D. C., Brown, R. G., & Morris, R. G. (2009). Anosognosia in Alzheimer's disease – The petrified self. *Consciousness and Cognition*, *18*(4), 989–1003. https://doi.org/10.1016/J.CONCOG.2009.07.005

Monden, K. R., Gentry, L., & Cox, T. R. (2016). Delivering Bad News to Patients. *Baylor University Medical Center Proceedings*, *29*(1), 101–102. https://doi.org/10.1080/08998280.2016.11929380

Moore, V., & Cahill, S. (2013). Diagnosis and disclosure of dementia - A comparative qualitative study of Irish and Swedish General Practitioners

[Article]. *Aging & Mental Health*, *17*(1), 77–84. https://doi.org/10.1080/13607863.2012.692763

Mormont, E., Jamart, J., & Jacques, D. (2014). Symptoms of depression and anxiety after the disclosure of the diagnosis of alzheimer disease. *Journal of Geriatric Psychiatry and Neurology*, *27*(4), 231–236. https://doi.org/10.1177/0891988714532021/FORMAT/EPUB

Moudatsou, M., Stavropoulou, A., Philalithis, A., & Koukouli, S. (2020). The Role of Empathy in Health and Social Care Professionals [Article]. *Healthcare (Basel)*, *8*(1), 26. https://doi.org/10.3390/healthcare8010026

Munoz Sastre, M. T., Sorum, P. C., & Mullet, E. (2011). Breaking Bad News: The Patient's Viewpoint. *Health Communication*, *26*(7), 649–655. https://doi.org/10.1080/10410236.2011.561919

Naidoo, N., Nguyen, V. T., Ravaud, P., Young, B., Amiel, P., Schanté, D., Clarke, M., & Boutron, I. (2020). The research burden of randomized controlled trial participation: a systematic thematic synthesis of qualitative evidence [Article]. *BMC Medicine*, *18*(1), 6–6. https://doi.org/10.1186/s12916-019-1476-5

Narayanan, V., Bista, B., & Koshy, C. (2010). "BREAKS" protocol for breaking bad news [Article]. *Indian Journal of Palliative Care*, *16*(2), 61–65. https://doi.org/10.4103/0973-1075.68401

Nembhard, I. M., David, G., Ezzeddine, I., Betts, D., & Radin, J. (2023). A systematic review of research on empathy in health care. *Health Services Research*, *58*(2), 250–263. https://doi.org/10.1111/1475-6773.14016

Nguyen, T., & Li, X. (2020). Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature. *Dementia*, *19*(2), 148–181. https://doi.org/10.1177/1471301218800122/FORMAT/EPUB

NHS. (2019). *The NHS Long Term Plan*. https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf

NHS Digital. (2023). *For Information: Preparations for the Implementation of ICD-11.* For Information: Preparations for the Implementation of ICD-11. https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/scci0021-international-statistical-classification-of-diseases-and-health-related-problems-icd-10-5th-edition

NHS Health Research Authority. (2024). *Public involvement*.

Nielsen, K. D., & Boenink, M. (2021). Ambivalent anticipation: How people with Alzheimer's disease value diagnosis in current and envisioned future practices [Article]. *Sociology of Health & Illness*, *43*(2), 510–527. https://doi.org/10.1111/1467-9566.13238

Nyberg, L., Mcintosh, A. R., Houle, S., Nilsson, L.-G., & Tulving, E. (1996). *Activation of medial temporal structures during episodic memory retrieval*.

O'Connor, M. L., & McFadden, S. H. (2012). A Terror Management Perspective on Young Adults' Ageism and Attitudes Toward Dementia. *Educational Gerontology*, *38*(9), 627–643. https://doi.org/10.1080/03601277.2011.595335

Office of National Statistics. (2023, April 11). *Death registration summary statistics, England and Wales: 2022*. ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathregistrationsummarystatisticsenglandandwales/2022

Phillips, J., Pond, C. D., Paterson, N. E., Howell, C., Shell, A., Stocks, N. P., Goode, S. M., & Marley, J. E. (2012). Difficulties in disclosing the diagnosis of dementia: a qualitative study in general practice [Article]. *British Journal of General Practice*, *62*(601), e546–e553. https://doi.org/10.3399/bjgp12X653598

Poyser, C. A., & Tickle, A. (2019). Exploring the experience of the disclosure of a dementia diagnosis from a clinician, patient and carer perspective: a

systematic review and Meta-ethnographic synthesis. *Aging & Mental Health*, *23*(12), 1605–1615. https://doi.org/10.1080/13607863.2018.1506747

Pratt, R., & Wilkinson, H. (2001). *"Tell Me the Truth". The Effect of Being Told the Diagnosis of Dementia from the Perspective of the Person with Dementia.*

Pratt, R., & Wilkinson, H. (2003). A Psychosocial Model of Understanding the Experience of Receiving a Diagnosis of Dementia [Article]. *Dementia (London, England)*, *2*(2), 181–199. https://doi.org/10.1177/1471301203002002004

Provencher, V., Mortenson, W. B., Tanguay-Garneau, L., Bé Langer B, K., & Dagenais, M. (2014). Challenges and strategies pertaining to recruitment and retention of frail elderly in research studies: A systematic review. *Archives of Gerontology and Geriatrics*, *59*, 18–24. https://doi.org/10.1016/j.archger.2014.03.006

Ranson, J. M., Kuźma, E., Hamilton, W., Muniz-Terrera, G., Langa, K. M., & Llewellyn, D. J. (2019). Predictors of dementia misclassification when using brief cognitive assessments [Article]. *Neurology. Clinical Practice*, *9*(2), 109–117. https://doi.org/10.1212/CPJ.0000000000000566

Raslau, F. D., Marl, I. T., Klein, J. L., Ulmer, V., Mathews, V., & Mark, L. P. (2015). Memory Part 2: The Role of the Medial Temporal Lobe. *American Journal of Neuroradiology*, *35*(5), 846–849. https://doi.org/10.3174/ajnr.A4169

Richardson, T. (2014). Clinical psychologists and research: Do we do any and should we do more? *Psychology Postgraduate Affairs Group Quarterly*, *90*, 7–11.

Ripley, E. B. D. (2006). A Review of Paying Research Participants: It's Time to Move Beyond the ethical Debate [Article]. *Journal of Empirical Research on Human Research Ethics*, *1*(4), 9–20. https://doi.org/10.1525/jer.2006.1.4.9

Ritchie, J., & Spencer, L. (1994a). Qualitative data analysis for applied policy research. In A. Bryman & B. Burgess (Eds.), *Analyzing Qualitative Data* (pp.

173–194). Routledge. https://doi.org/https://doi.org/10.4324/9780203413081

Ritchie, J., & Spencer, L. (1994b). Qualitative data analysis for applied policy research [Bookitem]. In *Analyzing Qualitative Data* (pp. 187–208). Routledge. https://doi.org/10.4324/9780203413081-14

Ritchie, J., & Spencer, L. (2002). Qualitative data analysis for applied policy research. [Book]. In A. M. Huberman & M. B. Miles (Eds.), *The Qualitative Researcher's Companion* (pp. 305–328). SAGE.

Robinson, L., Clare, L., & Evans, K. (2005). Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples. *Aging and Mental Health*, *9*(4). https://doi.org/10.1080/13607860500114555

Robinson, L., Gemski, A., Abley, C., Bond, J., Keady, J., Campbell, S., Samsi, K., & Manthorpe, J. (2011). The transition to dementia – individual and family experiences of receiving a diagnosis: a review [Article]. *International Psychogeriatrics*, *23*(7), 1026–1043. https://doi.org/10.1017/S1041610210002437

Robinson, L., Tang, E., & Taylor, J.-P. (2015). Dementia: timely diagnosis and early intervention [Article]. *BMJ (Online)*, *350*(jun15 14), h3029–h3029. https://doi.org/10.1136/bmj.h3029

Royal College of Psychiatrists. (2022). *Quality Standards for Memory Services*.

Schindler, S. E., Jasielec, M. S., Weng, H., Hassenstab, J. J., Grober, E., McCue, L. M., Morris, J. C., Holtzman, D. M., Xiong, C., & Fagan, A. M. (2017). Neuropsychological measures that detect early impairment and decline in preclinical Alzheimer disease. *Neurobiology of Aging*, *56*, 25–32. https://doi.org/10.1016/J.NEUROBIOLAGING.2017.04.004

Schöll, M., Lockhart, S. N., Schonhaut, D. R., O'Neil, J. P., Janabi, M., Ossenkoppele, R., Baker, S. L., Vogel, J. W., Faria, J., Schwimmer, H. D., Rabinovici, G. D., & Jagust, W. J. (2016). PET Imaging of Tau Deposition in

the Aging Human Brain [Article]. *Neuron (Cambridge, Mass.)*, *89*(5), 971–982. https://doi.org/10.1016/j.neuron.2016.01.028

Scott, S. D., Hirschinger, L. E., Cox, K. R., McCoig, M., Brandt, J., & Hall, L. W. (2009). The natural history of recovery for the healthcare provider “second victim” after adverse patient events [Article]. *Quality & Safety in Health Care*, *18*(5), 325–330. https://doi.org/10.1136/qshc.2009.032870

Sekhon, M., Cartwright, M., & Francis, J. (2016). Application of a theoretical framework to assess intervention acceptability: a semi-structured interview study. *European Health Psychologist*, *18*(Supplementary), 565–566.

Sekhon, M., Cartwright, M., & Francis, J. J. (2017a). Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework [Article]. *BMC Health Services Research*, *17*(1), 88–88. https://doi.org/10.1186/s12913-017-2031-8

Sekhon, M., Cartwright, M., & Francis, J. J. (2017b). Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework [Article]. *BMC Health Services Research*, *17*(1), 88–88. https://doi.org/10.1186/s12913-017-2031-8

Sekhon, M., Cartwright, M., & Francis, J. J. (2022). Development of a theory-informed questionnaire to assess the acceptability of healthcare interventions [Article]. *BMC Health Services Research*, *22*(1), 279–279. https://doi.org/10.1186/s12913-022-07577-3

Shepherd, V., Wood, F., Griffith, R., Sheehan, M., & Hood, K. (2019). Protection by exclusion? The (lack of) inclusion of adults who lack capacity to consent to research in clinical trials in the UK [Article]. *Current Controlled Trials in Cardiovascular Medicine*, *20*(1), 474–474. https://doi.org/10.1186/s13063-019-3603-1

Sheridan, R., Martin-Kerry, J., Hudson, J., Parker, A., Bower, P., & Knapp, P. (2020). Why do patients take part in research? An overview of systematic reviews of psychosocial barriers and facilitators [Article]. *Current Controlled*

Trials in Cardiovascular Medicine, *21*(1), 259–259. https://doi.org/10.1186/s13063-020-4197-3

Siberski, J. (2012). Dementia and DSM-5: Changes, cost and confusion. *Aging Well*, *5*(6), 12.

Skivington, K., Matthews, L., Simpson, S. A., Craig, P., Baird, J., Blazeby, J. M., Boyd, K. A., Craig, N., French, D. P., Mcintosh, E., Petticrew, M., Rycroft-Malone, J., White, M., & Moore, L. (2021). A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *BMJ*, *374*(n2061). https://doi.org/10.1136/bmj.n2061

Social Care Institute for Excellence. (2020, March). *Is dementia a terminal illness?* scie.org.uk/demenita/advanced-dementia-and-end-of-life-care/end-of-life-care/introduction.asp

Spector, A., Orrell, M., Davies, S., & Woods, B. (2001). Can reality orientation be rehabilitated? Development and piloting of an evidence-based programme of cognition-based therapies for people with dementia [Article]. *Neuropsychological Rehabilitation*, *11*(3–4), 377–397. https://doi.org/10.1080/09602010143000068

Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M., & Orrell, M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: Randomised controlled trial [Article]. *British Journal of Psychiatry*, *183*(3), 248–254. https://doi.org/10.1192/bjp.183.3.248

Srivastava, A., & Thomson, S. (2009). A qualitative methodology for applied policy research. *JOAAG*, *4*(2).

Starkstein, S. E. (2014). Anosognosia in Alzheimer's disease: Diagnosis, frequency, mechanism and clinical correlates. *Cortex*, *61*, 64–73. https://doi.org/10.1016/J.CORTEX.2014.07.019

Stokes, L. A., Combes, H., & Stokes, G. (2014). Understanding the dementia diagnosis: The impact on the caregiving experience. *Dementia*, *13*(1), 59–

78. https://doi.org/10.1177/1471301212447157/ASSET/IMAGES/LARGE/10.1177_1471301212447157-FIG1.JPEG

Swaffer, K. (2015). Dementia and Prescribed Disengagement [Article]. *Dementia*, *14*(1), 3–6. https://doi.org/10.1177/1471301214548136

Thorne, S. (2020). The Great Saturation Debate: What the “S Word” Means and Doesn’t Mean in Qualitative Research Reporting. *Canadian Journal of Nursing Research*, *52*(1), 3–5. https://doi.org/10.1177/0844562119898554

Tulving, E. (2002). Episodic memory: From mind to brain [Article]. *Annual Review of Psychology*, *53*(1), 1–25. https://doi.org/10.1146/annurev.psych.53.100901.135114

Vernooij-Dassen, M., Derksen, E., Scheltens, P., & Moniz-Cook, E. (2006). Receiving a diagnosis of dementia [Article]. *Dementia (London, England)*, *5*(3), 397–410. https://doi.org/10.1177/1471301206067114

Walsh, S., O’Neill, A., Hannigan, A., & Harmon, D. (2019). Patient-rated physician empathy and patient satisfaction during pain clinic consultations [Article]. *Irish Journal of Medical Science*, *188*(4), 1379–1384. https://doi.org/10.1007/s11845-019-01999-5

Wang, H., Kline, J. A., Jackson, B. E., Laureano-Phillips, J., Robinson, R. D., Cowden, C. D., D’etienne, J. P., Arze, S. E., & Zenarosa, N. R. (2018). *Association between emergency physician self-reported empathy and patient satisfaction*. https://doi.org/10.1371/journal.pone.0204113

Werner, P., Karnieli-Miller, O., & Eidelman, S. (2013). Current knowledge and future directions about the disclosure of dementia: A systematic review of the first decade of the 21st century [Article]. *Alzheimer’s & Dementia*, *9*(2), e74–e88. https://doi.org/10.1016/j.jalz.2012.02.006

Whitehead, A. L., Sully, B. G. O., & Campbell, M. J. (2014). Pilot and feasibility studies: Is there a difference from each other and from a randomised

controlled trial? [Article]. *Contemporary Clinical Trials*, *38*(1), 130–133. https://doi.org/10.1016/j.cct.2014.04.001

Wittenberg, R., Hu, B., Barraza-Araiza, L., & Rehill, A. (2019). *Projections of older people living with dementia and costs of dementia care in the United Kingdom*.

Wolff, J. L., & Roter, D. L. (2011). Family presence in routine medical visits: A meta-analytical review [Article]. *Social Science & Medicine (1982)*, *72*(6), 823–831. https://doi.org/10.1016/j.socscimed.2011.01.015

World Health Organisation. (2023, March 14). *Dementia: key facts*. https://www.who.int/news-room/fact-sheets/detail/dementia

World Health Organisation (WHO). (2021). *International Classification of Diseases, Eleventh Revision (ICD-11)*. icd.who.int/en

Wu, A. W. (2000). Medical Error: The Second Victim: The Doctor Who Makes the Mistake Needs Help Too [Article]. *BMJ (Online)*, *320*(7237), 726–727. https://doi.org/10.1136/bmj.320.7237.726

Zachariae, R., Pedersen, C. G., Jensen, A. B., Ehrnrooth, E., Rossen, P. B., & Von Der Maase, H. (2003). Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease [Article]. *British Journal of Cancer*, *88*(5), 658–665. https://doi.org/10.1038/sj.bjc.6600798

Zaleta, A. K., & Carpenter, B. D. (2010). Patient-centered communication during the disclosure of a dementia diagnosis. *American Journal of Alzheimer's Disease and Other Dementias*, *25*(6), 513–520. https://doi.org/10.1177/1533317510372924

Extended Paper

1 Extended introduction

This section of the paper provides further contextual information on dementia and memory assessment in the UK. Psychological understandings of sharing a diagnosis of dementia are explained before the current literature around people's experiences and interventions relating to this are explored. The rationale for a feasibility trial and relevance to clinical psychology are also explained.

1.1 Dementia

The term dementia is used to refer to several diseases that affect memory, thinking and the ability perform daily activities, that get worse over time (World Health Organisation [WHO], 2023). Symptoms include changes in mood and behaviour, difficulties with memory, problem solving, word finding and perceiving visual information as well as decision making (WHO, 2023). There are over 200 different subtypes of dementia, each with a different disease process that impacts on the functioning of the brain (Dementia UK, 2023b). The most common types of dementia include Alzheimer's disease, vascular dementia, Frontotemporal dementia and dementia with Lewy bodies. Some people develop multiple types of dementia which is known as mixed dementia (Alzheimer's Society, 2022b). The way individuals are impacted varies. However, many people require high levels of care, particularly in the later stages of the illness when, as well as cognitive changes, physical functioning such as eating, sleeping and moving also become compromised. According to the Office of National Statistics (ONS) the leading cause of death in 2022 was dementia and Alzheimer's disease (Office of National Statistics, 2023). Whilst dementia is not always recognised as such, it is a terminal illness (Social Care Institute for Excellence, 2020).

In 2013, the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013) eliminated the term "dementia" and replaced it with major or minor neurocognitive disorder. This was done to reduce stigma attached to the word "dementia", specifically for older people, placing

more of a focus on decline in functioning than deficits (Siberski, 2012). Limitations of using the word dementia also include it being used synonymously with Alzheimer's disease as well as it being commonly associated with older people, which does not accurately represent the range of aetiology that cause dementias along with it also affecting younger people (Emmady et al., 2022).

The World Health Organization's (2021) International Statistical Classification of Diseases and Related Health Problems (11th ed.; ICD-11 (World Health Organisation (WHO), 2021) is the internationally accepted diagnostic nomenclature and is currently being introduced across the NHS (NHS Digital, 2023). Whilst this system classifies dementia under neurocognitive disorders, the term "dementia" is retained. As the term dementia is most used clinically in the UK, as well as by patients and their carers, this term will be used throughout the study.

1.1.1 Prevalence

In the UK, there are currently around 900 000 people with a diagnosis of dementia (Wittenberg et al., 2019). It is predicted this will rise to over 1 million by 2025 and to nearly 1.6 million by 2040 (Wittenburg, 2019). It is therefore important that research focussing on a better understanding of how people can be best helped is conducted.

The prevalence rate of dementia in the over 65s in the UK is estimated to be 7.1% (Wittenburg, 2019). As age is the biggest risk factor for developing dementia, the percentage of people living with the illness increases as people get older, ranging from 1.7% of people aged 65-69 years to 41.1% of people aged 95 and over. The estimated prevalence of young onset dementia, where diagnosis was made between the ages of 30-64, is 92 per 100 000 of the general population (Dementia UK, 2023). Prevalence rates for young onset dementia among minoritized groups are higher than for the wider population, and people with a learning disability are also at a greater risk of developing dementia at a younger age (Dementia UK, 2023a).

1.1.2 Interventions for dementia

National Institute for Health and Care Excellence [NICE] (2018) recommends a range of interventions that promote cognition, wellbeing and independence for people living with dementia. Group cognitive stimulation therapy (Spector et al., 2001) has been found to be effective in improving people with mild to moderate dementia's quality of life as well as cognition (Spector et al., 2003). Other interventions suggested include group reminiscence, activities that match people's preferences and cognitive rehabilitation to support functional ability.

Pharmacological interventions for dementia include acetylcholinesterase inhibitors that can be used to slow down the progression of symptoms for people with a diagnosis of Alzheimer's disease, dementia with Lewy bodies, Parkinson's disease dementia and mixed dementia (NICE, 2018). Memantine is recommended for use with people who cannot tolerate acetylcholinesterase inhibitors or for those who have moderate to severe Alzheimer's disease, dementia with Lewy bodies and mixed dementia (NICE, 2018). Whilst controversial due to overuse (Barnes et al., 2012), anti-psychotic medication is recommended for people who show persistent aggression or extreme distress and for whom other strategies have not been effective.

1.2 Background to assessment for, and diagnosis with, dementia in the UK.

1.2.1 Memory Assessment in the UK

Memory assessment services were first developed following the introduction of a National Dementia Strategy (Department of Health, 2009). This strategy sought to develop specialist services whose aim was to achieve early diagnosis and treatment of dementia (Department of Health, 2009). The Prime Minister's Challenge on Dementia 2020 (Department of Health, 2015) set the aim of two thirds of people living with dementia receiving a formal diagnosis by the year

2020. A key part of the aims of these services were that the way people were informed of a diagnosis be done sensitively and well. Prior to this, memory clinics were more specialised services that focussed on recruiting people with early Alzheimer's disease into clinical trials (NHS England, 2014) and most diagnoses of dementia were being delivered in primary care, with associated low rates of diagnosis (Department of Health, 2009). This led to the development of specialist services known as Memory Assessment Services (MAS).

MAS provide specialist assessment and treatment for people who have concerns about their memory by multidisciplinary teams. Treatment can include pharmacological as well as non-pharmacological interventions such as education and help to access support (Healthcare Quality Improvement Partnership, 2022). Referrals into services come from GPs who have identified potential symptoms of dementia in a person where reversible causes of cognitive decline have been investigated and dementia is still suspected (NICE, 2018) see Figure 2 for a summary diagram of the dementia care pathway in the UK. The National Collaborating Centre for Mental Health's dementia care pathway (NCCMH) 2018 sets out what good quality care and assessment look like through formal guidance as well as from expectations of people living with dementia and their carers. One of the aims of setting up memory services was to provide local services (Department of Health, 2009) but there have been efforts made to reduce the variability in both rates of diagnosis and quality of care (NCCMH, 2018). An audit of MAS in 2014 shows that the way in which services are delivered varies between areas (NHS England, 2014). Therefore, a description of the MAS that hosted this research is provided.

1.2.2 Information about the service setting of the research

This study was hosted by services within a single NHS trust that has oversight of four MAS across the geographical area it covers. These services provide specialist assessment for people over the age of 65 who are experiencing cognitive changes that could be a result of dementia. People are referred to the service through their GP and are then invited to an assessment appointment with

either a specialist nurse or a consultant psychiatrist. These appointments take place in both the homes of patients as well as in clinics in a hospital setting depending on the discipline of the person conducting the appointment. Following this initial appointment, patients are often referred for a brain scan before the findings of the assessments are then discussed in a multidisciplinary team meeting. Patients who present with increased complexity may require further assessment in the form of functional assessments with an Occupational Therapist (OT) or neuropsychological assessment with an assistant psychologist. Once all necessary assessments have been completed, information is then synthesised, and a diagnostic decision is made by the consultant psychiatrist. This diagnosis is shared with the patient during a 60-minute appointment with the same clinician who conducted their initial assessment. Between appointments, the clinician who conducted the initial assessment is responsible for co-ordinating their case and delivers the appointment to discuss the outcomes of assessments. Depending on the outcome of the assessment, patients are then either discharged from the MAS if they are not given a diagnosis of dementia or given options for treatment and post-diagnostic support. Patients who are prescribed cognitive enhancer medications are offered an annual review with a specialist nurse.

Throughout the assessment process, patients are encouraged to bring someone to appointments with them to provide support and contribute to the provision of collateral information for the assessment process. Arrangements are also in place to work closely with third sector organisations that provide carer support for those supporting someone living with dementia through a joint post-diagnostic group that is run for both patients and their companions.

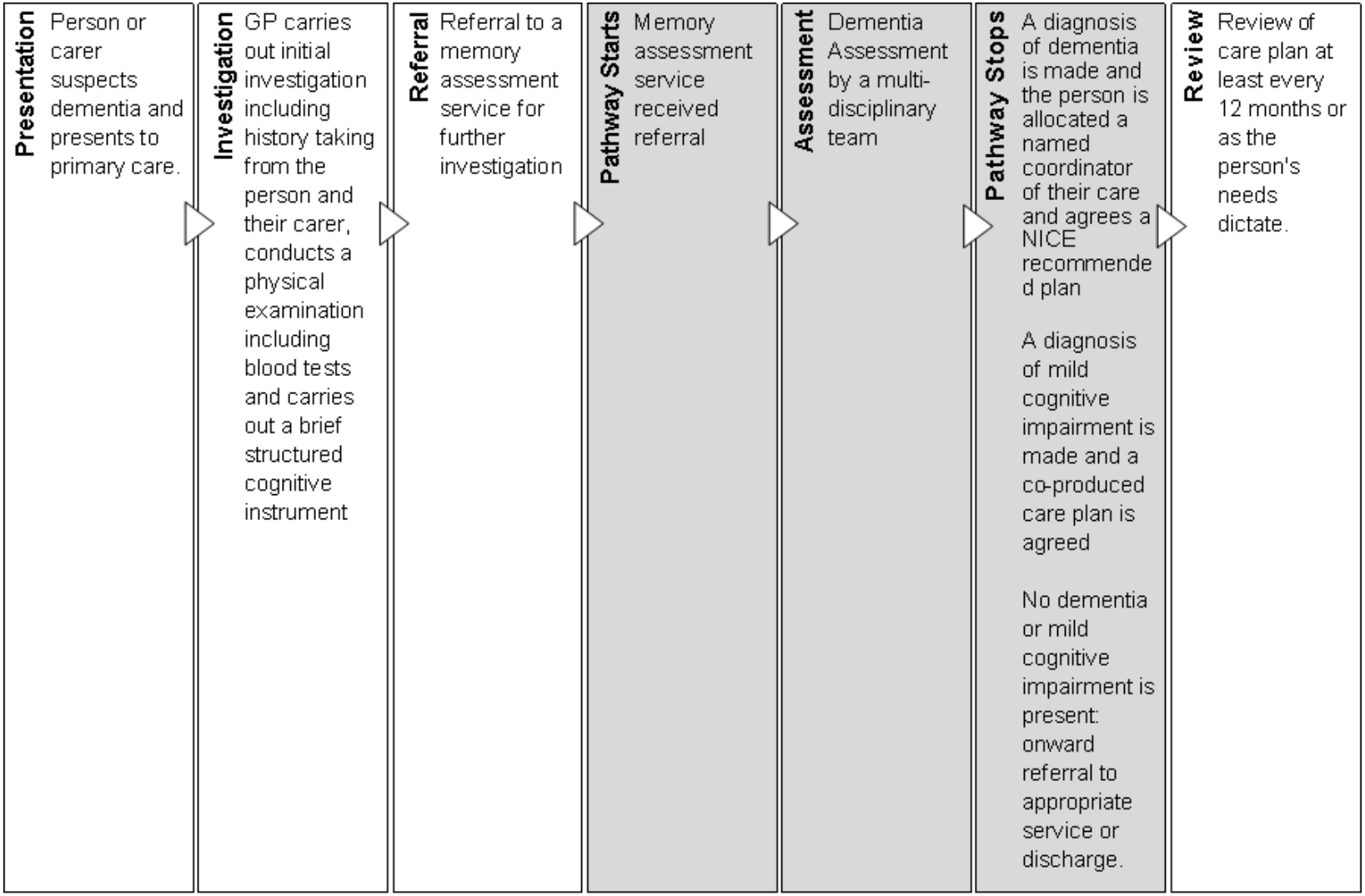
1.2.3 Impact of COVID-19 outbreak on MAS

During the data collection period of this study, the MAS hosting was impacted by the outbreak of COVID-19. The service was closed to new referrals for a period during 2020 and staff were redeployed to other areas. Following this initial shut down, reduced numbers of assessments were conducted using remote

technology to facilitate assessment. This resulted in longer waiting times than usual for initial assessments and subsequent diagnosis.

This is a pattern that was seen nationally. An audit carried out in 2021 (Healthcare Quality Improvement Partnership, 2022), highlighted the impact of the COVID-19 pandemic on MAS. Around 66% of services experienced both closure and redeployment of staff and subsequently average waiting times for assessment and diagnosis in MAS increased from 13 weeks pre-pandemic to 17.7 weeks at the time of the audit. Further barriers to accessing support from MAS during the pandemic included people avoiding face to face services due to a fear of contracting COVID-19 or being a burden on the healthcare system. The backlog in referrals from GPs for assessment and the consequent waiting times means that people are less likely to receive a diagnosis early in their illness (Alzheimer's Society, 2022a) with consequent early-stage drug prescriptions reduced following the pandemic. This risks people living with dementia unable to plan for their futures and access relevant support.

Figure 2 *Dementia care pathway in the UK*



1.3 Psychological understandings of receiving a diagnosis of dementia.

1.3.1 Adjustment to a diagnosis of dementia

Awareness of the symptoms of dementia in people who are in the early stages of the illness was once viewed as a clinical feature, particularly of Alzheimer's disease (Green et al., 1993). Clare (2003) highlighted the role of psychological factors impacting on individual awareness of symptoms and the role of denial in protecting themselves from the changed view that a diagnosis of dementia can bring. Several longitudinal models of psychological responses to dementia have been developed including Cohen et al., (1984), who identified phases that people go through when adjusting to living with dementia. Similar to the five phases described by KuÌbler-Ross (1973) that people experience when they are dying, the model proposes that, whilst not every person experiences each phase and not necessarily in the order identified, the aim of the model is to conceptualise psychological responses to help clinicians and those supporting the person living with dementia to understand their needs at differing stages of the illness. Developed from interviews with several hundreds of people with Alzheimer's disease, Cohen et al. (1984) suggested six stages as follows: pre-diagnosis: recognition and concern; reaction to the diagnosis: denial, anger, guilt and sadness; following the diagnosis: coping, maturation and separation from self.

A similarly longitudinal model is presented by Keady and Nolan (1995a). Based on the findings of interviews with 10 people living with dementia, Keady and Nolan (1995b) developed a measure of coping for clinicians to use as a means of better understanding the needs of people with early dementia. This research then informed the development of the model of the stages that people living with dementia experience. The stages are slipping, suspecting, covering up, revealing, confirming, surviving, disorganisation, decline, death (Keady & Nolan, 1995b).

Whilst longitudinal models give a helpful description of individual psychological responses and identify common experiences of people who have received a diagnosis of dementia, there is little emphasis on the impact of the context in which the individual exists (Pratt & Wilkinson, 2001). The role of psychosocial

factors in influencing how people with dementia are understood was suggested by (Kitwood, 1990). Previous understandings were based on medical models that largely only considered neurological changes as a means of explaining people's experiences of dementia. Kitwood (1990) highlighted the role of a range of social factors that are referred to as 'malignant' and contribute to a loss of self-esteem for the person, which subsequently has a negative impact on their functioning that is often misattributed to being the result of dementia. It is therefore necessary to consider both individual psychological factors as well as the social context in which a person exists.

Pratt and Wilkinson (2003) present a psychosocial model of diagnosis disclosure from the perspective of the person with dementia. The model is based on interviews with 24 people in the early stages of dementia looking at their experiences of being told they have a diagnosis of dementia (Pratt & Wilkinson, 2001). The model suggests two axes that demonstrate the interaction between individual factors of the person and the social context in which they exist. Axis one is a combination of the individual's desire and ability to know or understand their diagnosis. Awareness of dementia is impacted on by a combination of cognitive and psychosocial factors. Psychosocial factors including previous coping styles, interactions with family or friends, the responses of healthcare systems and wider societal attitudes have the biggest impact on the early stages of dementia awareness (Clare, 2002). If someone is both able to understand and wants to know they would be considered 'high' on the axis; low desire and low ability would rate 'low'. This incorporates the individual psychological factors that influence the experience of diagnosis. It also allows for decline over time of cognitive functioning that might impact on the ability of people to understand their diagnosis.

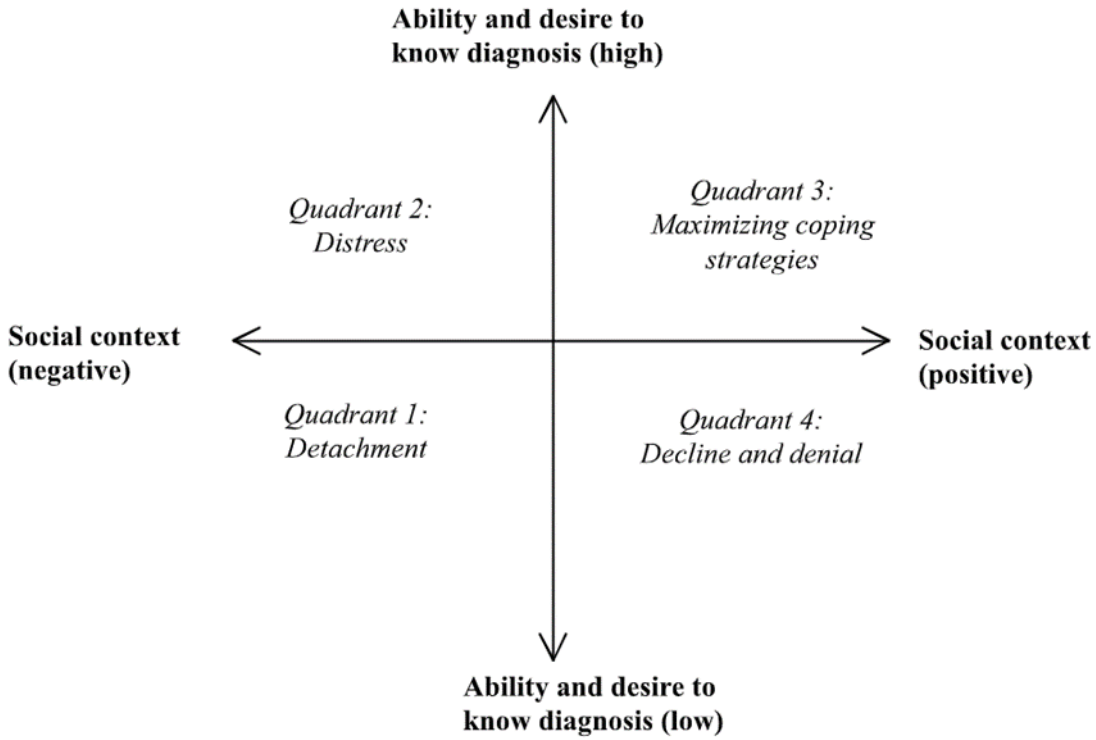
Axis two considers a range of social factors, including impact of family, carers, healthcare systems, social stigma and support. If the social context is supportive for the person, the impact of the social context is closer to the 'positive' end of the axis whereas when the influence is less supportive the impact is nearer the 'negative' end of the axis. (See figure 3 for diagram of the axis).

The aim of the model is to provide understanding of individuals' experiences of being diagnosed with dementia and is not intended to be prescriptive or limit these experiences to the themes described in each quadrant. The model proposes four quadrants produced by the two axes, each describing the possible experiences of an individual: Detachment, distress, maximising strategies and decline and denial.

This model has the potential to be a helpful tool for practitioners to inform the approach taken to individuals' care and what their needs might be. For example, if someone has a negative social context, it would be beneficial for them to be helped to access support services or to provide the people around the person with dementia with psychoeducation that helps them better understand the situation.

Figure 3

A Psychosocial Model of the Experience of People with Dementia (Pratt & Wilkinson, 2003).



However, the model is based on research with people in the early stages of their illness who have received a diagnosis and were willing to take part in research. It is therefore important to be cautious when considering how applicable the model is to people who find out their diagnosis in the later stages of the illness or who have not been told their diagnosis (Harman, 2004).

Milby et al., (2017) studied the perspective of clinicians and patients involved in the process of disclosing a dementia diagnosis. The findings of this study support the dynamic nature of the Pratt and Wilkinson (2003) model. It was found that the social context in which people were adjusting to their diagnosis, coupled with their use of avoidance versus acceptance, influenced their response to their diagnosis. However, other findings of the study contrast with the integration of people's ability and their desire to know their diagnosis proposed by the model, suggesting these are two separate factors. Participants demonstrated a high ability to understand their diagnosis but a low desire to know it. They were also found to use denial as a coping strategy within a negative social context (Milby et al., 2017). Denial was the most common response and allows people to preserve a sense of themselves, cope with loss and manage anxiety about the future.

It is important to note that many of these models are based on the experiences of people who are in the early stages of Alzheimer's disease, which is typically characterised by people first noticing changes in memory. People who are suffering from other types of dementia might experience no change in their memory and the applicability of these models might therefore be variable.

1.3.2 Cognitive psychology and the role of emotion in learning about a diagnosis of dementia

The process of sharing information about a diagnosis of dementia is the point at which the patient first learns of the outcomes of their assessment. Understanding the cognitive processes the action of learning involves, gives some insight into how people process information and the role of emotion in this is relevant when considering how people receive a life changing diagnosis such as dementia.

The working memory model, proposed by Baddeley and Hitch (1974), refers to a proposed brain system that allows the temporary storage and manipulation of information that is needed for cognitive tasks such as language, learning and reasoning known as the “working memory” (Baddeley, 1986). The model suggests working memory consists of three components: the central executive, the phonological loop, and the visuospatial sketch pad. All three components have limited capacity and perform a different role in working memory. The central executive resembles attention and is involved in active processing; it is also thought to have a role in planning and decision making. The phonological loop specialises in rote verbal rehearsal and the visuospatial sketch pad specialises in processing visual or spatial stimuli. The addition of the episodic buffer (Baddeley, 2000) was added after experimental results of several studies. The episodic buffer is thought to provide a link to both long-term memory and the working memory (Baddeley, 2000). The central executive is thought to be associated with activity in the frontal regions of the brain (Baddeley & Hitch, 1974).

The processing efficiency theory outlined by Calvo and Eysenck (1992), theorises that humans have evolved to have a mechanism through which threatening information is paid more attention to as a means of keeping ourselves safe. However, heightened levels of anxiety increase the potency of this stimuli, which is useful where there is a genuine increase in danger but can be problematic if an individual’s threshold for detecting threat is lowered due to previous adverse experiences or a predisposition to anxiety. Normal cognitive processing is disrupted as anxiety reduces the cognitive resources available for task processing activities and therefore reduces the efficiency of information processing (Calvo & Eysenck, 1992). This theory suggests that any task which places high demand on the central executive is more open to disturbance from anxiety or worry. People with Alzheimer’s disease have been found to have reduced functioning of the central executive (Baddeley, 1992).

In contrast to the impact of negative mood states, positive mood states can improve cognitive processing resulting in more creative or divergent thinking (Isen et al., 1987). Individuals in positive mood states are more likely to take in

global details about a situation than individuals in a negative mood state who are more likely to focus on specific details (Gasper & Clore, 2002). The analogy that positive mood means that people see the forest whereas negative mood means that people see the trees is given (Gasper & Clore, 2002). When considering the effects of this in the context of people learning about a diagnosis of dementia, there are clear implications for the type of information that is given as well as the timing of this.

As discussed in the journal article, people who have received a diagnosis of dementia, as well as their carers, report experiencing high levels of distress throughout the process of assessment for dementia (Cahill et al., 2008). This, coupled with potential deficits in cognitive abilities because of dementia, has the potential for the working memory to become overwhelmed and limit individuals' ability to take on board information and understand what is being shared with them in disclosure appointments. Aminzadeh et al., (2007) found evidence that people became overwhelmed by emotion at the time of the disclosure of a diagnosis to the extent that their cognitive ability to take in information was disrupted. This highlights the importance of clinicians making the disclosure doing so in a compassionate way to reduce the distress experienced (Poyser & Tickle, 2019).

1.3.3 The impact of episodic memory impairment on the assessment and diagnostic process.

Whilst a decline in cognitive functioning causing interruptions to a person's ability to complete their daily activities and maintain relationships are characteristic of all dementias, changes in memory are most often associated with the term. Impaired memory is a core feature of Alzheimer's disease, the most common type of dementia, and is why changes in memory are often the first indication of a problem. More specifically, impairments in episodic memory have been found to be one of the most reliable early indicators of Alzheimer's disease (Burnham et al., 2016; Schindler et al., 2017). Episodic memory has been defined as "memory

of events or experiences that can be recalled in relation to a specific time and in a proper order" (Tulving, 2002). The medial temporal lobe, incorporating the hippocampus, is the brain system most associated with episodic memory (Nyberg et al., 1996; Raslau et al., 2015). Whilst changes to the medial temporal lobe can be caused by many of the disease processes associated with dementia, it is particularly vulnerable to amyloid and tau deposits, the hallmarks of Alzheimer's disease (Braak & Braak, 1997; Schöll et al., 2016).

Lack of awareness of changes in memory is often observed in people with Alzheimer's disease, with estimates of the prevalence of this lack of awareness, often referred to as anosognosia, ranging from 20% to 80% (Starkstein, 2014). Mograbi et al., (2009) identified the role memory deficits in early Alzheimer's plays in the development of anosognosia, referring to the "petrified self". They proposed that whilst people with Alzheimer's disease have a stable view of themselves, reflections on the self are unmodified over time because of difficulties integrating new information with existing information to form a coherent view of the self (Mograbi et al., 2009). The person is therefore left with a sense of self that is frozen in time. Gagliardi & Vannini (2022) found episodic memory mediates the relationship between increased disease pathology and anosognosia, providing support for the concept of the "petrified self" for those who have Alzheimer's disease.

Models of how memory and the self are related can explain how awareness of deficits in early Alzheimer's disease, and other dementias affecting areas of the brain, are associated with memory. The Self Memory System framework model (Conway et al., 2004; Conway & Pleydell-Pearce, 2000) proposes that autobiographical memory acts as a database of the self, providing the self with examples, context and grounding to the underlying themes and concepts of which it consists (Conway, 2005). Autobiographical memory is formed from the competing demands of an experience-near record of ongoing goal activity (Adaptive Correspondence) and the need for a coherent and stable record of the self's interaction with the world (Self-Coherence). Being able to answer the demands of both demands is crucial to the healthy functioning of memory and the self (Conway et al., 2004). The model outlines the role of episodic memory in keeping record of recent activities that are combined with autobiographical

memories over a longer period to provide coherence to everyday activities. Disruptions to episodic memory causes difficulties with task completion and reduced adaptive correspondence which results in autobiographical memory becoming less inhibited. When this occurs, a remembered reality is processed in parallel with the present moment and if this continues there is a switch from adaptive correspondence to a greater demand for self-coherence and knowledge based in the long-term self dominates attention (Conway et al., 2004). This breakdown between episodic memory and the self, results in reduced coherence of memories and produces a version of the self that is detached from reality. Thus, the petrified self is caused by deficits in episodic memory resulting from damage to the medial temporal lobe caused by dementia processes and represents someone whose version of the self is detached from reality because of an inability to update said self.

An alternative model is suggested by Agnew and Morris (1998). They highlight the role of episodic memory in providing information to a 'comparator mechanism' in the central executive system that feeds information to 'personal knowledge base' in semantic memory, to identify discrepancies with information regarding ability. This personal knowledge base acts as a personal database against which current performance is compared. When information from the episodic memory highlights a discrepancy with existing information, the personal knowledge base is updated, and this then enters the cognitive awareness system where the individual will experience this as an awareness of a failure of their memory. Failures in episodic memory can therefore mean the personal knowledge base is not able to feed information to the cognitive awareness system about failures in memory and the person is not able to reflect on their own performance and their perception of their own abilities remains stable but inaccurate (Mograbi et al., 2009).

In contrast, Clare (2002) highlights that awareness in dementia is impacted by more than just changes in brain function. Psychological factors also play a part as they protect people from a threatening situation. What may appear as resulting from deficits in episodic memory may actually be a psychological defence against the threat to self that people experienced when in the early stages of dementia. A view also shared by Cheston et al., (2018) who suggest selective forgetting is

a means by which people protect themselves from the distress resulting from the stigma of dementia. A fuller understanding of awareness in dementia can be gained when the interaction between cognitive functioning and psychosocial factors are also considered. This view is in keeping with the model proposed by Pratt & Wilkinson (2003), which highlights the role of how social context impacts on how individuals adapt to a diagnosis of dementia.

Regardless of the causes of a lack of awareness of memory difficulties, the implications for the individual, their companion and for clinicians assessing for dementia are crucial. When someone has little awareness of changes in their cognition, this will result in difficulties comprehending the need for, as well as the process itself, of assessment for dementia. Retaining information from previous appointments that helps them to understand the process is more difficult for people whose episodic memory is affected by dementia. For some people with more advanced deficits in episodic memory, it may not be possible for them to retain information for the duration of the length of an appointment. The result of this is that people risk feeling confused about what is being discussed and how it relates to them. Similarly, the lack of awareness previously considered as either resulting from problems with episodic memory (Agnew & Morris, 1998; Conway et al., 2004), or as a psychological defence (Clare, 2002), is likely to impact on an individual's ability to accept that they have dementia. If they have no awareness of cognitive changes, it may be harder for them to accept that their presentation is in keeping with a diagnosis of dementia. This can subsequently impact on their motivation to act on or recognise the need to implement advice given to them by health professionals. They are also less likely to engage with interventions such as taking medication or social interventions aimed at helping to slow the progression of a dementia.

Furthermore, the absence of informant-rated poor memory is a predictor of misclassification of dementia diagnosis (Ranson et al., 2019). This finding has implications for the accuracy of diagnosis of dementia where episodic memory is not impacted, but also for those people who aren't aware of a memory deficit. The subjective nature of memory impairments means difficulties one person sees as a major problem, are viewed by others as minor (Hill et al., 2017) which is likely to have an impact on the way they portray themselves to others, including

clinicians assessing for dementia. Collection of collateral information from a companion is one means of overcoming the potential lack of awareness to gather information that provides an accurate picture of the person's difficulties.

However, the inclusion of a companion brings complexity to the process. When patients are accompanied to appointments, the nature of discussions can be more biomedical with less psychosocial information given (Wolff & Roter, 2011). Karnieli- Miller (2012) found patients and companions have different expectations of memory assessment appointments, something that is likely to be exacerbated by a lack of awareness of changes in memory by the person being assessed. It is therefore a potential point of conflict between the two parties. This requires clinicians to be skilled in navigating difficult conversations and holding in mind the two different perspectives, requiring advanced communication skills from the clinician (Karnieli-Miller et al., 2007). The inclusion of a companion, whilst helping to overcome the difficulties arising from episodic memory impairments can also change the nature of discussions in appointments with clinicians and result in more complex communication within the triad.

1.4 Breaking bad news

What constitutes bad news has been defined as news that drastically and negatively alters a person's view of their future (Buckman, 1992). However, it is important to note that how news is received varies greatly between individuals and therefore what constitutes bad news is idiosyncratic. Baile et al., (2000) point out the need to establish the person's expectations or understanding before being able to predict what their response to new information might be. Berger and Ribeiro Miller (2022) argue sharing of information about diagnosis should not be conceptualised as breaking bad news. "Sharing" information highlights the active role all parties take in the process. There are no prejudged ideas about how the patient will view the information, some people find it a relief to receive a diagnosis. They also suggest the role of clinicians is more than being the messenger of the news because of the emotional impact sharing information has on them. They highlight the clinician's countertransference as being highly relevant as they are

taking an active role in the exchange. Framing this as sharing helps to create a more reflective encounter, which is more in keeping with a person-centred approach to practice (Berger & Ribeiro Miller, 2022). However, people diagnosed with dementia are likely to have a significantly altered expectation of their future; therefore, receiving a diagnosis of dementia falls under the definition of bad news and patients and clinicians involved in these discussions about dementia diagnoses are similarly impacted (Lecouturier et al., 2008b).

Many clinicians express concern about the harm that sharing a diagnosis of dementia with the patient may have, which impacts on the way they share the outcomes of dementia assessments (Milby et al., 2017; Phillips et al., 2012). This is similar to the wider disparity in opinion about truthfulness in the disclosure of bad news in other areas of medicine (Fallowfield & Jenkins, 2004). Opinions vary about whether to use the term 'dementia' with some clinicians choosing not to use the term (Phillips et al., 2012; Moore & Cahill, 2013; Milby et al., 2017;). A systematic review found there are differences of opinion within the triad about how direct clinicians should be when communicating outcomes. Poyser & Tickle (2019), found patients prefer a direct approach to communicating the outcomes of an assessment for dementia, whereas some companions and clinicians preferred a less direct approach. This highlights a potential source of difficulty in navigating the triadic communication of a diagnosis for clinicians when there are varying opinions about how it should be approached. Meeting the needs of all parties can be challenging, resulting in confusion and unsatisfactory experiences of disclosure appointments (Karnieli-Miller et al., 2012).

Breaking bad news causes significant distress to clinicians to the extent that this aligns with literature on 'Second Victimhood' (Francis & Robertson, 2023). Second victimhood is a concept originally identified by Wu (2000) that recognises the emotional impact of errors and adverse events on the clinicians implicated in them. A process of emotional recovery from such events is necessary for clinicians (Scott et al., 2009). There are implications for staff burnout if this process is not supported in the working environment. This is also pertinent to clinicians sharing bad news with patients and companions and is accompanied by a lack of training and emphasis on self-care (Francis & Robertson, 2023). The

consequence for clinicians is they become less able to attend to patient distress, answer questions, and provide clear communication (Luz et al., 2017). They are also at increased risk of compassion fatigue and burnout (Francis & Robertson, 2023). There is evidence that one of the ways clinicians manage this distress is by using euphemisms or not being open about diagnosis (Karnieli-Miller et al., 2007). This lack of openness can negatively affect the clinician-patient relationship and lead to increased anxiety for patients (Aminzadeh et al., 2007; Karnieli-Miller et al., 2012). However, good communication can enhance the clinician patient relationship and allow better decision-making for treatment (Mastwyk et al., 2014).

There are several factors for clinicians to consider when breaking bad news, such as the setting in which the news is given, ensuring a quiet and private location is provided (Baile et al., 2000). Adequate time should also be given to allow the patient and whoever is supporting them time to ask questions. It is also important that the information is conveyed in a way that is empathic and respectful, using language that is easily understandable to the patient without relying on jargon and technical terms (Monden et al., 2016). Interventions have been developed that aim to develop the communication skills of clinicians in conjunction with experiential learning through role play. The two most used versions of these interventions are the SPIKES protocol (Baile et al., 2000) and the BREAKS protocol (Narayanan et al., 2010). SPIKES is an acronym where each letter represents a phase in a six step sequence: S stands for setting; P for perception; I for invitation; K for knowledge, E for empathy, and S for strategy and summary. BREAKS is similarly an acronym where B stands for background, R for rapport, E for explore, A for announce, K for kindling and S for sumarise. In a meta-analysis comparing observer rated news delivery skills, all protocols were associated with improved clinician confidence and improved quality of communication (Johnson & Panagioti, 2018). The SPIKES protocol was associated with the largest improvements in ratings. However, it was also noted the impact these interventions have on the experiences of patients is yet to be established (Johnson & Panagioti, 2018). Much of the advice about breaking bad news is based on evidence from other medical settings such as oncology services (British Psychological Society, 2014). The complexities of sharing a diagnosis of

dementia include the impact of cognitive changes and the need for clinicians to manage their own emotions whilst simultaneously attending to the needs of their patient and companion (Robinson et al., 2011). The direct application of guidelines developed in other healthcare settings is therefore not recommended for the delivery of a diagnosis of dementia (British Psychological Society, 2014).

1.5 Empathy and satisfaction with healthcare

Delivering healthcare in a way that is person-centred is promoted in the NHS Long Term Plan (NHS, 2019) and has been linked to increased levels of patient satisfaction and more positive experiences of communicating with healthcare professionals (Browne et al., 2010). Increased patient satisfaction is linked to better clinical safety and effectiveness (Doyle et al., 2013) and is, therefore, an important factor in delivering quality healthcare, hence monitoring of this is mandatory in the NHS (Department of Health, 2010). The case for positive patient experience is also a financial one as positive treatment outcomes, greater adherence to treatment, less unnecessary use of healthcare and higher staff satisfaction is also associated, meaning services are run more efficiently and effectively (Nembhard et al., 2023).

Increased levels of satisfaction with healthcare have been found to be associated with the preferences of individuals being considered, and the level of involvement in care offered by professionals matching the wishes of the patient (Campbell et al., 2007). The role of interpersonal factors in achieving person centred care that improves patient satisfaction have been found to be fundamental to effective patient care (Di Blasi et al., 2001). The mechanism through which improved interpersonal factors result in improved clinical outcomes has been suggested to be the perception of empathy in clinicians by patients (Mercer et al., 2008).

Empathy is considered to be the appreciation for another person's feelings, whilst maintaining one's own identity, distinct from sympathy in not joining the person in their feelings (Aring, 1958). Definitions of empathy in healthcare relationships have been more specifically identified as a cognitive attribute that involves understanding a patient's experiences, combined with a capacity to communicate

this understanding with intention to provide help to the patient (Fields et al., 2011). A distinction has been made between the cognitive aspects of empathy and the emotional or affective aspects of empathy, suggesting these are two separate abilities. Cognitive empathy is the capacity to take the perspective of another person and infer their mental state.

1.6 Experiences of people receiving a diagnosis of dementia

People go through an emotional process over the weeks following first receiving their diagnosis (Vernooij-Dassen et al., 2006). Often feelings of shock follow the initial disclosure (Mitchell et al., 2013) as well as grief/emotional crises related to the anticipated losses of living with dementia (Aminzadeh et al., 2007). There is evidence that a common response to diagnosis is denial and avoidance which can be understood as an attempt to manage these feelings of distress (Milby et al., 2017). Denial and avoidance can result in resistance to new information which has subsequent implications for the way people engage with post-diagnostic support (Bunn et al., 2012). Whilst there is evidence that people initially experience distress because of the disclosure of a diagnosis, longer term, people most people do not develop significant psychological distress (Robinson et al., 2005; Milby et al., 2017). Mormont et al. (2014) found disclosure of Alzheimer's disease is not associated with increased risk of developing depression or anxiety in patients or caregivers. There is evidence that people who go through a process of re-evaluation and readjustment to accommodate their diagnosis are less likely to experience continued distress than those who are unable to make sense of their experiences (Lee et al., 2014).

Use of the term 'Alzheimer's disease' has been found to be linked to a higher level of distress than the term 'dementia' or 'vascular dementia' (Aminzadeh et al., 2007). The social context in which a person is living with dementia is likely to have an impact on the response of an individual to a diagnosis and where there is a 'malignant social psychology' (Kitwood, 1990) and the stigma attached to the term 'Alzheimer's disease' is potentially greater than that of other subtypes of

dementia. Aminzadeh et al. (2007) highlight how a negative social context can result in people engaging in coping responses that maintain their distress.

The experiences of companions who have supported someone through the process of receiving a diagnosis of dementia suggest a lack of information contributed to feelings of confusion and frustration (Robinson et al., 2005; Karnieli-Miller et al., 2012; Lee et al., 2014; Stokes et al., 2014). They also identified a lack of guidance about the prognosis, what the next steps for treatment were and solutions (Robinson et al., 2005; Karnieli-Miller et al., 2012).

The need to express hope when sharing a diagnosis of dementia has been identified as important to both patients and companions (Byszewski et al., 2007; Phillips et al., 2012). Given the degenerative nature of dementia, this can be a difficult task for clinicians as there is a need to balance hope with honesty about prognosis of the illness. This can result in the truth of the diagnosis being presented in a way that is unclear or uncertain, leading to feelings of hopelessness for the patient (Low et al., 2018). The way a diagnosis is framed has as much impact on individuals as the impact of the disease on their cognitive abilities. Therefore, the way is shared by professionals and services has the potential to influence people's experience of it (Mastwyk et al., 2014) as well as subsequent adaptation to living with dementia (Hare, 2023). When done well, clinicians manage to balance hope and uncertainty (Bailey et al., 2019) the result of which is patients and their companions experience the truth, less hopelessness, and more hope for the future (Monden et al., 2016). This contrasts with the experiences people report of the way in which they first heard of their diagnosis. Low et al. (2018) found that health professionals often framed dementia negatively and that being diagnosed with dementia implied reduced social status, fitting with the stigmatised view of people with the diagnosis. The way a person views their diagnosis has been found to be linked to measures of wellbeing including low mood. Clare et al. (2016) found people who viewed their diagnosis as an illness were more likely to have better awareness of their condition but lower mood than people who did not use diagnostic labels and viewed their difficulties as resulting from the ageing process.

People find having a diagnosis brings them benefits. People have described feeling relieved that the difficulties they have been experiencing can be explained by the presence of a disease rather than merely aging (Mitchell et al., 2013). Other benefits include allowing a better understanding of their experiences; the opportunity to plan for the future; increased support from those around them and access to both pharmacological and psychological treatments (Bamford et al., 2004; Robinson et al., 2015).

However, people with dementia face stigma and discrimination because of their diagnosis (Merl et al., 2022; Nguyen & Li, 2020). There is evidence that reading and thinking about dementia, as well as having contact with people with dementia increases death related thoughts with subsequent heightened anxiety about death (Cheston et al., 2022; O'Connor & McFadden, 2012). Cheston et al. (2022) suggests strategies to protect younger people from this anxiety are what can result in development of ageist attitudes as they avoid contact with older people. This becomes more difficult as people age and other strategies are therefore relied upon to reduce anxiety, including types of selective forgetting (Cheston et al., 2018). When considering this in relation to the process of assessment for dementia, patients and companions facing the prospect of a diagnosis, as well as clinicians with whom they come into contact, are likely to similarly use psychological strategies to manage their feelings of anxiety. This has the potential to result in practice that is less patient centred and potentially increases the distress experienced by patients and companions.

Emotional or affective empathy is an observer's emotional response to another person's emotional state (Dziobek et al., 2007). Thus, there are several different facets to empathy. The development of empathy in healthcare professionals has been found to be possible through education and training (Hojat, 2009) and is included in the curriculum of professional training courses (Moudatsou et al., 2020).

The reason for inclusion in training is that ratings of empathy have been found to be correlated with higher levels of patient satisfaction (Walsh et al., 2019; Wang

et al., 2018). Whilst this correlation does not prove a cause and effect, it suggests that the two constructs are related. Empathy and improved therapeutic relationships are also linked with improved outcomes in psychotherapy (Luborsky, 1971; Horvarth & Luborsky, 1993). Similarly, the level of the bad news communicated has been found not to contribute to patient's acceptability of the news (Munoz Sastre et al., 2011). Quality of the information given, and the emotional supportiveness of the clinician accounted for 95% of the variance of patient's acceptability judgements. Low emotional supportiveness could not be compensated by high quality of information or the inverse. This suggests the process of sharing a diagnosis of dementia is likely to be linked to increased clinician empathy.

1.6.1 Existing guidance for sharing the outcomes of a memory assessment.

The recognition of the difficulties in sharing a diagnosis of dementia (Karnieli-Miller et al., 2012; Milby et al., 2017; Bailey et al., 2019) and the potential for this to have a negative impact on patients and carers (Swaffer, 2015; Low et al., 2018) has led to a recognition of the need for interventions that improve the process for clinicians, patients and companions (Werner et al., 2013; Poyser & Tickle, 2019).

A model for the disclosure of dementia was developed by Derksen et al., (2006). The model identified five phases of disclosure including introductions, sharing the diagnosis of dementia, space for emotions, further explanations and continuity of care. A separate counselling meeting with a nurse practitioner is the final element included in the model. Each phase has identified tasks as well as potential pitfalls. Training sessions are also stipulated in which the model is discussed, and role play provides a chance for feedback. Nurse practitioners then receive instructions separately on the content of the counselling meeting (Derksen et al., 2006)

A theory-based intervention that aimed to promote the appropriate disclosure of a diagnosis of dementia was devised (Foy et al., 2007). This intervention is a paper-based behavioural intervention that focused on three key elements of communicating a diagnosis of dementia. Establishing the current understanding the patient has of their diagnosis, using the words 'dementia' or 'Alzheimer's

Disease' and discussing the meaning the patient places on diagnosis are the behaviours identified by the intervention as key for clinicians to engage in (Foy et al., 2007). An evaluation of the intervention found that, whilst there was some improvement in attitudes and perceived control of clinicians in relation to finding out what the patient already knows, there were no significant differences observed because of the intervention (Eccles et al., 2009).

In recognition of the disclosure of dementia being a process rather than a one-off event, Lecouturier et al. (2008b) identified that the three behaviours targeted by the previous intervention were not sufficient. They used a literature review supplemented with interviews and a consensus process to identify eight categories of behaviours. These behaviours include preparing for disclosure, integrating family members, exploring the patient's perspective, disclosing the diagnosis, responding to the patient reactions, focusing on quality of life and well-being, planning for the future, and communicating effectively.

A comprehensive set of quality standards have been identified by the Memory Services National Accreditation Programme that cover all stages of dementia diagnostic care (Royal College of Psychiatrists, 2022).The full set of standards is aspirational, and it is recognised no service is likely to meet all of them. Standards are split into three categories which services are measured against to achieve accreditation. These guidelines are targeted at a service level rather than directly at MAS clinicians, patients and companions.

A tool to support the diagnostic delivery of dementia was developed by Bennett et al. (2018). This prototype tool was developed to be used by clinicians, patients and companions who are involved in the delivery of dementia. The tool was developed based on the perspectives of MAS clinicians, patients and companions on what makes a good delivery of a diagnosis. Two versions of the tool were created, one for clinicians working in MAS to support reflective practice and skill development. The other was for patients and companions using a MAS, including separate sections for patients and their companions to allow for both parties to represent their opinions. The patient and companion's version contains sections for people to write down their main concerns and choices. Preliminary findings of acceptability were found to be positive; however, this was based on

the opinions of the participants who had been involved in the development of the tool.

1.7 Feasibility Cluster Trial

The use of feasibility and pilot trials to assess feasibility and acceptability is recommended by the Medical Research Council (MRC) as a key stage in developing complex interventions (Skivington et al., 2021). The value of feasibility studies is established (Eldridge et al., 2016) as they provide a means of reducing uncertainty around recruitment, data collection, retention, outcomes, and analysis (Skivington et al., 2021). The MRC makes no distinction between feasibility and pilot studies and have developed the Consolidated Standards of Reporting Trials (CONSORT) statement as a guideline to improve the quality of feasibility randomised trials (Eldridge et al., 2016) as well as non-randomised pilot and feasibility studies (Lancaster & Thabane, 2019).

The value of preliminary work such as feasibility trials is recognised by funding streams, for example, the UK National Institute for Health Research (NIHR). Feasibility studies have been defined as studies used to estimate parameters that are needed to design the main study, for example, standard deviations of outcome measures, willingness of clinicians to recruit participants, number of eligible people, and response rates (Whitehead et al., 2014). Pilot studies are traditionally smaller versions of the main study, run with smaller sample sizes, used to determine if the components of a study work together (Whitehead et al., 2014).

1.8 Relevance for clinical psychology

Clinical psychology is well placed to aid the development of knowledge and practice in the early stages of dementia care, including the delivery of diagnoses (British Psychological Society, 2014). Clinical psychologists work in memory assessment providing psychological input to the process of assessment for

dementia through use of their skills in neuropsychological assessment. The therapeutic clinical skills in which psychologists are trained mean they are expert in both communication and providing emotional support; the latter are skills highly relevant to the communication of a diagnosis of dementia. This, coupled with the research skills required of clinical psychologists, places them in a strong position to develop training and provide support to other professionals to improve the communication of diagnoses of dementia (British Psychological Society, 2014).

1.9 Epistemological position

The epistemological position adopted for this study is pragmatism. Howe (1988) posited the use of the pragmatism paradigm to counter the argument of the incompatibility of the realism and constructivist paradigms. Beliefs about knowledge and reality dictated by these paradigms determine research questions and methodology based on the assumptions they make (Morgan, 2017). Tashakkori and Teddlie (1998) state the primacy of the research question as key in pragmatism and by using any research methods available research questions are addressed using the principle of “what works”. Less reliance on predetermined beliefs about knowledge and reality means that pragmatism allows the use of diverse approaches to research and values both objective and subjective knowledge (Morgan 2007) and this is what links it most directly to mixed methods research (Morgan, 2017).

2 Extended Methods

2.1 Recruitment

During the baseline recruitment period, it became apparent recruitment of patients and companions would not be as straightforward as hoped. One consequence of this was that an extension to the recruitment period for the baseline data was applied for. Meetings with MAS clinicians revealed that one clinician had been confused about what to do with participant information sheets.

Time was spent clarifying study procedures with clinicians ahead of recruitment in online meetings.

Meetings with administrators from each team were also conducted to explain the procedure for sending out study information with appointment letters. This gave them the opportunity to ask questions. Written instructions were also given via email.

Following no uptake from patients and companions during the first weeks of the recruitment period, attempts to improve recruitment to the study were made. This included sending weekly emails to clinicians updating them on recruitment to the study and encouraging them to ask questions or make suggestions. Meetings with assistant psychologists in both teams also took place to discuss recruitment. They raised recruitment to the study with clinicians during team meetings to maintain awareness of the study.

Clinicians suggested a possible solution could lie in patients and companions being provided with a prompt to look at study information during routine calls that were taking place to screen for the presence of COVID-19 symptoms prior to appointments taking place.

Once it became clear recruitment of patients and companions was not possible with the current strategy, the engagement of clinicians in both MAS teams was recognised as an opportunity to conduct a more detailed assessment of the acceptability of the guide from the perspective of clinicians using the Theoretical Framework of Acceptability (Sekhon et al., 2017b). Clinicians that had previously not responded to the invitation to participate in the study were contacted again to ask if they would consider taking part in semi-structured interviews giving their

opinions on the guide. This was done in an attempt to improve how representative the sample of clinicians was.

2.2 Measure

As previously described, the Consultation and Relational Empathy questionnaire (Mercer et al., 2004) was used to measure clinician empathy ratings by patients and their companions. Respondents are asked to rate 10 statements about their consultation with the clinician using a five-point Likert scale. An example item from the scale is given in figure 4. Each item is scored according to the scoring system of 'poor'=1, 'fair' = 2, 'good' = 3, 'very good' = 4, and 'excellent'= 5 with total scores ranging from a minimum of 10 to a maximum of 50. Higher scores indicate higher clinician empathy levels.

Figure 4.

Sample Item from the CARE Questionnaire (Mercer, 2004)

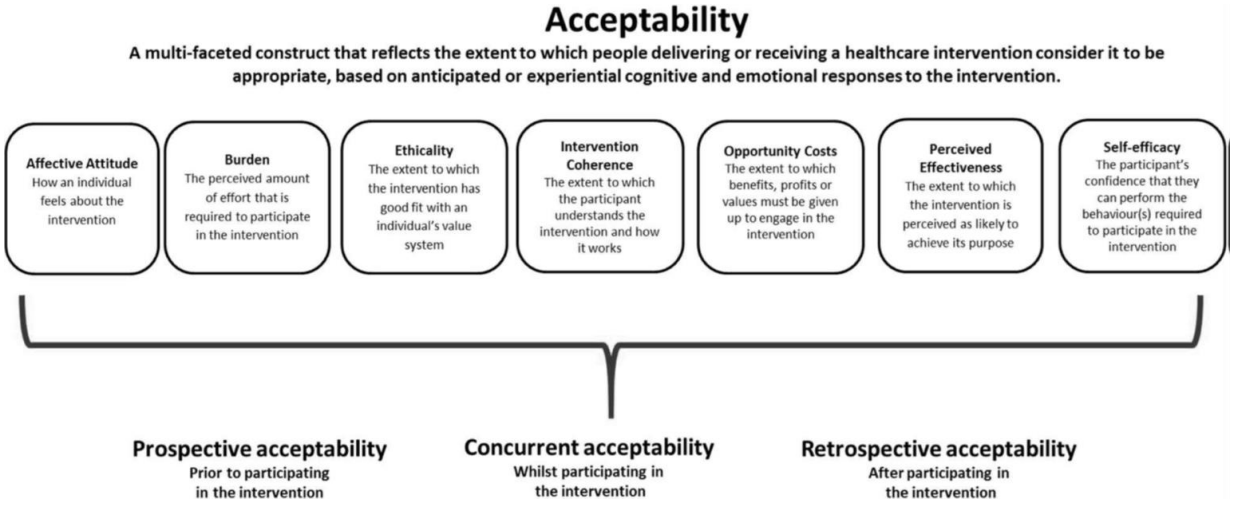
How was the clinician at…	Poor	Fair	Good	Very Good	Excellent	Does not Apply
5. …fully understanding your concerns? *(communicating that he/she had accurately understood your concerns; not overlooking or dismissing anything).*						

2.3 Theoretical Framework of Acceptability

As discussed in the journal article, the Theoretical Framework of Acceptability (TFA) was developed by (Sekhon et al., 2017b). This was used to develop the topic guide for semi-structured interviews assessing the acceptability of the guide. Figure 5 shows the TFA, including the seven constructs of which it is comprised. The constructs are presented alphabetically but it is recognised they may cluster together.

Figure 5

The theoretical framework of acceptability (Sekhon et al., 2017b)



A key feature of the framework is the recognition of temporal features of acceptability. The TFA distinguishes between prospective, concurrent and retrospective acceptability. The review of literature on which the framework is based found acceptability is assessed before (prospective), during (concurrent) and after (retrospective) using an intervention. Assessing acceptability at these different time points can reveal different aspects of acceptability. It is recommended that thought is given to the purpose of the acceptability assessment. This study focussed on concurrent acceptability as it was being assessed after clinicians had experience of using the clinician section of the guide

but did not yet have experience of using the guide to inform a consultation with patients and companions. The authors recommend the use of the TFA in the feasibility phase of evaluation of complex interventions as described by the Medical Research Council (MRC). The TFA has been used qualitatively in conjunction with the framework approach but can also be used to assess acceptability quantitatively using ratings or the recently developed questionnaire based on the theory (Sekhon et al., 2022).

2.4 Intervention

As discussed previously, the guide was originally developed by Bennett et al. (2018). The guide consists of two parts. The first part is a resource for clinicians that is intended to be used to inform practice and guide reflection and supervision on their experiences of sharing the outcomes of memory assessments. The clinician section of the guide is a written document covering five pages. An outline of the contents of the clinician version of the guide is provided in table 10.

Prior to conducting appointments with patients and companions, clinicians familiarise themselves with the contents of both sections of the guide. In this study, this was done with the aid of a training video prepared by the research team combined with a virtual meeting where clinicians had the opportunity to ask questions about how to implement the guide.

Table 10

Contents of the Clinician Section of the Bennett et al., (2019) Guide

Section	Sub section	Content
Introduction		Background and aims of the guide
Looking after yourself		Discussion of the emotional impact of the disclosure of a diagnosis on clinicians.
What makes a good delivery?	Attending the appointment	Attending the appointment and access issues
	Environment	The environment in which the appointment takes place
	Terminology	The use of terminology and using the word 'dementia' from the outset.
	Patient as the focus	Keeping the patient as the focus whilst balancing the needs of the companion.
	Consent	Consideration of the Mental Capacity Act (2005) and informed consent.
	Engagement	Promoting conversation in appointments
	Information and understanding	Providing information to promote understanding of a diagnosis
	Emotional support	How to incorporate emotional support into conversations.
	Adaptation	Addressing the needs of individuals
	Closing an appointment	What to consider when ending an appointment.

The second part of the guide is for patients and their companions who are supporting them through the assessment process. Like the clinician section, this is a written document. It contains written information about what to expect from the assessment, information about dementia and where support can be found. There is a section for patients to identify what changes they have noticed and their preferences for how they would like to be told about the outcome of the

assessment. There is a separate section for use by companions that gathers the same information as for patients but from the perspective of the companion. An outline of the patient/companion version of the guide is provided in table 11.

Table 11

Contents of the Patient Companion Section of the Bennett et al., (2019) Guide.

Section	Content
Introduction	Information about what is contained in the guide.
Memory Assessment Service	A summary of what a MAS is, the format appointments will take and the type of assessments that patients might be asked to complete.
Bringing someone with you	an invitation to bring someone to appointments and the reasons why this can be helpful.
Main concerns and Questions	An explanation of why it can be helpful to write down things to discuss at appointments.
Making Choices	Options for patients to consider about how much they would like to know about a diagnosis and who to share it with.
What is dementia?	A summary of what dementia is and the types there are.
Extra information and help	Information on sources of support available.
Appointment notes sheet	This contains questions and space for responses to be recorded about changes they have noticed and difficulties they may have been having.
Second appointment notes sheet	This is provided for the use by the person supporting the patient at the appointment, allowing information from a different perspective to be sought.

2.5 Ethical Approval

The study protocol and supporting documentation were prepared and submitted for ethical approval via the Integrated Research Application System (IRAS) for Health Research Authority (HRA) approval. The University of Nottingham Research Governance Team granted ethical approval prior to submission for consideration by a Research Ethics Committee (REC). Approval was granted through the Brighton and Sussex REC (approval number: 21/LO/0214) (See Appendix A for approval letter). To recruit from Northamptonshire Healthcare NHS Foundation Trust, ethical approval was sought and granted through the trust Research and Innovation Team (see Appendix B for approval letter). This study was also carried out in accordance with the Code of Human Research Ethics (British Psychological Society, 2021).

An application for a non-substantial amendment was made to the recruitment process for the extension of the recruitment period for baseline data collection as this was not included in the original procedure. As this was a non-substantial amendment, approval from the University of Nottingham Research Sponsor was sufficient and no further approval was required.

2.6 Informed consent

All participants provided written informed consent. Participants in the baseline cohort provided implied consent by returning completed questionnaires. For the study cohort, the Informed Consent Form (See Appendices I to M for consent form) was signed and dated by the participant before they entered the trial. The Investigator explained the details of the trial and provided a Participant Information Sheet (See Appendices N to T for all PIS related to the study), and ensured participants had enough time to consider participating or not. The Investigator answered any questions that the participant had concerning study participation.

Informed consent was collected from each participant before they underwent any interventions related to the study. One copy of this was kept by the participant, one by the investigator, and a third was retained in the patient's hospital records where relevant.

MAS clinicians were familiar with the principles of the Mental Capacity Act (2005) and used these to guide decisions regarding an individual's capacity to give informed consent to the study. There was potential for changes and fluctuations in capacity to give informed consent for patients undergoing assessment for cognitive deficits. It was therefore important that patient's capacity to consent was considered at each stage of their involvement in the study. If there was reason to doubt a person's capacity to give informed consent, they were withdrawn from the study.

Consideration was given to including patients who do not have the capacity to give informed consent under the Mental Capacity Act (2005). The reliance on MAS clinicians to recruit participants during initial assessment appointment meant the responsibility would be theirs to conduct and document capacity assessments to formally establish this. This would have added further burden onto both the MAS clinician and the patient whilst the ultimate responsibility for the study lay with the Chief Investigator who had no means of ensuring this process was carried out to the required standard. Therefore, if the clinician had any reason to doubt the person's ability to give informed consent, they were asked not to recruit the person to the study.

2.7 Confidentiality

Individual participant medical information obtained as a result of this study was considered confidential. Participant confidentiality was further ensured by utilising identification code numbers to correspond to treatment data in electronic files. Hardcopy participant data was stored securely in the trial folder in a locked office at the University of Nottingham. Following scanning of hard copies of data onto

the University of Nottingham's secure server, hard copies were securely destroyed.

The exception to confidentiality was if information was disclosed during the study that could pose a risk of harm to the participant or others; the researcher was required to discuss this with the chief investigator and where appropriate report accordingly. This was included in participant information sheets. Participants were aware that where possible, any breach of confidentiality would be shared with them before information was shared outside of the research team.

2.8 Framework analysis

Framework analysis, initially developed by Ritchie & Spencer, (1994), is an approach to Thematic Analysis that uses a structure to inform the approach. A central feature of framework analysis is the development of a detailed coding framework by the researcher (Barker et al., 2016). This can be done using *a priori* based on previous research, theory or the questions asked in the interview protocol but can also be done inductively, based on the data collected. The output of the approach is a matrix of themes that can be used to answer research questions. This matrix provides a structure into which researchers can systematically reduce the data to analyse it case by case and code by code (Gale et al., 2013).

The five stages of framework analysis identified by Ritchie & Spencer (1994b) were followed in the analysis of the qualitative data. A summary of each stage and how analysis was conducted by researcher (AS) is provided below:

2.8.1 Stage 1. Transcription

Audio recordings of interviews were transcribed using a paid transcription service. The transcripts developed were formatted to include large margins,

which allowed for later coding and note making. Any spelling errors made during transcription were corrected by listening back to audio recordings of interviews whilst reading transcripts.

2.8.2 Stage 2. Familiarisation with the interview

This stage of the analysis involves becoming familiar with each interview, using recording or transcripts as well as reflections. This was done by listening back to each interview and making reflective notes. See Appendix S for example section of a transcript with notes and codes. I also spent time reading the reflective notes made after conducting each interview in my research diary. All data was reviewed at this stage due to the small amount of data collected, however, Srivastava & Thomson (2009) suggest this is not a necessary requirement of the analysis.

2.8.3 Stage 3. Coding

Each line of the transcript is then coded, with all important aspects labelled. This was done using the deductive codes from the TFA, as well as feasibility aspects of the study (recruitment, burden of procedure, measures). Inductive codes were also identified using open coding (Gale et al., 2013) to identify data relevant to the research questions that did not fit with these deductive codes.

2.8.4 Stage 4. Charting and developing the framework

Once this process had been done for one transcript, the coding was shared and discussed with other members of the research team to reach consensus before the other transcripts were then coded. Codes were then grouped together to form the working framework. An iterative process was then followed to develop a framework that incorporated all the codes.

2.8.5 Stage 5. Applying the analytical framework and charting the data

The working framework was then applied to index all transcripts, using the existing categories and codes. Any new codes or categories that emerged were incorporated into the working framework. The matrix was generated using a paper chart where each column represented deductive and inductive codes, and each row, a participant. Appendices T and U shows extracts from the process. Regular meetings with DDB and NGM helped to develop the codes into themes.

2.8.6 Critique of Framework

A strength of the framework approach is that it can help the management of large amounts of unwieldy qualitative data (Gale et al., 2013). The charting process that is a key feature of the approach is also a way in which all members of the research team can interact with the data (Gale et al., 2013). This was particularly useful in this study due to the lack of experience of AS who led the data analysis. It also helped to build the credibility of the analysis. Another strength of the approach is that data is kept within the context of the case and thereby maintains detail. A further strength of the approach for this project is that it is not aligned with a particular epistemological stance, which allowed both inductive and deductive analysis of the data and fits with the pragmatic approach taken to this study.

Further strengths of the approach have been identified by Ritchie and Spencer (2002), which have been repeated by Goldsmith (2021) and are summarised in table 12.

Table 12

Strengths of Framework Analysis (Ritchie & Spencer, 2002).

Feature	Description
Grounded or generative	Heavily based in and driven by the original accounts and observations of the people it is about.
Dynamic	Open to change, addition and amendment throughout analysis.
Systematic	It allows methodical treatment of all similar units of analysis.
Comprehensive	It allows a full, not partial or selective, review of the material.
Enables easy retrieval	Allows access to, and retrieval of, the original textual material.
Allows between and within-case analysis	Enables comparisons between, and associations within, cases to be made.
Accessible to others	The analytic process, and the interpretations derived from it, can be viewed and judged by people other than the primary analyst.

Criticisms of the framework approach include the risk of it being seen as a technical approach to qualitative analysis because of the matrix and its similarities with a spreadsheet. Gale et al., (2013) argue there is a risk of this detracting from the interpretation, reflexivity and conceptualisation that is key to qualitative analysis. They also point out the large amounts of time that it takes to use the approach, especially when multiple stakeholders are involved in analysis.

2.9 Researcher Impact

Guidelines for framework analysis identified by Gale et al., (2013) recommend the use of a reflective diary to maintain reflexivity in relation to qualitative data. A research diary was kept, which noted practical steps taken during the delivery of the trial as well as reflections on my experiences of conducting it. This helped me to become aware of my own assumptions or biases and think about how these might be managed to limit the impact on the findings. One such example is the

enthusiasm I felt about the guide at the outset of the study[15]. This had the potential to bias the way I conducted the semi-structured interviews. By using a reflective diary, I became aware of this risk and was able to take steps to minimise the impact.

Use of regular supervision with two experienced researchers who were also clinical psychologists helped me to think objectively about inferences made of the data during analysis and incorporate alternative interpretations.

[15] For a detailed reflection on this please see the reflective section 5.

3 Extended Results

The impact of COVID-19 pandemic on recruitment

Clinicians estimated that around 50% of the patients they were seeing once the service re-opened after being decommissioned during the first wave of the pandemic lacked the capacity to consent to taking part in the study. Clinicians gave anecdotal evidence that this was higher than prior to the pandemic when waiting times for assessment were shorter. Attempts to gain data to establish if this was a contributing factor to the difficulties experienced with recruitment were made. Diagnosis numbers and ACE-III scores from February 2020, prior to the COVID-19 pandemic and February 2022 when most of the restrictions to mitigate against the risk of COVID-19 were lifted were compared to provide a more objective measure of whether people were more impaired at the point of initial assessment. Data was available from one of the services that took part in the study. In February 2020, 11 diagnoses were made and 22 in February 2022. A comparison of ACE-III scores found that scores were slightly lower in February 2022 (*M*=68.69, *SD*=22.32) than in February 2020 (*M*= 71.62, *SD*=22.32). Small sample sizes make statistical comparisons of the two time points unreliable, however, these scores do not support the suggestion that people presenting post-pandemic were more cognitively impaired than prior to the pandemic.

4 Extended Discussion

This section will expand upon the issues discussed in the journal paper beginning with a consideration of the findings in relation to the original aims and objectives the study which were to firstly ,explore the acceptability of a guide to inform the diagnostic delivery of dementia with MAS clinicians, patients, and companions and secondly, to establish the feasibility of the current study design for a full trial to establish effectiveness of the Bennett et al., (2019) guide – a discussion of how the study met these aims can be found in the journal article discussion. The strengths and limitations of the study will also be considered along with areas for future research.

4.1 Aim 1: Explore the acceptability of a guide to inform the diagnostic delivery of dementia with MAS clinicians, patients, and companions.

For a review of how this aim has been met, see the journal article discussion section.

4.2 Primary objective: To determine the acceptability of a guide supported consultation for MAS clinicians, patients, and companions, in comparison to usual care using the TFA.

Framework analysis allowed the use of the TFA to structure the development of themes around the constructs that contribute to the acceptability of interventions as well as inductive themes that clinicians spoke about that were not related to the TFA constructs but were relevant to the acceptability of the intervention.

Clinicians spoke about the guide in relation to its potential use in their own practice. This also provided their perspectives of how the guide would be experienced by patients and companions. Clinicians identified the function of the guide that allows the views of patients and companions to be collected separately, and confidentially, without the knowledge of what the other person has written, was helpful to them as providing separate forums allowed patients and companions to express their views even if they differed. Clinicians felt this

helped reduce distress arising from disagreements within appointments and made it easier for them to facilitate what can sometimes be emotionally charged conversations. This was particularly relevant to the Ethicality construct in the TFA as clinicians recognised there is potential for the questions they ask during assessments to be probing and cause distress to patients possibly aggravating existing tensions in relationships between patients and companions. Therefore, the guide presents a means through which relevant information needed for the diagnostic process can be gathered without causing unnecessary distress.

The guide was viewed as a vehicle for standardising how assessment for dementia can be conducted. This was seen as beneficial by clinicians as the features of assessment would then be common and consistent to all practice, regardless of discipline or personal style improving the quality of service that patients experience, regardless of who conducts the assessment. Similarly, if adopted more widely, this would ensure a standard of practice across MAS services. This links to the perceived effectiveness construct of the TFA, as clinicians valued that the guide supported them in delivering high quality, standardised care.

The potential for the guide to be used as a training resource for new clinicians to the process of dementia assessment was also indicated. Clinicians spoke about their feelings when they first joined the service and how they were expected to share diagnoses without having formal training. The guide provides them with explicit guidelines on the processes of delivering a positive disclosure, which was previously absent. Whilst this theme did not relate to any of the constructs of the TFA, it is relevant to the acceptability of the guide for clinicians, as it demonstrates an enthusiasm and willingness to use it in future practice.

The balance between honesty about the purpose and outcomes of assessments, and the potential to cause distress in patients through discussion of sensitive subjects, was something clinicians expressed ambivalence about. Some clinicians liked how the guide explicitly discusses the purpose of the assessment from the outset as this means patients and companions can give informed consent. However, other clinicians were concerned that by using the word ‘dementia’ from the outset of the process, there is a risk that patients will become

unnecessarily worried. Similar ambivalence was felt around the option for people to not be told the outcome of their assessment if this was their wish. Similar concerns about the potential for emotional harm for the patient in the future by finding out in an uncontrolled manner about their diagnosis were expressed by some clinicians. The practicalities of not sharing a diagnosis presented clinicians with a dilemma. They are required to carry out tasks related to the patient's diagnosis of dementia, such as discussing medication and informing the relevant agencies about the diagnosis for things such as council tax discounts and driving insurance companies, without the person being told that they have a diagnosis. Clinicians felt these conversations would require them to speak euphemistically about the implications of the diagnosis and potentially administer medication without informed consent. There was a feeling that even if the patient is not informed, their companion needs to be as a means of taking care of some of these practicalities. The need to balance patient-centred practice with informed consent is one of the ethical dilemmas faced by clinicians; the solution proposed by the guide did not align with the values of all clinicians interviewed.

Clinicians discussed how patients and companions might experience the guide. Whilst overall perceptions of the guide from patient and companion perspectives were high; all clinicians identified the amount of reading and paperwork patients and companions were required to complete as a potential barrier. Clinicians felt the guide placed a burden on the patient and companion that their existing practice does not. This was attributed to the amount of reading expected of patients and carers and the expectation that they will complete paperwork prior to their appointment. As discussed previously, the levels of distress experienced during the assessment process can make it more difficult for people to engage with new information, something clinicians identified as having the potential to prevent them from making use of the guide prior to their initial appointment in its current format. This indicates a need for further development of the guide, however, lack of acceptability data directly from patients and companions means it is not currently possible to make conclusions about this; recruitment difficulties experienced by clinicians may also have contributed to this opinion. However, it is not possible to determine if acceptability of the guide was a contributing factor to the difficulties recruiting to the study. The lack of recruitment in both arms of

the study suggest that the guide itself is not necessarily a causal factor as it was only sent to patients and companions at one site.

4.3 Aim 2: To establish the feasibility of the current study design for a full trial to establish effectiveness of the Bennett et al., (2018) guide.

For discussion of how the study met this aim please see the journal article discussion.

4.4 Primary objective: To inform the feasibility of future research establishing recruitment processes and study uptake.

Framework analysis was used to develop explanatory themes about the feasibility of the recruitment strategy and experiences of taking part in the study.

Overall, clinicians felt that the procedure did not place a burden upon them. It did not require them to complete extra work in the form of additional appointments or extra tasks. Most clinicians found the procedure easy to understand and felt clear about what was expected of them. Retention of information was reported to have been difficult at times for a small minority of the clinicians and they reported sometimes forgetting to ask patients and companions if they would like to take part in the study, something that was likely to have impacted recruitment.

Themes explaining why recruitment had not been possible were developed based on observations of clinicians when they tried to recruit potential participants at initial assessment appointments. A lack of knowledge of the study was the most common reason participants provided for not looking at the study paperwork prior to the appointment. Other reasons included not having time to read all the information, or an indication that there was an intention to read the information but that it was not a priority for them. Clinicians suggested that patients and companions focussed on the information about the appointment as this was what was most important to them. As it was not possible to gain the opinions of patients and companions directly, it can be proposed that these explanations are

somewhat speculative. Therefore, literature relevant to recruitment of people under-going assessment for dementia is more likely to provide a reliable insight into why recruitment problems occurred - this is discussed in further detail in section 4.8

Clinicians gave opinions of steps that could be taken to promote increased participation in the study, including sending study information out separately to the initial appointment letter as this would give patients and companions time to consider the materials without being distracted by information about their appointment. Clinicians felt that if people did not know when direct contact with the service was going to happen, they may be more likely to engage with the guide prior to their appointment. Direct contact from the research team prior to the initial appointment via telephone was another suggestion made by some clinicians as this would provide participants with an opportunity to ask any questions or raise any concerns they might have about taking part. The latter was thought likely to reduce confusion or uncertainty and therefore potentially positively impact recruitment. Issues around data protection meant that this had not been possible as patients had not consented to their contact details being shared with the study team. It is unlikely that clinicians would have time to make such calls, and this would increase the burden of the procedure on them considerably.

4.5 Primary objective: To establish how well the chosen measurement strategy provides evaluation of the intervention (including completion rates, perceived relevance, and burdensomeness).

It was not possible to meet this objective because of the lack of recruitment of patients and companions to the study.

4.6 Acceptability and the TFA

Sekhon's Theoretical Framework of Acceptability was used to provide a detailed and multifaceted understanding of acceptability of the guide. The TFA provided a structure to analyse qualitative data when combined with framework analysis. Themes related to all seven constructs of the TFA were identified as it was used to inform the topic guide for the semi-structured interviews. Thus, the TFA facilitated detailed discussions with clinicians about different aspects of acceptability that may have been overlooked without the use of the framework.

Perceived Effectiveness was the most populated construct of the TFA suggesting that clinicians could easily identify how the guide has the potential to improve the experiences of patients and companions. Intervention Coherence was more difficult to code and had some overlap with Perceived Effectiveness. Use of the definitions provided by Sekhon et al., (2017) helped to provide distinction between the constructs where delineation of ideas was ambiguous. The Ethicality construct was also highly populated; this demonstrated increased impetus on clinicians working with people experiencing a decline in their cognitive functioning to ensure their practice is in the best interests of patients as they may be less able to advocate for themselves. It is therefore consistent that MAS clinicians discussed this aspect of acceptability of the guide in depth. Clinicians had an awareness of the power they hold in their relationships with patients and companions and how the guide would help ensure a more equal the balance of power between clinician, patient, and companion.

The TFA recognises the value of assessing acceptability from three temporal perspectives: prospective, concurrent, and retrospective. This can provide different insights into aspects of acceptability. Lack of recruitment of patients and companions meant that it was only possible to establish concurrent acceptability of the guide. By assessing acceptability before clinicians had direct experience using the guide with patients and companions, it was possible to establish anticipated acceptability. Understanding anticipated acceptability has helped identify features of the guide that could be adapted to improve its acceptability, including making it more concise to improve accessibility.

4.7 Acceptability of the guide for clinicians.

Clinicians suggested reassurance that their practice is of a good standard, and a recognition of the emotional impact of their work, were two factors that contributed to the acceptability of the guide. Both factors are linked to the emotional experiences of clinicians. The concept of secondary victimhood outlined by Wu (2000), and the consequent emotional process that follows (Scott et al., 2009), are potential explanations as to why these factors were pertinent to the clinicians' acceptability of the guide. By acknowledging the emotional impact on clinicians, the guide provides validation for their emotional experiences and has the potential to reduce anxiety resulting from feeling isolated in their distress, which Francis & Roberson (2023) also support. Similarly, clinicians identified that the guide has a potential role in the training of sharing diagnoses, as currently, the lack of existing training is recognised as contributing to increased feelings of stress in clinicians (Francis & Robertson, 2023); this is likely to have contributed to the acceptability of the guide.

4.8 Recruitment

4.8.1 Theoretical Understandings

As discussed in the journal article, recruitment of older people, those living with dementia, and carers of people with dementia, is hard to achieve (Mody et al., 2008; Provencher et al., 2014; Beattie et al., 2018;). Factors contributing to the difficulties of recruitment experienced in this study may be explained by theoretical understandings of how people adjust to a diagnosis of dementia. The role of individual social and psychological factors has been identified as being important in understanding adjustment to a dementia diagnosis (Kitwood, 1990).

The Psychosocial Model (Pratt & Wilkinson, 2003) explains the role that social context can play in people's experience of being diagnosed with dementia. The social context includes factors including social stigma, social support and medical practices which intersect with individual factors to determine the how the person responds to the diagnosis. The time around assessment for dementia is one of

distress for both the patient and companion (Cahill et al., 2008; Gruters et al., 2021; Nielsen & Boenink, 2021), which contributes to a negative social context within which assessments take place.

During the recruitment period of this study, the MAS hosting was responding to the COVID-19 pandemic. The impact of the pandemic meant patients and companions were left with longer than usual waiting times and increased difficulties with accessing health services; narratives around the risk posed to older people by COVID-19 exacerbated this, with increased pressure on the health service during this time. Carers have been reported to have experienced higher levels of stress and poor mental health because of the pandemic (Care Quality Commission, 2021). Thus, patients and companions were facing a more prolonged period of uncertainty which is likely to have added to the distress and uncertainty experienced whilst under-going the process of assessment. The social support and medical practices that contribute to social context were more likely to be negative which has implications for how patients adjust to a diagnosis of dementia according to Pratt and Wilkinson's model (2003). Where the social context is negative, people are more likely to experience distress when their ability and willingness to understand their diagnosis is high and, therefore, detach when their ability and willingness to understand their diagnosis is low (Pratt & Wilkinson, 2003). When patients were experiencing higher levels of distress or detaching themselves from their situation as a means of coping, the likelihood of them consenting to take part in the study is reduced. Naidoo et al., (2020) identified anxiety around being assessed for dementia, as well as feeling cognitively overwhelmed and stressed by taking part in research trials, negatively impacts recruitment which provides an explanation as to why recruitment to this study was not possible. The pandemic was also found to negatively impact recruitment in other studies recruiting people with dementia (Baker et al., 2023).

The time of year when recruitment takes place has also been found to impact on uptake to trials; the summer holiday period and Christmas being found to create troughs in recruitment (Baker et al., 2023). The recruitment period for the main part of this study spanned the Christmas period and this is likely to have further impacted recruitment while staff take leave from work; consequently, the number

of assessments is likely to be reduced compared to other times of year, further impacting recruitment.

Increased levels of distress in both patients and companions, coupled with cognitive difficulties associated with dementia, make the processing of information more difficult (Aminzadeh et al., 2007). Clinicians in the study raised the possibility that the amount of information patients and companions were being asked to read before consenting to take part could be overwhelming. The processing efficiency theory (Calvo & Eysenck, 1992) suggests that where anxiety levels are raised, the potency of potentially threatening stimuli, such as information relating to a diagnosis of dementia, is heightened. This makes information processing more difficult as the resources available for task processing are reduced – something further exacerbated in people with dementia (Baddeley, 1992). Gasper and Clore (2002) suggest this can result in people seeing the trees rather than the wood, as global detail is missed in favour of specific details. Clinicians' reports of patients and companions only paying attention to details of their appointment, and dismissing information pertaining to the study, can thus be explained by Calvo and Eysenck's (1992) theory.

4.8.2 Barriers and Facilitators

Attempts to identify ways of overcoming difficulties with recruiting people to participate in dementia-based studies have been made. Clinical research networks such as the Dementias and Neurodegenerative Diseases Research Network DeNDRoN have been developed to provide practical support that aims to increase the amount of research taking place within the NHS in England including people with dementia and neurodegenerative diseases (Darbyshire et al., 2011). This network developed the Join Dementia Research (JDR) service, matches people interested in participating in research with researchers and has been found to be effective in increasing engagement with research and removing barriers to participation (Kotting et al., 2021). However, use of this database would not have been suitable for this study as recruitment was aimed at people

who did not yet have a diagnosis of dementia. It also required clinicians working with the patient to consent to participation.

Field et al., (2019) shared the challenges faced when recruiting people with dementia and their companions to a study by evaluating a psychosocial intervention. The study used multiple strategies to recruit participants from MAS services in England including MAS clinicians identifying potential participants, researchers attending memory clinics, and use of the JDR database to identify participants; in total 17 different strategies were used in the study. A key factor contributing to the rates of recruitment included having established working relationships between clinicians and researchers that are based on site. Moreover, recruitment was also found to be higher in services with previous experience of delivering psychosocial dementia research, possibly overcoming some of the potential for clinicians to act as gatekeepers.

Other factors that contributed to people not consenting to take part in the study included having difficulties with language because of their dementia meaning they could not take part in the intervention. There were further indications that potential participants perceived taking part in research to be burdensome with reference to the amount of time it would take without offering the required benefits to compensate for this. Physical ill-health of the person with dementia, or their companion, was another reason outlined for non-participation. Recommendations to overcome barriers include making the potential benefits of taking part in the research as more transparent and, where possible, directly asking the person with the condition about participation. Ensuring clinical services hosting research perceive engagement in research as relevant to them and the people they work with is identified as a further way of increasing participation. The authors also recommend using multiple recruitment strategies and not relying on one.

The findings of Field et al., (2019) are relevant to this study. There is potential for clinicians to act as gatekeepers to recruitment with evidence that they can feel responsible for, yet they have little control over it (Lowery et al., 2011). Clinicians may not be confident researchers and struggle to understand what is being asked of them or research may not be their priority due to time constraints (Lowery et

al., 2011). There is recognition that clinicians are distanced from research due to a culture in NHS mental health services not being conducive to it (Borschmann et al., 2014). Whilst most clinicians in the current study reported feeling confident in what was expected of them, one clinician expressed feeling confused about instructions and required extra support from the research team to understand the process. It is possible clinicians who did not consent to participating in the study did so for similar reasons.

The current study relied on a single recruitment strategy that relied on clinicians to ask potential participants if they wanted to take part. Field et al., (2019) highlight the need for a variety of recruitment strategies to be used. Patients and companions were the specific participant sample in this study at the point of dementia diagnosis meaning recruitment strategies used in other studies were unsuitable in this research. The guide requires patients and companions to engage with the study materials prior to their first contact with clinicians. Therefore, because they had not completed the required sections of the guide prior to the appointment, it was not possible for them to take part in the study. Thus, researchers approaching people attending clinics would not benefit recruitment as they would not have engaged with the guide – for similar reasons, advertising the study in waiting rooms at MAS clinics would also not be viable. The requirement to recruit people prior to having a diagnosis of dementia means that there were fewer opportunities to identify potential participants in large numbers using databases or pre-screening of clinical records. For example, it was not possible to recruit people through local support groups or through third sector organisations that provide support to people with a diagnosis of dementia.

The need for people to be approached early in their route could be achieved by recruiting through GP services that are the source of referrals to MAS. Here, earlier in the process, advertising the study in GP waiting rooms is a way that people who are due to be seen by MAS are made aware of the opportunity to take part in research. However, this would require co-ordination and communication between GPs and MAS as both patients and clinicians conducting the memory assessment would need to consent to taking part. Alternatively, study information being sent out prior to appointment letters could

reduce the risk of patients and companions focussing solely on the appointment information, encouraging them to engage with the study materials.

Another potential means of improving recruitment would be having someone employed by the participating NHS trust as part of the research team. This would mean they would have access to the contact details of potential participants and would be able to approach them directly to explain the study and answer any questions prior to the initial assessment. This would mean patients and companions would be more prepared at the point of initial assessment and there would be less reliance on clinicians to answer questions and facilitate the process. Attempts to prompt people to look at study material were attempted as part of routine calls aimed at screening for COVID-19 by the service but were only conducted the day before appointments, giving little time for people to look at the study materials prior to their appointment. The addition of someone whose expertise and roles crosses both the research and clinical teams would provide an opportunity to promote the study in a less hurried way. This was not a resource that was available when developing the design of this study.

Understanding what motivates people to take part in research may provide insights into what could be done to promote participation. Sheridan et al. (2020) conducted a systematic review of reasons why participants took part in studies identifying three main facilitators: the potential for personal benefit; altruism; and trust. A study looking specifically at the reasons why people with dementia and their companions take part in research identified further reasons including wanting to learn, hoping to get more support by taking part and financial incentives (McPhillips et al., 2022). Compensating people for their time taking part in the study provides a potential means of improving recruitment but requires consideration of the impact this might have on the study as well as the ethics of doing so (Ripley, 2006). The early stage at which recruitment was attempted meant patients and companions had no existing relationship with the clinician recruiting them. It is possible that the trust aspect, identified by Sheridan et al., (2020), as a motivational tool to engage participants in research, was not yet present so early in their relationship with the service.

Broadening the parameters required of participants to increase potential sample size is another means by which recruitment can be helped. However, the eligibility criteria for patients and companions in this study was broad and there is no evidence that people were excluded from taking part in the study because of it. Therefore, there is little scope for broadening the eligibility criteria of participants in this way.

Another strategy is to recruit from multiple sites. The decision to recruit from only two of the four MAS services was based on the willingness of services to participate. Referral rates prior to the study were also assessed to be sufficient to recruit the small number of participants required by the study design. Multi-centre recruitment from more than one NHS Trust has the potential to provide a more representative sample of participants and improves the chances of achieving recruitment targets. However, this would be a resource intensive method that is outside of the scope of a feasibility study.

4.9 Researcher impact

During the first interview with a clinician, it became apparent they thought I was involved in the development of the guide. Once they were informed this was not the case, they spoke more openly about their opinions, giving suggestions of areas for improvement as well as positive feedback about the things they liked. It was therefore necessary to inform other clinicians from the outset of the interview that I/the researcher had not been involved in the development of the guide as a means of reducing the risk of feedback being biased by social desirability. It is possible this initial belief influenced the development of their opinions of the guide prior to their interview and despite being informed otherwise, continued to influence opinions they shared. My previous professional relationships with some of the clinicians taking part in the study and the knowledge of my experience of working in MAS services could have meant clinicians felt I understood the challenges they face in their work, resulting in them speaking more openly in interviews.

However, this experience could have meant I had unconscious preconceptions of how clinicians would view the guide. This potentially meant I did not ask the same follow up questions as someone who had no experience of working in the team would have done, risking missing out on detailed explanations from participants. I was aware of this prior to conducting interviews and made a conscious effort to make use of my professional training in maintaining a reflexive stance when conducting my clinical work during interviews. I also spent time in supervision discussing how to conduct interviews in a way that elicits details and maintains a stance of curiosity.

4.10 Strengths

A strength of this study is that it has established the acceptability of the guide developed by Bennett et al., (2019) with a group of clinicians that were not part of the development of the intervention. This provides evidence that the guide has potential utility as a means of supporting clinicians to follow best practices during diagnostic delivery of dementia. Poyser and Tickle (2019) highlighted the need for the development of interventions that support the process, and this study contributes to the development of such an intervention.

The mixed methods approach used in the study was a strength as despite the lack of recruitment of patients and companions, it was possible to use the engagement from MAS clinicians to further the evaluation of a potential intervention that is much needed. This is an efficient use of resources as considerable work was put into the development and implementation of the study. Being able to adapt the focus of semi-structured interviews to obtain a detailed understanding of acceptability of the guide meant that this resource was not wasted.

The purpose of the feasibility aims of the study were to analyse the viability of the study design to determine whether a full trial would succeed. The difficulties with recruitment of patients and companions provides clear evidence that a full trial using the present design is not feasible. This is valuable information to have

gained as it has saved further resources being put into a project that is unlikely to provide further recommendations for practice and improve provision.

4.11 Limitations

As discussed, the inability to recruit patients and companions to the trial meant an understanding of the acceptability of the guide through its direct use as intended, was not possible. This limited the assessment of acceptability to the perspectives of clinicians who had experience of only partial implementation of the guide. It was also not possible to establish the feasibility of other aspects of the study including the use of the CARE as a means of measuring effectiveness of the intervention.

The number of clinicians who were recruited to the study was also small. They were recruited from one NHS Trust and therefore, the findings of the study may not be representative of a larger sample that is more geographically diverse. Areas covered by the teams who participated included urban and rural areas as well as a range of socio-demographic and cultural backgrounds which meant clinicians were likely to have diverse experiences which improved the transferability of these findings.

The reasons for recruitment difficulties have been discussed at length, however, the design of the study did not incorporate a means of gathering data on why participation was declined and therefore explanations remain speculative. Attempts were made to gather reasons for declining participation from eligible clinicians, but no responses were received.

All clinicians who participated were RMNs and female. The sample included one participant/clinician who is racially minoritised contributing to increased diversity of the sample, however, this is still not representative of the wider population. Despite being eligible to take part, no medics were recruited to the study. Findings from the study in which the guide was developed suggested there was a risk clinicians would find the guide patronising (Bennett et al., 2019). Medics receive training in how to deliver sensitive news and diagnosis and it is possible

medics felt less inclined to take part in the research because of this. However, research suggests medics continue to feel inadequately prepared for this aspect of their role (Monden et al., 2016) and therefore could potentially benefit from the guide. In the MAS services hosting the study, medics were part time members of the team, and it is therefore possible the study would be a further competing demand on their time. Lack of recruitment of medics might also be suggestive of how acceptable an intervention such as that being evaluated in this study is to members of this discipline. However, their non-inclusion limits the generalisability of the findings.

The eligibility criteria of the study excluded people who did not have capacity to consent to take part. By not including them in the research, the applicability of findings to this group of people is limited. It is recognised that exclusion of people who lack capacity from research has resulted in an evidence base for their care that is poorer (Shepherd et al., 2019). Consideration was given to how people who lacked capacity could be included in the study. By using clinicians to obtain consent from patients and companions, the ethical considerations required when recruiting people who lack capacity to consent for themselves would have been the responsibility of MAS clinicians. This was viewed as an unreasonable burden to ask of participating clinicians. Members of the research team being present when consent was obtained was more time intensive than the scope of the study allowed for and therefore, people who lacked capacity to consent were excluded. It is important to note that companions of people who lacked capacity were eligible for inclusion and this would have been a way in which their experiences could still have been captured.

Finally, the development of the study was conducted with input from clinicians who work in MAS but not patients or companions of people with a diagnosis of dementia. Plans had been made to attend local memory cafes run by the third sector to gain the opinions of people with a diagnosis of dementia and their companions. Because of the restrictions in place to mitigate against the spread of COVID-19, memory cafes were not open and therefore public involvement in the design of the study was not included. The Health Research Authority (HRA) recommend public involvement in research. This means people with relevant

experience contribute to all stages of research including how it is designed, conducted and disseminated (NHS Health Research Authority, 2024) The exclusion of people with dementia from the design, implementation and dissemination of research is established and recognised as a weakness (Brooke, 2019). By not including people with dementia in all stages, the findings of this study are more limited than they could have been if people with lived experience had been involved. One important role of public involvement is to ensure research studies are designed in a way that is acceptable and patient information is accessible for potential participants (NHS Health Research Authority, 2024). Gaining input from people who already have a diagnosis of dementia as well as their carers prior to submitting the study for ethical approval is one possible way in which this could have been achieved could have identified issues that would not be obvious to those who do not have lived experience of dementia. This could potentially have improved the recruitment of patients and companions to the study, as lack of recruitment of any patients and companions suggests the recruitment strategy was not acceptable to them.

4.12 Clinical implications

The finding that the clinician version of the guide is acceptable to MAS clinicians outside of those involved in its development has implications for practice when delivering a diagnosis of dementia. The clinician version of the guide provides a promising means for clinicians being better supported in their role of sharing diagnoses of dementia and provides a resource for use in supervision and training, separate from its use with the patient and companion version. Further evaluative work looking at effectiveness is required before the value of wide-spread implementation is recommended.

4.13 Future Research

The finding that the clinician version of the guide is acceptable to clinicians working in MAS suggests that further evaluation of the guide is warranted as it

has potential to be a useful resource to clinicians. Evaluation of whether the guide is effective in improving patient and companion experiences of the diagnosis of dementia is also required but further consideration needs to be given to how this is possible given restraints on recruitment. Furthermore, the small sample size on which the findings of this study are based means the acceptability of the guide with a larger sample of clinicians, from a more diverse range of clinical disciplines, would give more representative findings and has the potential to identify areas of development for the guide.

The acceptability of the guide with patients and companions remains outstanding and requires further investigation before the guide can be implemented in MAS services. Such evaluation would also provide an opportunity to further refine the contents of the guide. Similarly, the effectiveness of the guide in improving patient and companion satisfaction with diagnostic experiences requires evaluation. The findings of this study could be used to inform the design of a future trial.

5 Reflective section

I maintained a reflective diary throughout the project. I have used this to inform a reflection on my experience of conducting this project and identify learning that I can take forward into my post-doctoral practice.

Prior to embarking on the clinical doctorate, I had been employed in a MAS and had experienced frustrations with the lack of training for clinicians sharing the outcomes of assessment for dementia and the consequences of that for patients, their companions and for the clinicians themselves. I was also aware of the negative experiences that people I had worked with had reported to me about the way their diagnosis had been shared with them, and was aware of the evidence that this was not unique to the service I had been working in. The experiences of clinicians sharing diagnoses that have life changing consequences for the patient were also familiar to me as they often shared how difficult they found this aspect of their work. The lack of research into interventions that might improve this situation was at odds with the need highlighted in the literature.

I was enthusiastic about conducting research that would benefit people with a dementia diagnosis, and following preliminary discussions with a research tutor, I became aware of the potential for a project looking at the problem that had caused me frustration in my previous post. As I discussed the project with research tutors in more detail, it became apparent my experience of working in a MAS and the contacts with services that this gave me, meant the project was possible. I noticed feelings of excitement about what the project could become and motivated to develop it further as I could see the potential clinical utility of the guide. I also noticed feelings of relief that I had identified a project I felt I could

make a positive contribution towards, and could envision completing, which gave me hope that I could achieve what was required of me to complete my training. I was also pleased I had identified a project early which gave the benefit of increased time to develop the project in detail.

Prior to deciding on the project, I had felt very uncertain about my ability to conduct research, which created feelings of anxiety about this aspect of my training. The positive feelings I experienced once I had decided on the project are likely to have been enhanced by the contrast with these feelings of anxiety and self-doubt.

After discussion with two clinical psychologists from the MAS service I had previously worked in, my enthusiasm for the project grew further as they also recognised the clinical need for the development of interventions to improve the experiences of patients. Their willingness to support the project meant that many of the practical aspects of the study were made possible as I had access to services I'd had experience of working within and in which I understood the processes of assessment and diagnosis used. This gave me the significant advantage of being able to predict what would and wouldn't be possible when designing the procedure without burdening clinicians who are under pressure to meet the considerable demands placed on MAS services.

This experience has helped me to recognise the benefit of carrying out research into a topic that was aligned with my personal values and allowed me to use existing professional contacts to realise the project. At times, when the project felt difficult, this enthusiasm and recognition of the clinical value of the findings helped me to persist and see the project through to completion. When conducting

future research projects, I will endeavour to ensure a similar level of enthusiasm for the project. This is likely to be of added benefit to me when thinking about post-doctoral research. Working in a clinical role in the NHS, where there are many demands on my time, increases the risk that that research activity will be neglected. The amount of research undertaken by clinical psychologists in the NHS is limited and, despite wanting to be more research active, many barriers are in place that make this difficult (Richardson, 2014). By finding projects that I am enthusiastic about, and can see the clinical utility of, this will make me more likely to feel motivated to persevere even when facing barriers and difficulties.

Whilst this enthusiasm was beneficial in helping me to feel motivated, my prior feelings of frustration about practice in MAS services risked me being biased to find a solution to the problem and view the guide favourably. Prior to conducting interviews with clinicians, I was aware of this desire for the findings of the study to be supportive of the guide as an intervention. I spent time reflecting on this which helped me to recognise how the desire to help others that has resulted in me pursuing a career in clinical psychology can sometimes lead me to be optimistic about potential solutions to problems. It was important that I maintained a neutral stance when conducting the interviews so that my opinion of the guide did not influence the clinicians I was interviewing. By being conscious of this potential source of bias I was able to maintain an awareness of it when conducting my interviews. I ensured I gave clinicians opportunity to be critical of the guide by asking questions about what they thought could be improved. Following the first interview, I shared the transcript with my supervisors and spent time reflecting on my influence in the interviews. This has taught me the role that reflection plays in encouraging a neutral stance and helping to bring potential bias

to awareness and take steps to reduce the influence on the findings of the research.

Whilst my initial feelings about the study were positive, subsequent experiences of conducting the study meant that the enthusiasm I initially felt diminished. Interruptions to services caused by the COVID-19 pandemic meant there were delays to the project being given authorisation by the hosting NHS Trust's research department. This meant recruitment to the study was delayed by four months. Once it started, uptake by patients and companions for the baseline phase was low, resulting in an amendment to ethical approval being applied for to extend the period of recruitment. Despite this extension, the return rate of baseline measures remained low. This left me feeling pessimistic about recruitment to the main part of the study as this required more of a time commitment from patients and companions than returning the baseline measures.

When recruitment of patients and companions to the main part of the trial started and uptake was non-existent, I began to feel further demoralised. I noticed feeling disappointed that the study would not provide insights into how the guide would be received by patients and companions. I also felt concerned that the study was a failure, and this was because of my involvement. Spending time discussing the difficulties I faced with my supervisors reminded me that the purpose of a feasibility study is to establish if a larger scale study is likely to be successful and therefore the study had achieved its aim. After some time reflecting on the situation, I recognised the opportunity to assess the acceptability of the guide, with clinicians who had not been involved in its development, in more depth than

was initially intended. Whilst the findings of the study were not what I had initially thought they would be, I had nevertheless managed to produce a project of value.

Data analysis triggered feelings of confusion and being overwhelmed. Prior to this study, I had limited experience of qualitative analysis, and this had mostly been as part of a larger team where I was not taking a lead. I had never used framework analysis and therefore this presented me with a challenge and pushed me beyond what I felt was my capability. This resulted in feelings of anxiety. One way that I cope with feelings of anxiety about not knowing about something is to spend time reading about the topic. I therefore sought out literature that explained the approach and ensured I maintained regular contact with my supervisors whilst carrying out the analysis. This helped to build my confidence as I worked my way through the stages of analysis, as I shared ideas with my supervisors, and as they gave positive and constructive feedback on my progress.

I also noticed, during the identification of codes and whilst developing the framework, that I was craving a feeling of certainty and wanting to 'know' and quantify. A key aspect of all research is the synthesis of new knowledge and therefore the position of not knowing is always present. The pragmatist epistemological stance adopted in this study posits that knowledge is not reality, it is constructed through inquiry, with a purpose to improve one's situation and to take part in the world (Goldkuhl, 2012). The purpose of the qualitative nature of the enquiry was to generate new knowledge, which necessitated me maintaining a position of inquiry. My natural tendency is to want to know and understand, but qualitative data analysis required me to pioneer the development of that knowledge, rather than learn it through the work of others. This experience has

taught me that by tolerating feelings of uncertainty and persevering, I have been able to achieve something that I did not think I could do, as well as contribute towards scientific knowledge of the dementia diagnosis process.

This project has been challenging as well as exciting. By putting myself in situations that required me to develop my research skills I have built my capacity to conduct research post-training.

Extended Section Word Count: 19080

References

Agnew, S. K., & Morris, R. G. (1998). The heterogeneity of anosognosia for memory impairment in Alzheimer's disease: A review of the literature and a proposed model. *Aging and Mental Health*, *2*(1), 7–19. https://doi.org/10.1080/13607869856876

Alzheimer's Society. (2022a). *People with dementia face up to a two year wait for diagnosis*. https://www.alzheimers.org.uk/news/2022-09-23/people-dementia-face-two-year-wait-diagnosis#:~:text=The%20National%20Audit%20of%20Memory,from%2013%20weeks%20in%202019%3B

Alzheimer's Society. (2022b, August 3). *What is dementia? Symptoms, causes and treatments*. alzheimers.org.uk/about-dementia/types-dementia/what-is-dementia

Aminzadeh, F., Byszewski, A., Molnar, F. J., & Eisner, M. (2007). Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. *Aging and Mental Health*, *11*(3), 281–290. https://doi.org/10.1080/13607860600963695

Aring, C. D. (1958). Sympathy and empathy. *Journal of the American Medical Association*, *167*(4), 448–452. https://doi.org/10.1001/JAMA.1958.02990210034008

Baddeley, A. (1992). Working Memory. *New Series*, *255*(5044), 556–559.

Baddeley, A. (2000). The episodic buffer: a new component of working memory? *Trends in Cognitive Sciences*, *4*(11), 417–423. https://doi.org/10.1016/S1364-6613(00)01538-2

Baddeley, A. D. (1986). *Working memory* [Book]. Clarendon.

Baddeley, A. D., & Hitch, G. (1974). Working Memory. *Psychology of Learning and Motivation - Advances in Research and Theory*, *8*(C), 47–89. https://doi.org/10.1016/S0079-7421(08)60452-1

Baile, W. F., Buckman, R., Lenzi, R., Glober, G., Beale, E. A., & Kudelka, A. P. (2000). SPIKES—A six-step protocol for delivering bad news: application to the patient with cancer. *The Oncologist*, *5*(4), 302–311. https://doi.org/10.1634/THEONCOLOGIST.5-4-302

Bailey, C., Dooley, J., & McCabe, R. (2019). 'How do they want to know?' Doctors' perspectives on making and communicating a diagnosis of dementia. *Dementia*, *18*(7–8), 3004–3022. https://doi.org/10.1177/1471301218763904

Baker, F. A., Blauth, L., Bloska, J., Bukowska, A. A., Flynn, L., Hsu, M.-H., Janus, E., Johansson, K., Odell-Miller, H., Miller, H., Petrowitz, C., Pool, J., Stensæth, K., Tamplin, J., Teggelove, K., Wosch, T., & Sousa, T. V. (2023). Recruitment approaches and profiles of consenting family caregivers and people living with dementia: A recruitment study within a trial [Article]. *Contemporary Clinical Trials Communications*, *32*, 101079–101079. https://doi.org/10.1016/j.conctc.2023.101079

Bamford, C., Lamont, S., Eccles, M., Robinson, L., May, C., & Bond, J. (2004). Disclosing a diagnosis of dementia: a systematic review [Article]. *International Journal of Geriatric Psychiatry*, *19*(2), 151–169. https://doi.org/10.1002/gps.1050

Barker, C., Pistrang, N., & Elliot, R. (2016). *Research methods in clinical psychology: an introduction for students and practitioners* (N. Pistrang & R. Elliott, Eds.; 3rd ed.) [Book]. Wiley Blackwell.

Barnes, T. R. E., Banerjee, S., Collins, N., Treloar, A., McIntyre, S. M., & Paton, C. (2012). Antipsychotics in dementia: prevalence and quality of antipsychotic drug prescribing in UK mental health services [Article]. *British Journal of Psychiatry*, *201*(3), 221–226. https://doi.org/10.1192/bjp.bp.111.107631

Beattie, E., Fielding, E., O'Reilly, M., Brooks, D., MacAndrew, M., & McCrow, J. (2018). Recruitment of individuals with dementia and their carers for social research: lessons learned from nine studies [Article]. *Research in*

Gerontological Nursing, *11*(3), 119–128. https://doi.org/10.3928/19404921-20180308-01

Bennett, C. E., De Boos, D., & Moghaddam, N. G. (2018). Developing a tool to support diagnostic delivery of dementia. *Dementia*, *18*(7–8), 2505–2525. https://doi.org/10.1177/1471301217750936

Berger, J. T., & Ribeiro Miller, D. (2022). Physicians Should Stop Breaking Bad News [Article]. *Journal of General Internal Medicine : JGIM*, *37*(13), 3475–3476. https://doi.org/10.1007/s11606-022-07566-6

Borschmann, R., Patterson, S., Poovendran, D., Wilson, D., & Weaver, T. (2014). *Influences on recruitment to randomised controlled trials in mental health settings in England: a national cross-sectional survey of researchers working for the Mental Health Research Network*. https://doi.org/10.1186/1471-2288-14-23

Braak, H., & Braak, E. (1997). Frequency of Stages of Alzheimer-Related Lesions in Different Age Categories [Article]. *Neurobiology of Aging*, *18*(4), 351–357. https://doi.org/10.1016/S0197-4580(97)00056-0

Braun, V., & Clarke, V. (2013). *Successful qualitative research: a practical guide for beginners* (V. Clarke, Ed.) [Book]. SAGE.

British Psychological Society. (2014). *Clinical Psychology in the Early Stage Dementia Care Pathway*.

British Psychological Society. (2021). *BPS code of human research ethics.* https://www.bps.org.uk/guideline/bps-code-human-research-ethics

Brooke, J. (2019). Equity of people with dementia in research, why does this issue remain? [Article]. *Journal of Clinical Nursing*, *28*(21–22), 3723–3724. https://doi.org/10.1111/jocn.14957

Browne, K., Roseman, D., Shaller, D., & Edgman-Levitan, S. (2010). analysis & commentary Measuring Patient Experience As A Strategy For Improving

Primary Care [Article]. *Health Affairs*, *29*(5), 921–925. https://doi.org/10.1377/hlthaff.2010.0238

Buckman, R. (1992). How to break bad news [Book]. In *How to break bad news* (1st ed.). University of Toronto Press. https://doi.org/10.3138/9781487596989

Bucks, R. S., Ashworth, D. L., Wilcock, G. K., & Siegfried, K. (1996). Assessment of activities of daily living in dementia: development of the Bristol Activities of Daily Living Scale. *Age and Ageing*, *25*(2), 113–120. https://doi.org/10.1093/AGEING/25.2.113

Bunn, F., Goodman, C., Sworn, K., Rait, G., Brayne, C., Robinson, L., McNeilly, E., & Iliffe, S. (2012). Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies [Article]. *PLoS Medicine*, *9*(10), e1001331–e1001331. https://doi.org/10.1371/journal.pmed.1001331

Burnham, S. C., Bourgeat, P., Doré, V., Savage, G., Brown, B., Laws, S., Maruff, P., Salvado, O., Ames, D., Martins, R. N., Masters, C. L., Rowe, C. C., & Villemagne, V. L. (2016). Clinical and cognitive trajectories in cognitively healthy elderly individuals with suspected non-Alzheimer's disease pathophysiology (SNAP) or Alzheimer's disease pathology: a longitudinal study [Article]. *Lancet Neurology*, *15*(10), 1044–1053. https://doi.org/10.1016/S1474-4422(16)30125-9

Burns, A., Beevor, A., Lelliott, P., Wing, J., Blakey, A., Orrell, M., Mulinga, J., & Hadden, S. (1999). Health of the Nation Outcome Scales for elderly people (HoNOS 65+). *The British Journal of Psychiatry : The Journal of Mental Science*, *174*(MAY), 424–427. https://doi.org/10.1192/BJP.174.5.424

Byszewski, A. M., Molnar, F. J., Aminzadeh, F., Eisner, M., Gardezi, F., & Bassett, R. (2007). Dementia diagnosis disclosure : A study of patient and caregiver perspectives [Article]. *Alzheimer Disease and Associated Disorders*, *21*(2), 107–114. https://doi.org/10.1097/WAD.0b013e318065c481

Cahill, S. M., Gibb, M., Bruce, I., Headon, M., & Drury, M. (2008). I was worried coming in because I don't really know why it was arranged' [Article]. *Dementia*, *7*(2), 175–189. https://doi.org/10.1177/1471301208091157

Calvo, M. G., & Eysenck, M. W. (1992). Anxiety and Performance: The Processing Efficiency Theory. *Cognition and Emotion*, *6*(6), 409–434. https://doi.org/10.1080/02699939208409696

Campbell, T. A., Auerbach, S. M., & Kiesler, D. J. (2007). Relationship of interpersonal behaviors and health-related control appraisals to patient satisfaction and compliance in a university health center. *Journal of American College Health*, *55*(6), 333–340. https://doi.org/10.3200/JACH.55.6.333-340

Care Quality Commission. (2021). *State of Care*.

Cheston, R., Dodd, E., Christopher, G., Jones, C., Wildschut, T., & Sedikides, C. (2018). Selective forgetting of self-threatening statements: Mnemic neglect for dementia information in people with mild dementia [Article]. *International Journal of Geriatric Psychiatry*, *33*(8), 1065–1073. https://doi.org/10.1002/gps.4894

Cheston, R., Dodd, E., Christopher, G., White, P., Wildschut, T., & Sedikides, C. (2022). The Development and Validation of the Threat of Dementia Scale. *International Journal of Aging and Human Development*, *94*(4), 496–514. https://doi.org/10.1177/0091415020957388

Clare, L. (2002). Developing Awareness about Awareness in Early-Stage Dementia [Article]. *Dementia (London, England)*, *1*(3), 295–312. https://doi.org/10.1177/147130120200100303

Clare, L. (2003). Managing threats to self: awareness in early stage Alzheimer's disease [Article]. *Social Science & Medicine (1982)*, *57*(6), 1017–1029. https://doi.org/10.1016/S0277-9536(02)00476-8

Clare, L., Quinn, C., Jones, I. R., & Woods, R. (2016). “I Don’t Think Of It As An Illness”: Illness representations in mild and moderate dementia. *Journal of Alzheimer’s Disease*, *51*(1), 139–150.

Cohen, D., Kennedy, G., & Eisdorfer, C. (1984). Phases of Change in the Patient with Alzheimer’s Dementia: A Conceptual Dimension for Defining Health Care Management. *Journal of the American Geriatrics Society*, *32*(1), 11–15. https://doi.org/10.1111/J.1532-5415.1984.TB05143.X

Conway, M. A. (2005). Memory and the self [Article]. *Journal of Memory and Language*, *53*(4), 594–628. https://doi.org/10.1016/j.jml.2005.08.005

Conway, M. A., & Pleydell-Pearce, C. W. (2000). The Construction of Autobiographical Memories in the Self-Memory System [Article]. *Psychological Review*, *107*(2), 261–288. https://doi.org/10.1037/0033-295X.107.2.261

Conway, M. A., Singer, J. A., & Tagini, A. (2004). The Self and Autobiographical Memory: Correspondence and Coherence [Article]. *Social Cognition*, *22*(5), 491–529. https://doi.org/10.1521/soco.22.5.491.50768

Cooper, C., Ketley, D., & Livingston, G. (2014). Systematic review and meta-analysis to estimate potential recruitment to dementia intervention studies [Article]. *International Journal of Geriatric Psychiatry*, *29*(5), 515–525. https://doi.org/10.1002/gps.4034

Darbyshire, J., Sitzia, J., Morgan, C., Riley, A., Rosser, M., Kotting, P., McKeith, I., Smye, S., Gower, J., Brown, V., Smyth, R., Poustie, V., Cameron, D., Van’t Hoff, W., Wallace, P., Ellis, T., Wykes, T., Burns, S., Rosenberg, W., … Chaturvedi, N. (2011). Extending the clinical research network approach to all of healthcare [Article]. *Annals of Oncology*, *22*, vii36–vii43. https://doi.org/10.1093/annonc/mdr424

Dementia UK. (2023a). *Young onset dementia: facts and figures*. https://www.dementiauk.org/information-and-support/young-onset-dementia/young-onset-dementia-facts-and-figures/

Dementia UK. (2023b, March). *What is dementia?* dementiauk.org/information-and-support/about-dementia/what-is-dementia/

Department of Health. (2010). *Equity and Excellence: Liberating the NHS*.

Department of Health. (2015). *Prime Minister's challenge on dementia 2020*.

Derksen, E., Vernooij-Dassen, M., Scheltens, P., & Olde-Rikkert, M. (2006). A model for disclosure of the diagnosis of dementia [Article]. *Dementia (London, England)*, *5*(3), 462–468. https://doi.org/10.1177/147130120600500313

Derrer-Merk, E., Reyes-Rodriguez, M.-F., Soulsby, L. K., Roper, L., & Bennett, K. M. (2023). Older adults' experiences during the COVID-19 pandemic: a qualitative systematic literature review [Article]. *BMC Geriatrics*, *23*(1), 1–580. https://doi.org/10.1186/s12877-023-04282-6

Di Blasi, Z., Harkness, E., Ernst, E., Georgiou, A., & Kleijnen, J. (2001). Influence of context effects on health outcomes: A systematic review. *Lancet*, *357*(9258), 757–762. https://doi.org/10.1016/S0140-6736(00)04169-6

Division of Clinical Psychology. (2016). *Communicating a diagnosis of dementia*.

Doyle, C., Lennox, L., & Bell, D. (2013). *A systematic review of evidence on the links between patient experience and clinical safety and effectiveness*. *3*, 1570. https://doi.org/10.1136/bmjopen-2012

Dubois, B., Padovani, A., Scheltens, P., Rossi, A., & Dell'agnello, G. (2016). Timely Diagnosis for Alzheimer's Disease: A Literature Review on Benefits and Challenges. *Journal of Alzheimer's Disease*, *49*(3), 617–631. https://doi.org/10.3233/JAD-150692

Dziobek, I., Kimberley, A. E., Ae, R., Fleck, S., Markus, A. E., Ae, B., Heekeren, H. R., Oliver, A. E., & Ae, T. W. (2007). *Dissociation of Cognitive and Emotional Empathy in Adults with Asperger Syndrome Using the Multifaceted Empathy Test (MET)*. https://doi.org/10.1007/s10803-007-0486-x

Eccles, M. P., Francis, J., Foy, R., Johnston, M., Bamford, C., Grimshaw, J. M., Hughes, J., Lecouturier, J., Steen, N., & Whitty, P. M. (2009). Improving Professional Practice in the Disclosure of a Diagnosis of Dementia: A Modeling Experiment to Evaluate a Theory-Based Intervention [Article]. *International Journal of Behavioral Medicine*, *16*(4), 377–387. https://doi.org/10.1007/s12529-008-9023-3

Eldridge, S. M., Chan, C. L., Campbell, M. J., Bond, C. M., Hopewell, S., Thabane, L., & Lancaster, G. A. (2016). CONSORT 2010 statement: extension to randomised pilot and feasibility trials. *BMJ*, *355*(i5239). https://doi.org/10.1136/bmj.i5239

Emmady, P. D., Schoo, C., & Tadi, P. (2022). Major Neurocognitive Disorder (Dementia). *StatPearls*. https://www.ncbi.nlm.nih.gov/books/NBK557444/

Fallowfield, L., & Jenkins, V. (2004). Communicating sad, bad, and difficult news in medicine. *Lancet*, *363*(9405), 312–319. https://doi.org/10.1016/S0140-6736(03)15392-5

Field, B., Mountain, G., Burgess, J., Di Bona, L., Kelleher, D., Mundy, J., & Wenborn, J. (2019). Recruiting hard to reach populations to studies: breaking the silence: an example from a study that recruited people with dementia [Article]. *BMJ Open*, *9*(11), e030829–e030829. https://doi.org/10.1136/bmjopen-2019-030829

Fields, S. K., Mahan, P., Tillman, P., Harris, J., Maxwell, K., & Hojat, M. (2011). Measuring empathy in healthcare profession students using the Jefferson Scale of Physician Empathy: Health provider-student version. *Journal of Interprofessional Care*, *25*(4), 287–293. https://doi.org/10.3109/13561820.2011.566648

Fogarty, L. A., Curbow, B. A., Wingard, J. R., Mcdonnell, K., & Somerfield, M. R. (1999). Can 40 seconds of compassion reduce patient anxiety? [Article]. *Journal of Clinical Oncology*, *17*(1), 371–379. https://doi.org/10.1200/JCO.1999.17.1.371

Folstein, M. F., Folstein, S. E., & Mchugh, P. R. (1975). “Mini-Mental State” a practical method for grading the cognitive state of patients for the clinician. *J. Gsychiaf. Res*, *12*, 189–198.

Foy, R., Francis, J., Johnston, M., Eccles, M., Lecouturier, J., Bamford, C., & Grimshaw, J. (2007). *The development of a theory-based intervention to promote appropriate disclosure of a diagnosis of dementia* [Article]. https://doi.org/10.1186/1472-6963-7-207

Francis, L., & Robertson, N. (2023). Healthcare practitioners’ experiences of breaking bad news: A critical interpretative meta synthesis. *Patient Education and Counseling*, *107*, 107574. https://doi.org/10.1016/j.pec.2022.107574

Gagliardi, G., & Vannini, P. (2022). Episodic Memory Impairment Mediates the Loss of Awareness in Mild Cognitive Impairment [Article]. *Frontiers in Aging Neuroscience*, *13*, 802501–802501. https://doi.org/10.3389/fnagi.2021.802501

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research [Article]. *BMC Medical Research Methodology*, *13*(1), 117–117. https://doi.org/10.1186/1471-2288-13-117

Gasper, K., & Clore, G. L. (2002). Attending to the Big Picture: Mood and Global versus Local Processing of Visual Information [Article]. *Psychological Science*, *13*(1), 34–40. https://doi.org/10.1111/1467-9280.00406

Goldkuhl, G. (2012). Pragmatism vs interpretivism in qualitative information systems research. *European Journal of Information Systems*, *21*(2), 135–146. https://doi.org/10.1057/EJIS.2011.54

Goldsmith, L. (2021). Using Framework Analysis in Applied Qualitative Research [Article]. *Qualitative Report*, *26*(6), 2061–2076. https://doi.org/10.46743/2160-3715/2021.5011

Green, J., Goldstein, F. C., Sirockman, B. E., & Green, R. C. (1993). Variable awareness of deficits in Alzheimer's disease [Article]. *Neuropsychiatry, Neuropsychology, and Behavioral Neurology*, *6*(3), 159–165.

Gruters, A. A. A., Christie, H. L., Ramakers, I. H. G. B., Verhey, F. R. J., Kessels, R. P. C., & de Vugt, M. E. (2021). Neuropsychological assessment and diagnostic disclosure at a memory clinic: A qualitative study of the experiences of patients and their family members [Article]. *Clinical Neuropsychologist*, *35*(8), 1398–1414. https://doi.org/10.1080/13854046.2020.1749936

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? [Article]. *Field Methods*, *18*(1), 59–82. https://doi.org/10.1177/1525822X05279903

Hare, P. (2023). *Dementia and Hope: Our vision for dismantling the barriers which disable a million people in the UK* .

Harman, G. (2004). *The impact of information on illness representations and coping in early dementia from the perspective of the person with dementia - A phenomenological approach*. University of London.

Healthcare Quality Improvement Partnership. (2022). *National Audit of Dementia: Memory Assessment Services Spotlight Audit 2021*. https://www.hqip.org.uk/wp-content/uploads/2022/08/Ref-317-NAD-Memory-Assessment-Services-Spotlight-Audit-2021_FINAL.pdf

Hill, N., Mogle, J., Kitko, L., Gilmore-Bykovskyi, A., Wion, R., Kitt-Lewis, E., & Kolanowski, A. (2017). *Aging & Mental Health Incongruence of subjective memory impairment ratings and the experience of memory problems in older adults without dementia: a mixed methods study Incongruence of subjective memory impairment ratings and the experience of memory problems in older adults without dementia: a mixed methods study*. https://doi.org/10.1080/13607863.2017.1337715

Hojat, M. (2009). Ten Approaches for Enhancing Empathy in Health and Human Services Cultures [Article]. *Journal of Health and Human Services Administration*, *31*(4), 412–450.

Horvarth, A., & Luborsky, L. (1993). The Role of the Therapeutic Alliance in Psychotherapy. *Journal of Consulting and Clinical Psychology*, *61*(4), 561–573. https://oce.ovid.com/article/00004730-199308000-00004/HTML

Hsieh, S., Schubert, S., Hoon, C., Mioshi, E., & Hodges, J. R. (2013). Validation of the Addenbrooke's Cognitive Examination III in Frontotemporal Dementia and Alzheimer's Disease [Article]. *Dementia and Geriatric Cognitive Disorders*, *36*(3–4), 242–250. https://doi.org/10.1159/000351671

Johnson, J., & Panagioti, M. (2018). Interventions to Improve the Breaking of Bad or Difficult News by Physicians, Medical Students, and Interns/Residents: A Systematic Review and Meta-Analysis [Article]. *Academic Medicine*, *93*(9), 1400–1412. https://doi.org/10.1097/ACM.0000000000002308

Joshi, S., Park, T., Brody, L., Cruz, K., Mukhi, P., Reid, M. C., Herr, K., Pillemer, K., & Riffin, C. (2023). Recruitment of family caregivers of persons with dementia: Lessons learned from a pilot randomized controlled trial [Article]. *Frontiers in Pain Research*, *4*, 1125914–1125914. https://doi.org/10.3389/fpain.2023.1125914

Kaplan, S. H., Greenfield, S., & Ware, J. E. (1989). Assessing the Effects of Physician-Patient Interactions on the Outcomes of Chronic Disease [Article]. *Medical Care*, *27*(3), S110–S127. https://doi.org/10.1097/00005650-198903001-00010

Karnieli-Miller, O., Werner, P., Aharon-Peretz, J., & Eidelman, S. (2007). Dilemmas in the (un)veiling of the diagnosis of Alzheimer's disease: Walking an ethical and professional tight rope [Article]. *Patient Education and Counseling*, *67*(3), 307–314. https://doi.org/10.1016/j.pec.2007.03.014

Karnieli-Miller, O., Werner, P., Aharon-Peretz, J., Sinoff, G., & Eidelman, S. (2012). Expectations, experiences, and tensions in the memory clinic: the

process of diagnosis disclosure of dementia within a triad. *International Psychogeriatrics*, *24*(11). https://doi.org/10.1017/S1041610212000841

Keady, J., & Nolan, M. (1995a). IMMEL 2: working to augment coping responses in early dementia [Article]. *British Journal of Nursing (Mark Allen Publishing)*, *4*(7), 377–380. https://doi.org/10.12968/bjon.1995.4.7.377

Keady, J., & Nolan, M. (1995b). IMMEL: assessing coping responses in the early stages of dementia [Article]. *British Journal of Nursing (Mark Allen Publishing)*, *4*(6), 309–314. https://doi.org/10.12968/bjon.1995.4.6.309

Kitwood, T. (1990). The Dialectics of Dementia: With Particular Reference to Alzheimer's Disease [Article]. *Ageing and Society*, *10*(2), 177–196. https://doi.org/10.1017/S0144686X00008060

Kotting, P., Smith, A., O'Hare, M. B., Giebel, C., Mendis, L., Shaw, C., Shillito, I., & Rossor, M. N. (2021). A national open-access research registry to improve recruitment to clinical studies [Article]. *Alzheimer's & Dementia : Translational Research & Clinical Interventions*, *7*(1), e12221-n/a. https://doi.org/10.1002/trc2.12221

KuÌbler-Ross, E. (1973). *On death and dying* [Book]. Routledge.

Lancaster, G. A., & Thabane, L. (2019). Guidelines for reporting non-randomised pilot and feasibility studies. In *Pilot and Feasibility Studies* (Vol. 5, Issue 1). BioMed Central Ltd. https://doi.org/10.1186/s40814-019-0499-1

Langbaum, J. B., Zissimopoulos, J., Au, R., Bose, N., Edgar, C. J., Ehrenberg, E., Fillit, H., Hill, C. V., Hughes, L., Irizarry, M., Kremen, S., Lakdawalla, D., Lynn, N., Malzbender, K., Maruyama, T., Massett, H. A., Patel, D., Peneva, D., Reiman, E. M., … Aisen, P. S. (2023). Recommendations to address key recruitment challenges of Alzheimer's disease clinical trials [Article]. *Alzheimer's & Dementia*, *19*(2), 696–707. https://doi.org/10.1002/alz.12737

Lecouturier, J., Bamford, C., Hughes, J. C., Francis, J. J., Foy, R., Johnston, M., & Eccles, M. P. (2008a). Appropriate disclosure of a diagnosis of dementia:

identifying the key behaviours of “best practice.” *BMC Health Services Research*. https://doi.org/10.1186/1472-6963-8-95

Lecouturier, J., Bamford, C., Hughes, J. C., Francis, J. J., Foy, R., Johnston, M., & Eccles, M. P. (2008b). Appropriate disclosure of a diagnosis of dementia: identifying the key behaviours of “best practice.” *BMC Health Services Research*, *8*, 95. https://doi.org/10.1186/1472-6963-8-95

Lee, S. M., Roen, K., & Thornton, A. (2014). The psychological impact of a diagnosis of Alzheimer’s disease [Article]. *Dementia (London, England)*, *13*(3), 289–305. https://doi.org/10.1177/1471301213497080

Low, L., McGrath, M., Swaffer, K., & Brodaty, H. (2019). Communicating a diagnosis of dementia: A systematic mixed studies review of attitudes and practices of health practitioners. *Dementia*, *18*(7–8), 2856–2905. https://doi.org/10.1177/1471301218761911

Low, L.-F., Swaffer, K., Mcgrath, M., & Brodaty, H. (2018). Do people with early stage dementia experience Prescribed Disengagement ®? A systematic review of qualitative studies. *International Psychogeriatrics*, *30*(6). https://doi.org/10.1017/S1041610217001545

Lowery, D. P., Warner, J., Cerga-Pashoja, A., Thuné-Boyle, I., & Iliffe, S. (2011). Clinicians as recruiters to dementia trials: lessons from the EVIDEM-E project [Article]. *International Journal of Geriatric Psychiatry*, *26*(7), 767–769. https://doi.org/10.1002/gps.2671

Luborsky, L. (1971). Factors influencing the outcome of psychotherapy: A review of quantitative research [Article]. *Psychological Bulletin*, *75*(3), 145–185. https://doi.org/10.1037/h0030480

Luz, R., George, A., Spitz, E., & Vieux, R. (2017). Breaking bad news in prenatal medicine: a literature review [Article]. *Journal of Reproductive and Infant Psychology*, *35*(1), 14–31. https://doi.org/10.1080/02646838.2016.1253052

Mastwyk, M., Ames, D., Ellis, K. A., Chiu, E., & Dow, B. (2014). Disclosing a dementia diagnosis: what do patients and family consider important?

[Article]. *International Psychogeriatrics*, *26*(8), 1263–1272. https://doi.org/10.1017/S1041610214000751

McCormack, B., Dewing, J., Breslin, L., Coyne-Nevin, A., Kennedy, K., Manning, M., Peelo-Kilroe, L., Tobin, C., & Slater, P. (2010). Developing person-centred practice: nursing outcomes arising from changes to the care environment in residential settings for older people [Article]. *International Journal of Older People Nursing*, *5*(2), 93–107. https://doi.org/10.1111/j.1748-3743.2010.00216.x

McPhillips, M. V., Petrovsky, D. V., Brewster, G. S., Li, J., Gooneratne, N. S., Hodgson, N. A., & Sefcik, J. S. (2022). Recruiting Persons with Dementia and Caregivers in a Clinical Trial: Dyads Perceptions [Article]. *Western Journal of Nursing Research*, *44*(6), 557–566. https://doi.org/10.1177/01939459211008563

Mercer, S. W., Higgins, M., Bikker, A. M., Fitzpatrick, B., McConnachie, A., Lloyd, S. M., Little, P., & Watt, G. C. M. (2016). General Practitioners' empathy and health outcomes: A prospective observational study of consultations in areas of high and low deprivation [Article]. *Annals of Family Medicine*, *14*(2), 117–124. https://doi.org/10.1370/afm.1910

Mercer, S. W., Maxwell, M., Heaney, D., & Watt Mercer SW, G. C. (2004). The consultation and relational empathy (CARE) measure: development and preliminary validation and reliability of an empathy-based consultation process measure. *Family Practice*, *21*(6). https://doi.org/10.1093/fampra/cmh621

Mercer, S. W., & Murphy, D. J. (2008). Validity and reliability of the CARE Measure in secondary care. *Clinical Governance: An International Journal*, *13*(4), 269–283. https://doi.org/10.1108/14777270810912969

Mercer, S. W., Neumann, M., Wirtz, M., Fitzpatrick, B., & Vojt, G. (2008). General practitioner empathy, patient enablement, and patient-reported outcomes in primary care in an area of high socio-economic deprivation in Scotland—A pilot prospective study using structural equation modelling. *Patient*

Education and Counselling, *73*(2), 240–245. https://doi.org/10.1016/J.PEC.2008.07.022

Merl, H., Veronica Doherty, K., Alty, J., & Salmon, K. (2022). Truth, hope and the disclosure of a dementia diagnosis: A scoping review of the ethical considerations from the perspective of the person, carer and clinician. *Dementia*, *21*(3), 1050–1068. https://doi.org/10.1177/14713012211067882/ASSET/IMAGES/LARGE/10.1177_14713012211067882-FIG1.JPEG

Milby, E., Murphy, G., & Winthrop, A. (2017). Diagnosis disclosure in dementia: Understanding the experiences of clinicians and patients who have recently given or received a diagnosis. *Dementia*, *16*(5), 611–628. https://doi.org/10.1177/1471301215612676/FORMAT/EPUB

Mitchell, G., McCollum, P., & Monaghan, C. (2013). The personal impact of disclosure of a dementia diagnosis: a thematic review of the literature [Article]. *British Journal of Neuroscience Nursing*, *9*(5), 223–228. https://doi.org/10.12968/bjnn.2013.9.5.223

Mody, L., Douglas Miller, Ã. K., McGloin, J. M., Div, M., Freeman, M., Marcantonio, E. R., Ã Jay Magaziner, Ã., & Studenski, S. (2008). Recruitment and Retention of Older Adults in Aging Research. *Journal of American Geriatric Society*, *56*, 2340–2348. https://doi.org/10.1111/j.1532-5415.2008.02015.x

Mograbi, D. C., Brown, R. G., & Morris, R. G. (2009). Anosognosia in Alzheimer's disease – The petrified self. *Consciousness and Cognition*, *18*(4), 989–1003. https://doi.org/10.1016/J.CONCOG.2009.07.005

Monden, K. R., Gentry, L., & Cox, T. R. (2016). Delivering Bad News to Patients. *Baylor University Medical Center Proceedings*, *29*(1), 101–102. https://doi.org/10.1080/08998280.2016.11929380

Moore, V., & Cahill, S. (2013). Diagnosis and disclosure of dementia - A comparative qualitative study of Irish and Swedish General Practitioners

[Article]. *Aging & Mental Health*, *17*(1), 77–84. https://doi.org/10.1080/13607863.2012.692763

Mormont, E., Jamart, J., & Jacques, D. (2014). Symptoms of depression and anxiety after the disclosure of the diagnosis of alzheimer disease. *Journal of Geriatric Psychiatry and Neurology*, *27*(4), 231–236. https://doi.org/10.1177/0891988714532021/FORMAT/EPUB

Moudatsou, M., Stavropoulou, A., Philalithis, A., & Koukouli, S. (2020). The Role of Empathy in Health and Social Care Professionals [Article]. *Healthcare (Basel)*, *8*(1), 26. https://doi.org/10.3390/healthcare8010026

Munoz Sastre, M. T., Sorum, P. C., & Mullet, E. (2011). Breaking Bad News: The Patient's Viewpoint. *Health Communication*, *26*(7), 649–655. https://doi.org/10.1080/10410236.2011.561919

Naidoo, N., Nguyen, V. T., Ravaud, P., Young, B., Amiel, P., Schanté, D., Clarke, M., & Boutron, I. (2020). The research burden of randomized controlled trial participation: a systematic thematic synthesis of qualitative evidence [Article]. *BMC Medicine*, *18*(1), 6–6. https://doi.org/10.1186/s12916-019-1476-5

Narayanan, V., Bista, B., & Koshy, C. (2010). "BREAKS" protocol for breaking bad news [Article]. *Indian Journal of Palliative Care*, *16*(2), 61–65. https://doi.org/10.4103/0973-1075.68401

Nembhard, I. M., David, G., Ezzeddine, I., Betts, D., & Radin, J. (2023). A systematic review of research on empathy in health care. *Health Services Research*, *58*(2), 250–263. https://doi.org/10.1111/1475-6773.14016

Nguyen, T., & Li, X. (2020). Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature. *Dementia*, *19*(2), 148–181. https://doi.org/10.1177/1471301218800122/FORMAT/EPUB

NHS. (2019). *The NHS Long Term Plan*. https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf

NHS Digital. (2023). *For Information: Preparations for the Implementation of ICD-11.* For Information: Preparations for the Implementation of ICD-11. https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/scci0021-international-statistical-classification-of-diseases-and-health-related-problems-icd-10-5th-edition

NHS Health Research Authority. (2024). *Public involvement*.

Nielsen, K. D., & Boenink, M. (2021). Ambivalent anticipation: How people with Alzheimer's disease value diagnosis in current and envisioned future practices [Article]. *Sociology of Health & Illness*, *43*(2), 510–527. https://doi.org/10.1111/1467-9566.13238

Nyberg, L., Mcintosh, A. R., Houle, S., Nilsson, L.-G., & Tulving, E. (1996). *Activation of medial temporal structures during episodic memory retrieval*.

O'Connor, M. L., & McFadden, S. H. (2012). A Terror Management Perspective on Young Adults' Ageism and Attitudes Toward Dementia. *Educational Gerontology*, *38*(9), 627–643. https://doi.org/10.1080/03601277.2011.595335

Office of National Statistics. (2023, April 11). *Death registration summary statistics, England and Wales: 2022*. ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathregistrationsummarystatisticsenglandandwales/2022

Phillips, J., Pond, C. D., Paterson, N. E., Howell, C., Shell, A., Stocks, N. P., Goode, S. M., & Marley, J. E. (2012). Difficulties in disclosing the diagnosis of dementia: a qualitative study in general practice [Article]. *British Journal of General Practice*, *62*(601), e546–e553. https://doi.org/10.3399/bjgp12X653598

Poyser, C. A., & Tickle, A. (2019). Exploring the experience of the disclosure of a dementia diagnosis from a clinician, patient and carer perspective: a

systematic review and Meta-ethnographic synthesis. *Aging & Mental Health*, *23*(12), 1605–1615. https://doi.org/10.1080/13607863.2018.1506747

Pratt, R., & Wilkinson, H. (2001). *"Tell Me the Truth". The Effect of Being Told the Diagnosis of Dementia from the Perspective of the Person with Dementia.*

Pratt, R., & Wilkinson, H. (2003). A Psychosocial Model of Understanding the Experience of Receiving a Diagnosis of Dementia [Article]. *Dementia (London, England)*, *2*(2), 181–199. https://doi.org/10.1177/1471301203002002004

Provencher, V., Mortenson, W. B., Tanguay-Garneau, L., Bé Langer B, K., & Dagenais, M. (2014). Challenges and strategies pertaining to recruitment and retention of frail elderly in research studies: A systematic review. *Archives of Gerontology and Geriatrics*, *59*, 18–24. https://doi.org/10.1016/j.archger.2014.03.006

Ranson, J. M., Kuźma, E., Hamilton, W., Muniz-Terrera, G., Langa, K. M., & Llewellyn, D. J. (2019). Predictors of dementia misclassification when using brief cognitive assessments [Article]. *Neurology. Clinical Practice*, *9*(2), 109–117. https://doi.org/10.1212/CPJ.0000000000000566

Raslau, F. D., Marl, I. T., Klein, J. L., Ulmer, V., Mathews, V., & Mark, L. P. (2015). Memory Part 2: The Role of the Medial Temporal Lobe. *American Journal of Neuroradiology*, *35*(5), 846–849. https://doi.org/10.3174/ajnr.A4169

Richardson, T. (2014). Clinical psychologists and research: Do we do any and should we do more? *Psychology Postgraduate Affairs Group Quarterly*, *90*, 7–11.

Ripley, E. B. D. (2006). A Review of Paying Research Participants: It's Time to Move Beyond the ethical Debate [Article]. *Journal of Empirical Research on Human Research Ethics*, *1*(4), 9–20. https://doi.org/10.1525/jer.2006.1.4.9

Ritchie, J., & Spencer, L. (1994a). Qualitative data analysis for applied policy research. In A. Bryman & B. Burgess (Eds.), *Analyzing Qualitative Data* (pp.

173–194). Routledge. https://doi.org/https://doi.org/10.4324/9780203413081

Ritchie, J., & Spencer, L. (1994b). Qualitative data analysis for applied policy research [Bookitem]. In *Analyzing Qualitative Data* (pp. 187–208). Routledge. https://doi.org/10.4324/9780203413081-14

Ritchie, J., & Spencer, L. (2002). Qualitative data analysis for applied policy research. [Book]. In A. M. Huberman & M. B. Miles (Eds.), *The Qualitative Researcher's Companion* (pp. 305–328). SAGE.

Robinson, L., Clare, L., & Evans, K. (2005). Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples. *Aging and Mental Health*, *9*(4). https://doi.org/10.1080/13607860500114555

Robinson, L., Gemski, A., Abley, C., Bond, J., Keady, J., Campbell, S., Samsi, K., & Manthorpe, J. (2011). The transition to dementia – individual and family experiences of receiving a diagnosis: a review [Article]. *International Psychogeriatrics*, *23*(7), 1026–1043. https://doi.org/10.1017/S1041610210002437

Robinson, L., Tang, E., & Taylor, J.-P. (2015). Dementia: timely diagnosis and early intervention [Article]. *BMJ (Online)*, *350*(jun15 14), h3029–h3029. https://doi.org/10.1136/bmj.h3029

Royal College of Psychiatrists. (2022). *Quality Standards for Memory Services*.

Schindler, S. E., Jasielec, M. S., Weng, H., Hassenstab, J. J., Grober, E., McCue, L. M., Morris, J. C., Holtzman, D. M., Xiong, C., & Fagan, A. M. (2017). Neuropsychological measures that detect early impairment and decline in preclinical Alzheimer disease. *Neurobiology of Aging*, *56*, 25–32. https://doi.org/10.1016/J.NEUROBIOLAGING.2017.04.004

Schöll, M., Lockhart, S. N., Schonhaut, D. R., O'Neil, J. P., Janabi, M., Ossenkoppele, R., Baker, S. L., Vogel, J. W., Faria, J., Schwimmer, H. D., Rabinovici, G. D., & Jagust, W. J. (2016). PET Imaging of Tau Deposition in

the Aging Human Brain [Article]. *Neuron (Cambridge, Mass.)*, *89*(5), 971–982. https://doi.org/10.1016/j.neuron.2016.01.028

Scott, S. D., Hirschinger, L. E., Cox, K. R., McCoig, M., Brandt, J., & Hall, L. W. (2009). The natural history of recovery for the healthcare provider “second victim” after adverse patient events [Article]. *Quality & Safety in Health Care*, *18*(5), 325–330. https://doi.org/10.1136/qshc.2009.032870

Sekhon, M., Cartwright, M., & Francis, J. (2016). Application of a theoretical framework to assess intervention acceptability: a semi-structured interview study. *European Health Psychologist*, *18*(Supplementary), 565–566.

Sekhon, M., Cartwright, M., & Francis, J. J. (2017a). Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework [Article]. *BMC Health Services Research*, *17*(1), 88–88. https://doi.org/10.1186/s12913-017-2031-8

Sekhon, M., Cartwright, M., & Francis, J. J. (2017b). Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework [Article]. *BMC Health Services Research*, *17*(1), 88–88. https://doi.org/10.1186/s12913-017-2031-8

Sekhon, M., Cartwright, M., & Francis, J. J. (2022). Development of a theory-informed questionnaire to assess the acceptability of healthcare interventions [Article]. *BMC Health Services Research*, *22*(1), 279–279. https://doi.org/10.1186/s12913-022-07577-3

Shepherd, V., Wood, F., Griffith, R., Sheehan, M., & Hood, K. (2019). Protection by exclusion? The (lack of) inclusion of adults who lack capacity to consent to research in clinical trials in the UK [Article]. *Current Controlled Trials in Cardiovascular Medicine*, *20*(1), 474–474. https://doi.org/10.1186/s13063-019-3603-1

Sheridan, R., Martin-Kerry, J., Hudson, J., Parker, A., Bower, P., & Knapp, P. (2020). Why do patients take part in research? An overview of systematic reviews of psychosocial barriers and facilitators [Article]. *Current Controlled*

Trials in Cardiovascular Medicine, *21*(1), 259–259. https://doi.org/10.1186/s13063-020-4197-3

Siberski, J. (2012). Dementia and DSM-5: Changes, cost and confusion. *Aging Well*, *5*(6), 12.

Skivington, K., Matthews, L., Simpson, S. A., Craig, P., Baird, J., Blazeby, J. M., Boyd, K. A., Craig, N., French, D. P., Mcintosh, E., Petticrew, M., Rycroft-Malone, J., White, M., & Moore, L. (2021). A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *BMJ*, *374*(n2061). https://doi.org/10.1136/bmj.n2061

Social Care Institute for Excellence. (2020, March). *Is dementia a terminal illness?* scie.org.uk/demenita/advanced-dementia-and-end-of-life-care/end-of-life-care/introduction.asp

Spector, A., Orrell, M., Davies, S., & Woods, B. (2001). Can reality orientation be rehabilitated? Development and piloting of an evidence-based programme of cognition-based therapies for people with dementia [Article]. *Neuropsychological Rehabilitation*, *11*(3–4), 377–397. https://doi.org/10.1080/09602010143000068

Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M., & Orrell, M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: Randomised controlled trial [Article]. *British Journal of Psychiatry*, *183*(3), 248–254. https://doi.org/10.1192/bjp.183.3.248

Srivastava, A., & Thomson, S. (2009). A qualitative methodology for applied policy research. *JOAAG*, *4*(2).

Starkstein, S. E. (2014). Anosognosia in Alzheimer's disease: Diagnosis, frequency, mechanism and clinical correlates. *Cortex*, *61*, 64–73. https://doi.org/10.1016/J.CORTEX.2014.07.019

Stokes, L. A., Combes, H., & Stokes, G. (2014). Understanding the dementia diagnosis: The impact on the caregiving experience. *Dementia*, *13*(1), 59–

78. https://doi.org/10.1177/1471301212447157/ASSET/IMAGES/LARGE/10.1177_1471301212447157-FIG1.JPEG

Swaffer, K. (2015). Dementia and Prescribed Disengagement [Article]. *Dementia*, *14*(1), 3–6. https://doi.org/10.1177/1471301214548136

Thorne, S. (2020). The Great Saturation Debate: What the “S Word” Means and Doesn’t Mean in Qualitative Research Reporting. *Canadian Journal of Nursing Research*, *52*(1), 3–5. https://doi.org/10.1177/0844562119898554

Tulving, E. (2002). Episodic memory: From mind to brain [Article]. *Annual Review of Psychology*, *53*(1), 1–25. https://doi.org/10.1146/annurev.psych.53.100901.135114

Vernooij-Dassen, M., Derksen, E., Scheltens, P., & Moniz-Cook, E. (2006). Receiving a diagnosis of dementia [Article]. *Dementia (London, England)*, *5*(3), 397–410. https://doi.org/10.1177/1471301206067114

Walsh, S., O’Neill, A., Hannigan, A., & Harmon, D. (2019). Patient-rated physician empathy and patient satisfaction during pain clinic consultations [Article]. *Irish Journal of Medical Science*, *188*(4), 1379–1384. https://doi.org/10.1007/s11845-019-01999-5

Wang, H., Kline, J. A., Jackson, B. E., Laureano-Phillips, J., Robinson, R. D., Cowden, C. D., D’etienne, J. P., Arze, S. E., & Zenarosa, N. R. (2018). *Association between emergency physician self-reported empathy and patient satisfaction*. https://doi.org/10.1371/journal.pone.0204113

Werner, P., Karnieli-Miller, O., & Eidelman, S. (2013). Current knowledge and future directions about the disclosure of dementia: A systematic review of the first decade of the 21st century [Article]. *Alzheimer’s & Dementia*, *9*(2), e74–e88. https://doi.org/10.1016/j.jalz.2012.02.006

Whitehead, A. L., Sully, B. G. O., & Campbell, M. J. (2014). Pilot and feasibility studies: Is there a difference from each other and from a randomised

controlled trial? [Article]. *Contemporary Clinical Trials*, *38*(1), 130–133. https://doi.org/10.1016/j.cct.2014.04.001

Wittenberg, R., Hu, B., Barraza-Araiza, L., & Rehill, A. (2019). *Projections of older people living with dementia and costs of dementia care in the United Kingdom*.

Wolff, J. L., & Roter, D. L. (2011). Family presence in routine medical visits: A meta-analytical review [Article]. *Social Science & Medicine (1982)*, *72*(6), 823–831. https://doi.org/10.1016/j.socscimed.2011.01.015

World Health Organisation. (2023, March 14). *Dementia: key facts*. https://www.who.int/news-room/fact-sheets/detail/dementia

World Health Organisation (WHO). (2021). *International Classification of Diseases, Eleventh Revision (ICD-11)*. icd.who.int/en

Wu, A. W. (2000). Medical Error: The Second Victim: The Doctor Who Makes the Mistake Needs Help Too [Article]. *BMJ (Online)*, *320*(7237), 726–727. https://doi.org/10.1136/bmj.320.7237.726

Zachariae, R., Pedersen, C. G., Jensen, A. B., Ehrnrooth, E., Rossen, P. B., & Von Der Maase, H. (2003). Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease [Article]. *British Journal of Cancer*, *88*(5), 658–665. https://doi.org/10.1038/sj.bjc.6600798

Zaleta, A. K., & Carpenter, B. D. (2010). Patient-centered communication during the disclosure of a dementia diagnosis. *American Journal of Alzheimer's Disease and Other Dementias*, *25*(6), 513–520. https://doi.org/10.1177/1533317510372924

From: brightonandsussex.rec@hra.nhs.uk <brightonandsussex.rec@hra.nhs.uk>
Sent: 17 March 2021 20:30
To: Danielle.Deboos@nottingham.ac.uk; Annabelle.Silvester@nottingham.ac.uk; Danielle.Deboos@nottingham.ac.uk; NMoghaddam@lincoln.ac.uk
Cc: sponsor@nottingham.ac.uk
Subject: IRAS 292410. HRA & HCRW Approval Status Update - Provisional Outcome

Dear Dr De Boos,

I am pleased to provide the following update regarding the status of your application.

Please provide a response to the requested information through IRAS by referring to the instructions on how to submit a response to provisional opinion electronically. Please provide your answers in the table(s) below and then submit this, with revised documentation where appropriate, underlining, tracking or otherwise highlighting the changes which have been made and giving revised version numbers and dates. You do not have to make any changes to the IRAS application form unless you have been specifically requested to do so.

Ethical Review – Further information required

The Research Ethics Committee reviewed the application on 04 March 2021 and issued a **Provisional Opinion**. Please provide the following information in order for a final ethical opinion to be issued:

Number	Ethical Review - Further Information required	Response from the applicant
1.	The Committee requested that a copy of the guide (to improve the delivery of a diagnosis of dementia) was submitted for review.	
2.	The Committee requested that the interview aspect of the study was removed from the main information sheet and consent form, and separate documents were submitted to be used for this smaller group of participants.	
3.	The Committee requested further information about any mitigation of the potential risk of	

	coercion when clinicians identified potential participants.	
4.	The Committee requested further information about how the team would mitigate against any potential bias of participant selection.	
5.	The Committee requested further information of how the team would deal with the issue of excluding adults lacking capacity, and whether the study could be biased by not including these participants.	
6.	The Committee requested that the participant information sheet and consent form were rewritten in simpler language, removing any unnecessary details. Further guidance can be found at: http://www.hra-decisiontools.org.uk/consent/examples.html	
7.	The Committee requested that the clinician information sheet detailed that any serious concerns about practice may need to be fedback to the services.	
8.	The Committee requested that the participant information sheet confirmed that the study was being completed as part of a PhD.	
9.	The Committee requested that an optional clause was included in the consent form for access to study results.	
The Committee delegated authority to confirm its final opinion on the application to the Chair, together with Ms Rosemary Murphy.		

Number	Recommendation
1.	The Committee recommended that the study was registered on a public database, for example www.researchregistry.com.
2.	The Committee recommended that support in responding to the action points was provided by the Chief Investigator and Academic Supervisor.

A response should be submitted by no later than 16 April 2021.

Membership of the Committee London - Brighton & Sussex Research Ethics Committee Attendance at Committee meeting on 04 March 2021

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr John Bull	Consultant Physician (retired)	Yes	
Dr Cynthia Ruth Butlin	Retired Medical Practitioner	Yes	
Mr Gerard Cronin	Business Development Manager	Yes	
Mr Andrew Finnegan	Company Director	Yes	
Dr Caroline Garrett	Human Tissue Governance Manager and Research Fellow	Yes	
Mrs Sarah Hutchins	Senior Manager, Clinical Operations	Yes	
Mrs Jane Jones	Bank medical secretary	Yes	
Mr Maurice Marchant	Public Health Information Specialist (retired)	Yes	
Dr Elizabeth Ann McCreadie	Professional Lead Social Work	Yes	
Ms Rosemary Murphy	Vice President Business Intelligence	Yes	
Mr William Payne	Retired Prisoner Governor	Yes	
Mrs Carrie Ridley	Clinical Research Nurse (Emergency Medicine)	Yes	
Revd Charles Edward Sargent	Property Manager / Farmer	Yes	
Dr Paul Seddon	Consultant Paediatrician	Yes	
Mrs Kathy Stott	Pharmacist	No	
Dr Simon Walton	Consultant in Anaesthesia and Intensive Care	No	
Dr Stuart White	Consultant Anaesthetist	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Ms Ann Abel	Digital Communications Officer
Mr Peter Angus	Observer
Miss Juliana Araujo	Approvals Specialist
Ms Caroline Cowley	Observer
Sarah Prothero	Approvals Officer
Ms Joanna Saville	Observer

To review response: Carrie Ridley and Rosemary Murphy

If you have any queries, please do not hesitate to contact me.

Kind regards,

Juliana Araujo

Approvals Specialist

Health Research Authority | 2 Redman Place | E20 1JQ

T. +44 (0) 207104 8202

E. brightonandsussex.rec@hra.nhs.uk

W. www.hra.nhs.uk

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Appendix B R&I Letter

Dear Annabelle

I am sending the email below and Organisational Information Document on behalf of Liz Sabin, Senior Clinical Research Nurse.

Please see attached Organisational Information Document in relation to the above study.

You will see I have amended the start date to the date it has been signed by the Medical Director of the Trust.

Full Study Title: The Acceptability and Feasibility of a guide for sharing the outcome of a memory assessment

Short title: Sharing the outcome of a memory assessment

This email confirms that Northamptonshire Healthcare NHS Foundation Trust has received all study documentation including HRA approval for the study.
We have reviewed the study protocol (version 1.0 dated 08-02-2021) and confirm that the study has the support and supervision of a clinical lead within the department where it will be carried out. This information is stored on our research data base.

Based on the above we give permission for this study to be carried out at Northamptonshire Healthcare NHS Foundation Trust.

We agree to start this study on a date to be agreed when the sponsor gives the green light to begin. Please can you advise us of the progress of this project and its completion.

If you wish to discuss further, please do not hesitate to contact me.

Kind regards

Liz

Liz Sabin
Senior Clinical Research Nurse
Northampton Innovation & Research Team
NIHR Clinical Research Network: East Midlands
Berrywood Hospital
Berrywood Drive
Northampton
NN5 6UD

Mob 07770 728 416

Elizabeth.Sabin@nhft.nhs.uk
www.nhft.nhs.uk

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Dementia Diagnostic Delivery – A guide for Deliverers

Prototype

Introduction

Information presented in this guide has been based on research evidence from detailed analysis of interviews about dementia diagnostic delivery with clinicians, patients, and people who support patients in appointments.

The aim of this guide is to help clinicians to think about how they deliver a diagnosis of dementia. It may be a helpful resource to refer to every so often. It may also be helpful if you have had a negative delivery to see what could be done differently or to use in supervision or reflective practice. It can be used alongside a guide and notes sheet for people who attend services where a diagnosis of dementia is likely to be delivered. These contain information about:

- The service and assessment process
- What to expect when attending for different appointments
- Bringing someone to support the patient at the appointment
- The possible outcomes of attending a Memory Service

They also help the patient, and those who attend alongside the patient, to:

- Consider and collate their concerns and questions prior to appointments,
- and provide a prompt to raise these in their appointment.
- Inform the clinician of any difficult to discuss concerns via a confidential disclosure sheet
- Make choices. This includes what they would like to know or not know about their diagnosis, and who else can be informed.

Looking after yourself

One of the most important elements of a good delivery is feeling able to do this yourself. Delivering a diagnosis is a difficult and energy consuming process. It can also be an emotional journey as you get to know the people and witness the potential impact that a diagnosis of dementia has on their lives.

Using processes such as reflective practice, supervision, or peer supervision may be helpful to continue to be able to deliver diagnoses. Remaining aware of your own feelings and emotional place is critical, as these can be barriers to feeling able to continue to deliver a diagnosis.

It is also highly likely that you will come across challenges to delivering a good diagnosis. For example, working in a time limited service, having waiting lists, or not being able to meet everybody's needs can all be highly challenging. Again, using reflective practice and supervision can help prevent these pressures impacting on individual appointments.

What makes a Good Delivery?

There are some essential tasks that are needed to deliver a diagnosis, such as telling someone their diagnosis and considering future options. However, the most important element of a good delivery are how these tasks are done. It is also extremely important that a positive relationship is built up between the person delivering the diagnosis and those receiving the news. This guide has some key elements of a good diagnosis for your consideration. It is not exhaustive and each person delivering a diagnosis will have their own style of how this is done.

Attending the appointment

Primarily a good delivery is one where people are able to attend their appointments. It could be that a reminder service helps people to recall when and where their appointment is. Other considerations are transport issues, and any access difficulties.

Environment

Often the physical location and space where an appointment is held is not in the direct control of the clinician. However, it is usually possible to make adjustments to the layout of the room to ensure the attendees feel as comfortable and welcome as possible. Simple changes to the layout of the chairs or ensuring that you are not seated behind a computer or desk can make a difference to a person's experience.

Terminology

It can be useful to gently introduce the word dementia as people can have different emotions, associations and understandings of the term. It could be helpful to find out what people know about the reasons for their appointment and exploring memory difficulties in the lead up to introducing the idea of dementia.

Despite needing a gentle introduction, it is really important that the term 'dementia' is used from the beginning of the person's assessment. It may be that people then choose to use another term or phrase to describe their difficulties. However, people told us that by openly using the word dementia, it helped them to be clear about what could be affecting them or the person they were supporting.

Patient as the focus

It is highly likely that the person who is being assessed for memory difficulties attends their appointments with another person. In fact, this can be very helpful for both the

patient and the clinician. However, it is critical that the patient remains as the focus of the appointment.

It is also important to not exclude the people who support the person receiving a diagnosis. To do this you may have to hold and work with different and multiple realities, held by each attendee. This can require careful management as the differences between each attendee can lead to conflict. This means that it can be difficult to manage the dynamics and focus of the appointment.

It maybe that it would be beneficial to offer to talk to each attendee individually or accept an attendee's concerns in written form in or a separate conversation. This could help manage difficult dynamics, as people can sometimes feel uneasy about discussing another person's difficulties in front of them.

At times it may feel easier to relay a person's diagnosis to the person who supports them in appointments. It could be helpful to use reflective practice to explore why this is and to help overcome these feelings in an appointment.

Consent

Asking people about their choices is a fundamental element in the process of diagnosis and diagnostic delivery. The patient's consent should be explored and respected for many areas including:

- who they wish to come into the appointment with them
- what they would or would not like to know about their diagnosis
- who diagnostic information can be shared with
- who letters can be sent to

Consent and choices can also change from one appointment to the next so it is always better to continually check rather than assume. It is important to explore consent in a supportive manner as people may need some guidance or help to make informed

choices. Don't forget the principles of mental capacity and making unwise choices as set out in the Mental Capacity Act 2005.

Engagement

People stated that they found appointments most helpful when there had been conversation in their appointment, and that the clinician was nice and approachable. Although this seems to be straightforward, engaging people in a time limited appointment can be hard. People may also be anxious when attending appointments and this can be a barrier to engagement.

Some ways that can help are to:

- giving people space and time to answer any questions or express themselves.
- it might be that one person who attends seems to do more talking, in this situation it can be helpful to politely invite the other person's view so that all attendees have space to express their opinions.

Information and Understanding

One of the key tasks of delivering a diagnosis is to help the person develop an understanding about the difficulties that they have been experiencing. How this is developed will be different for everybody.

It should also be noted that understanding is not something that can be turned on or off, it takes time and is a process. The person delivering the diagnosis needs to guide people through this process or journey. How you do this is likely to be different for everyone and getting the pacing of the delivery is important. Some people may prefer a prompt and direct delivery, while others may prefer a gentler and slower introduction to their diagnosis.

It is important to try and get the preferred balance of information for each person. Being under informed can be just as difficult as being overwhelmed with information. Try asking people how much they would like to know, or if they would like more or less

explanation. Use your observational skills to try and sense if the level of information is right for that person. Regularly checking out understanding can be useful. Asking people 'have you understood that?' may not reveal their understanding. Instead try asking someone to tell you in their own words about the information you have given.

Many people stated that going through the assessment, including scan results and psychometric tests, was really helpful in understanding how their diagnosis had been reached. It also helped when people adapted their language to suit the person, for example giving a scientific and a 'layman's' explanation. Also, some people may prefer a very black and white explanation.

Try to remember that the person has come into services with difficulties with memory. It may be really helpful to write down their diagnosis or give printed information to support any verbal information in the appointment. Also clinical letters can help with understanding.

Emotional Support

A good diagnostic delivery is not only about providing information. People who attend will require emotional support and consideration of their emotions. It can be difficult for someone to express how they are feeling before, during or after receiving the diagnosis, so it can be necessary to use non-verbal cues about the person's emotional experience. People react to the diagnostic news in many ways and express this in a range of emotions in an appointment. Try to never assume how someone will react, instead directly ask how someone is feeling. For most people receiving a diagnosis is a very important and potentially life changing piece of news so always support someone's reaction.

Taking on new information or trying to develop understanding is more difficult when we are experiencing an emotional reaction. Some emotional support, such as comfort

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or just a small period of time without any talking, could be required to help people be able to take on the information that you are trying to communicate.

It is also important that you try to remain calm so that you can provide a supportive and containing atmosphere in the appointment.

Adaptation

Underpinning everything is about your ability to adapt to the range of people who come into services. Adaptation may be also required as people progress through the service as choices and understanding evolves. This is one of the reasons why delivering a diagnosis of dementia is a tiring process to do!

Closing an Appointment

It can be difficult to manage ending an appointment when there are time pressures. However, it is important to strive for a positive closure to each appointment without rushing.

Some useful things to remember at the end of an appointment is to inform the attendees of what will be happening next in their contact with services. It could be helpful to write this down in the appointment and follow it up with a letter as well.

The end of an appointment is another good time to review someone's understanding of what has been discussed in the appointment. Again it could be useful to write this down.

Another helpful step can be to give people information about their diagnosis and where they can get help and support. Consider the national and local services, including the Alzheimer's Society, local Social Services, carers services, and health services

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contact points. Also consider discussing or signposting to other services to discuss legal implications of any diagnosis, for example driving and lasting power of attorney.

A final invitation of any outstanding questions or concerns can be appreciated by attendees at the end of the appointment.

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Memory Assessment Services – A Guide

Introduction

You have received this guide because you have been referred for an appointment at the Memory Assessment Service. This is because there are some worries about your memory at the moment. This guide aims to provide a support for you to use before, during and after your appointments at the Memory Assessment Service.

There is information about the Memory Assessment Service and what to expect, as well as making suggestions about how you might like to prepare and helping you in the appointment.

You might want to share this guide with your family or someone who knows you well, as they might find it helpful too.

You may have been given or you may receive more detailed information about the specific Memory Assessment Service that you might be attending. This is because each service can be slightly different. The information below is a brief, general summary about Memory Assessment Services.

Memory Assessment Service

What is the Memory Assessment Service?

The Memory Assessment Service is where specialist doctors and specialist nurses assess people's memory. It is their job to try and understand what is causing the person's difficulties with their memory.

What will happen to me at the Memory Assessment Service?

<u>Assessment Appointment</u>

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To start with, you will be asked to attend the Memory Assessment Service for an assessment. In this appointment you will also be asked about how things are going at the moment and what things you are finding difficult. You may be asked about your past and how long you have noticed changes in your memory. Any medication that you are taking and other health conditions are also likely to be discussed.

You may be asked to complete a memory test in this first appointment. A memory test is not something that you can prepare or revise for, so please try not to be worried about this.

Other tests

Some people will need other or more tests to help the specialist doctor or specialist nurse to know what could be wrong. This could include brain scan or visiting another specialist doctor for other tests. If you need any extra tests these will be discussed with you in the appointment. They will not happen in your first appointment.

Results Appointment

Once all the tests have been done you will be asked to come back to the Memory Assessment Service to find out what the results mean for you. People may find out that they have a diagnosis of a range of illnesses. This can include dementia, mild cognitive impairment, or no diagnosis. There is more information about dementia further on in this guide.

Follow up Appointment

Depending upon what the results of your tests showed, you may need to go back to the Memory Assessment Service for another appointment. This is to check any medication that you have been given. You will be told in your results appointment if you need to come again.

Bringing Someone with You

Many people say how helpful they found it when someone that knew them well came with them to their appointments. People said it helped them to understand and remember what

was said in the appointment, as well as finding them to be a big support. This is your choice if you want someone to come with you.

If you do want someone to come, please tell them when the appointment is. You could even give them a copy of your letter. If you would like the Memory Assessment Service to send them copies of letters, then you can tell the specialist doctor or specialist nurse in your appointment.

Whether you come on your own or come with someone else, you will be the main focus. The nurse will ask about your choices and what you think. However, if someone does come with you, the nurse is likely to want to ask them questions as well. The nurse should check if this is ok with you first. Please tell the nurse if you don't want this to happen.

Main Concerns and Questions

People have told us that it can be hard to remember in the appointment to say everything you wanted to. Therefore, it can be helpful for both you and the person who comes with you to write down things that you have noticed happening, any concerns or worries, and any questions.

It can also be difficult to say things in front of the person who has come with you, or for them to say things in front of you. You might find it easier to write these things down and hand them to the nurse in the appointment.

Making Choices

During your appointments there will be some decisions to make. This may include what you want to know about your test results, and how much information you would like.

It can be helpful to have thought about some of the following questions before your appointments:

- What is important for you right now

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- What you want to know
- Anything you don't want to know
- Who else can be told about your test results – for example do you want any family members to know?

What is Dementia?

Dementia is a medical term used to describe a set of symptoms that can include memory loss and difficulties with thinking, problem-solving or language. Someone who has dementia may also experience changes in their mood or behaviour too. These changes are likely to have started as small changes but have become worse over time and are now likely to be affecting daily life.

The term dementia is used to describe a number of diseases that damage the brain. One of the most common types of dementia is Alzheimer's disease, but this is not the only cause. Other common causes include; vascular dementia, mixed dementia, dementia with Lewy bodies, and frontotemporal dementia.

More information about these and other rarer dementias can be found in a fact sheet produced by the Alzheimer's Society called What is dementia?. This can be obtained by visiting www.alzheimers.org.uk, or telephoning the National Dementia Helpline on

0300 222 11 22.

Want extra information or help?

There are many places to find more information or to talk to someone for advice. Try talking to your GP or asking them for information leaflets or fact sheets. You could also research the internet or ask someone to help you to do this.

The Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. They can be contacted on the National Dementia Helpline

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0300 222 11 22 or by visiting their website www.alzheimers.org.uk Dementia UK also run the Admiral Nursing Direct dementia helpline 0800 888 6678 that can give you specialist practical and emotional support. More information is available via the website www.dementiauk.org

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Memory Assessment Services

Appointment Notes Sheet

It can be useful to have thought about your concerns before attending your appointment at the Memory Assessment Service.

This notes sheet has some areas that might be helpful to have thought about. You can use this sheet to make any notes about your choices, concerns and questions.

This is just for your own use. If you would like to share it in your appointment this will be ok, but it is not a requirement.

There are two copies of this form. You might want to give one to the person who is coming with you to your appointment to fill in too.

Your Name: **Today's Date:**

Main Concerns and Questions

What are your main concerns at the moment?

Appendix D Sharing the Outcome of a Memory Assessment. Guide Patient-Companion Version

Have you noticed any difficulties or changes in the following areas?

Circle those that apply

Shopping

Getting dressed

Housekeeping

Using the bath or the shower

Accounting or Banking

Eating and drinking

Cooking

Using the toilet

Managing Medication

Continence

Using the telephone

Personal Care – such as brushing your hair or shaving

Getting around – walking, moving around your home

In your occupation – such as paid work, voluntary roles, caring responsibilities

Using transport

Communication

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Are there any other areas that you have noticed any changes?

What questions would you like to find out about at the appointment?

Any other worries that you want to discuss?

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Making Choices

Use this section to record your wishes and choices. You can change your mind

or alter your decision at a later date if you wish.

Who do you wish to come into your appointment with you?

What do you want know about your results?

(for example: Tell me everything, give me a brief an overview, just tell me the name, nothing)

Who can information can be shared with?

(for example: family members)

Who letters can be sent to?

(for example: family members)

Any other choices or wishes?

Other important information to ask or remember in the appointment

Use this space to make any other notes for using in your appointment. You can

continue on other pieces of paper if you wish.

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Memory Assessment Services

Appointment Notes Sheet

This is the second copy of this form. It could be completed by a family member or someone who knows you well.

Use this sheet to make any notes about choices, concerns and questions. This is just for your own use. If you would like to share it in your appointment this will be ok, but it is not a requirement.

Your Name: Today's Date:

Main Concerns and Questions

What are your main concerns at the moment?

Have you noticed any difficulties or changes in the following areas?

Circle those that apply

Appendix D Sharing the Outcome of a Memory Assessment. Guide Patient-Companion Version

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Housekeeping

Using the bath or the shower

Accounting or Banking

Eating and drinking

Cooking

Using the toilet

Managing Medication

Continence

Using the telephone

Personal Care – such as brushing your hair or shaving

Getting around – walking, moving around your home

In your occupation – such as paid work, voluntary roles, caring responsibilities

Using transport

Communication

Are there any other areas that you have noticed any changes?

What questions would you like to find out about at the appointment?

Any other worries that you want to discuss?

Making Choices

Use this section to record your wishes and choices. You can change your mind

or alter your decision at a later date if you wish.

Who do you wish to come into your appointment with you?

What do you want know about your results?

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(for example: Tell me everything, give me a brief an overview, just tell me the name, nothing)

Who can information can be shared with?

(for example: family members)

Who letters can be sent to?

(for example: family members)

Any other choices or wishes?

Other important information to ask or remember in the appointment

Use this space to make any other notes for using in your appointment. You can continue on other pieces of paper if you wish.

Appendix E Interview schedule-Final

Interview Schedule. Clinicians

Aims: to understand MAS clinician's experiences of taking part in the study and the prospective acceptability of the intervention.

Duration: Around 30 minutes

Introduction: Introduce me and the person who is taking part in the interview. Explain that the interview is being recorded and that identities will be anonymised during the writing up process using pseudonyms. Reiterate that I was not involved in the development of the guide and am looking for honest opinions about it. PRESS RECORD

1. How did you find taking part in the study?

2. Ask regarding the person's opinion of the study procedure. What do you think of it? How easily were you able to follow the procedure?

3. What reasons did people give to you for not taking part in the study?

4. Is there anything you would suggest changing about the study design that would make it more likely people would feel able to take part?

Acceptability questions

1. When thinking about using the guide as part of the study, how did you feel about it? What did you like or dislike about it?

2. How much effort would it take for you to include the use of the guide in your usual practice? Would there be anything that would stop you?

3. Do you feel that the information included in the guide and the approach it takes to sharing the outcomes of assessments is in keeping with what you think is important?

4. What do you think the purpose of the guide is? Do you think it would achieve this purpose?

5. Is there anything about this guide that would make it difficult to use in your practice?

6. Do you think the guide has the potential to improve people's experiences of learning the outcomes of their assessment for dementia?

7. How able do you feel you could use the guide to inform your discussions with patients and their companions in your outcome appointments?

Clinicians will be given an opportunity to add any comments not already captured and will be thanked for their time.

Appendix F Sharing the Outcome of a Memory Assessment. CARE Questionnaire for Companions

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The Consultation and Relational Empathy (CARE) Questionnaire for Patients

Participant study number:

Date of appointment:

Time of appointment:

Type of appointment (please circle your answer)

Initial Appointment Results Appointment

Please rate the following statements about today's appointment. Please tick the box for each statement and answer every statement.

How was the clinician at…	Poor	Fair	Good	Very Good	Excellent	Does Not Apply

Appendix F Sharing the Outcome of a Memory Assessment. CARE Questionnaire for Companions

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1. … making you feel at ease? *(being friendly and warm towards you, treating you with respect; not cold or abrupt)*						
2. … letting you tell your "story"? *(giving you time to fully describe your illness in your own words; not interrupting or diverting you)*						
3. … really listening? *(paying close attention to what you were saying; not looking at the notes or computer as you were talking)*						
4. …being interested in you as a whole person? *(asking/knowing relevant details about your life, your situation; not treating you as "just a number")*						
5. … fully understanding your concerns? *(communicating that he/she had accurately understood your concerns; not overlooking or dismissing anything)*						
6. … showing care and compassion? *(seeming genuinely concerned, connecting with you on a human*						

level; not being indifferent or "detached")						
7. … being positive? *(having a positive approach and a positive attitude; being honest but no negative about your problems)*						
8. … explaining things clearly? *(fully answering your questions, explaining clearly, giving you adequate information; not being vague)*						
9. … helping you to take control? *(exploring with you what you can do to improve your health yourself; encouraging rather than "lecturing you"*						
10. … making a plan of action with you? *(discussing the options, involving you in decision as much as you want to be involved; not ignoring your views)*						

Appendix G Sharing the Outcome of a Memory Assessment. CARE questionnaire for Patients

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The Consultation and Relational Empathy (CARE) Questionnaire for Patients

Participant study number:

Date of appointment:

Time of appointment:

Type of appointment (please circle your answer)

Initial Appointment Results Appointment

Please rate the following statements about today's appointment. Please tick the box for each statement and answer every statement.

How was the clinician at…	Poor	Fair	Good	Very Good	Excellent	Does Not Apply

Appendix G Sharing the Outcome of a Memory Assessment. CARE questionnaire for Patients

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1. … making you feel at ease? *(being friendly and warm towards you, treating you with respect; not cold or abrupt)*						
2. … letting you tell your "story"? *(giving you time to fully describe your illness in your own words; not interrupting or diverting you)*						
3. … really listening? *(paying close attention to what you were saying; not looking at the notes or computer as you were talking)*						
4. …being interested in you as a whole person? *(asking/knowing relevant details about your life, your situation; not treating you as "just a number")*						
5. … fully understanding your concerns? *(communicating that he/she had accurately understood your concerns; not overlooking or dismissing anything)*						
6. … showing care and compassion? *(seeming genuinely concerned, connecting with you on a human*						

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level; not being indifferent or "detached")						
7. … being positive? *(having a positive approach and a positive attitude; being honest but no negative about your problems)*						
8. … explaining things clearly? *(fully answering your questions, explaining clearly, giving you adequate information; not being vague)*						
9. … helping you to take control? *(exploring with you what you can do to improve your health yourself; encouraging rather than "lecturing you"*						
10. … making a plan of action with you? *(discussing the options, involving you in decision as much as you want to be involved; not ignoring your views)*						

Appendix H Journal Submission

The Journal identified for submission of article is Dementia. Submission guidelines can be found at the following link:

https://journals.sagepub.com/author-instructions/DEM

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Interview CONSENT FORM (Companion)
(Final version 1.0: 18.3.2021)

Title of Study: **The acceptability and feasibility of a guide for the delivery of memory assessment outcomes**
6

IRAS Project ID: 292410

Name of Researcher: Dr Nima Moghaddam, Dr Danielle De Boos and Annabelle Silvester

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet version number 1.0 dated 18.3.2021 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, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐
6. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐
7. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	**Date**	**Signature**
_____	_____	_____
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the project notes

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Interview CONSENT FORM (Clinician)
(Final version 1.0: 18.3.2021)

Title of Study: **The Acceptability and Feasibility of a guide for the delivery of memory assessment outcomes**

7

IRAS Project ID: 292410

Name of Researcher: Dr Nima Moghaddam, Dr Danielle De Boos and Annabelle Silvester

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet version number 1.0 dated 18.3.2021 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, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐
5. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐
6. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	**Date**	**Signature**
_____	_____	_____
Name of Person taking consent	Date	Signature

3 copies: 1 for participant, 1 for the project notes

Appendix K Sharing the Outcome of a Memory Assessment Interview Consent Form-Patient

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Interview CONSENT FORM (Patient)
(Final version 1.0: 18.3.2021)

Title of Study: **The acceptability and feasibility of a guide for the delivery of memory assessment outcomes**
8

IRAS Project ID: 292410

Name of Researcher: Dr Nima Moghaddam, Dr Danielle De Boos and Annabelle Silvester

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet version number 2.0 dated 18.3.2021 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, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3. I understand that relevant sections of my medical notes and data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

4. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐

6. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers. ☐

7. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	**Date**	**Signature**
_____	_____	_____
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the project notes and 1 for the medical notes

Appendix L Sharing the Outcome of a Memory Assessment. Companion Consent Form

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CONSENT FORM-Companion
(Final Version 2.0 18.3.2021)

Title of Study: The acceptability and feasibility of a guide for sharing the outcome of a memory assessment

IRAS Project ID: 292410

Name of Researcher(s): Dr Nima Moghaddam, Dr Danielle De Boos and Annabelle Silvester

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet version 2.0 dated 18.3.2021 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, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3. I understand that the data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

4. I give permission for appointments to be audio-recoded and understand that these recordings will be deleted after they have been coded by the researcher. ☐

5. I give permission to be contacted via the telephone about the questionnaires I have been asked to complete. ☐

6. I understand that the information collected about me may be used to support other research in the future and may be shared anonymously with other researchers. ☐

7. I wish for the results of the study to be shared with me via post once they are available ☐

8. I agree to take part in the above study. ☐

Turn over

Appendix L Sharing the Outcome of a Memory Assessment. Companion Consent Form

_____	_____	_____
Name of Participant	**Date**	**Signature**

_____	_____	_____
Name of Person taking consent	Date	Signature

2 copies: 1 for participant and 1 for the project notes

Appendix M Sharing the Outcome of a Memory Assessment. Patient Consent Form

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CONSENT FORM-Patient
(Final Version 2.0 18.3.2021)

Title of Study: The Acceptability and Feasibility of a guide for the delivery of memory assessment outcomes

IRAS Project ID: 292410

Name of Researchers: Dr Nima Moghaddam, Dr Danielle DeBoos and Annabelle Silvester

Name of Participant: **Please initial box**

1. I confirm that I have read and understand the information sheet version number 2.0 dated 18.3.2021 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, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3. I understand that relevant sections of my medical notes and data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

4. I agree that the information gathered about me can be stored by the University of Nottingham at the School of Medicine, for possible use in future studies. I understand that some of these studies may be carried out by researchers other than the current team who ran the first study, including researchers working for commercial companies. Any samples or data used will be anonymised, and I will not be identified in anyway. ☐

5. I give permission for my appointments to be audio-recoded and understand that these recordings will be deleted after they have been coded by the researcher. ☐

6. I give permission to be contacted via the telephone about the questionnaires I have been asked to complete. ☐

7. I understand that the information collected about me may be used to support other research in the future and may be shared anonymously with other researchers. ☐

8. I wish for the results of the study to be shared with me via post once they are available ☐

9.I agree to take part in the above study. ☐

Please Turn Over

Appendix M Sharing the Outcome of a Memory Assessment. Patient Consent Form

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

3 copies: 1 for participant, 1 for the project notes and 1 for the medical notes

Appendix N Participant Information Sheet. Companion-Intervention.

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Participant Information Sheet-(Companion-Intervention Group)
(Final Version 2.0 18.3.2021)

Title of Study: The acceptability and feasibility of a guide for the delivery of memory assessment outcomes
IRAS Number: 292410
Name of Researchers: Dr Nima Golijani Moghaddam, Dr Danielle De Boos and Annabelle Silvester. **PI Northampton:** Dr Louise Birkett-Swan

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

This study is being conducted by a research team that is independent of the Memory Assessment Service to which you have been referred. It is important that you feel able to decide whether to participate in the study without feeling obliged. Memory Assessment Clinicians are impartial, and you will not be judged negatively based on your decision whether to take part in the study or not.

What is the purpose of the study?

A guide has been developed that aims to improve people's experiences of the way outcomes of memory assessments are shared with them. This guide requires evaluation to find out if it is effective in achieving this aim. The purpose of this study is to begin the process of evaluation by looking at how acceptable the guide is felt to be by the people who use it. This study will also look at some of the practicalities involved which will inform future research looking into guide's effectiveness.

Why have I been invited?

You are being invited to take part because someone you support has been referred to a Memory Assessment Service and their initial assessment appointment is due to take place during the time period that this study is recruiting participants. We are inviting 48 participants like you to take part in the study.

Do I have to take part?

It is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights. If you decide not to take part in the study, you may wish to look at the guide. Please be assured there is no expectation that you must then participate in the study.

What will happen to me if I take part?

If you choose to take part, you will be required to read through the enclosed information titled "Memory Assessment Services-A Guide" and answer the questions in the guide prior to your initial assessment appointment. This information will also be given to the person you support.

At the initial assessment appointment, you will be asked to read and sign a written consent form. A 10-item questionnaire will then be given to you and, where applicable, the person attending the appointment with you. This questionnaire asks for information on your views of the appointment you have attended and will be posted back to the research team without being seen by anybody

in the Memory Assessment Service. Following the appointments with the Memory Assessment Service a member of the research team will contact you via telephone to remind you to complete the questionnaire and answer any queries you may have.

At the Memory Assessment outcome appointment, you will be encouraged to use the information guide provided at the initial assessment appointment. At this appointment you will again be given a copy of a 10-item questionnaire asking for your views on the appointment. This questionnaire will also be posted back to the research team without being seen by anybody at the Memory Assessment Service. We would like to audio-record your appointments with the clinician, so the researchers can evaluate how closely the clinician follows the intervention tool.
You will also be offered the opportunity to take part in a short interview about your experiences of the outcome appointment. Please see the separate information sheet titled "Participant Information Sheet- (Patient/Companion Interview)" for details of what this will involve.

Expenses and payments
Participants will not be paid to participate in the study.
What are the possible disadvantages and risks of taking part?
The guide that is being evaluated as part of this study has been developed in line with government guidelines on how to share the outcomes of memory assessments. It has also been developed using the views of others who have been through the memory assessment process. It is therefore felt that the risks of taking part are minimal. However, it is also unknown if taking part in the study will provide any benefits. Previous research suggests that communicating the outcomes of memory assessments with consideration to the wishes of the patient are viewed more positively by those taking part in them, further evaluation of the guide being used in this study is required to establish if it is helpful in improving this communication.

Whilst discussion of outcomes may feel uncomfortable this is something that the Memory Assessment Service will do with you, even if you choose not to take part in the study.

What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get from this study may help to inform future practice in the delivery of information in memory assessment outcome appointments and therefore there is potential for it to benefit others.

What happens when the research study stops?
There is no requirement for on-going participation in the study following your memory assessment outcome appointment.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting PALS on 0800 917 8505/ 01536 452070 or email complaints@nhft.nhs.uk

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?
We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Where possible information about you which leaves the Memory Assessment Service will have your name and address removed and a unique code will be used so that you cannot be recognised from it, however sometimes we need to ensure that we can recognise you to link the research data with your medical records so in these instances we will need to know your name and date of birth.

We will ask you to share your contact information with us so that we can contact you regarding completion of the questionnaire and to arrange an interview where applicable.

Your contact information will be kept by the University of Nottingham for 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All research data will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information, we will seek your consent

for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?
Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. Your care with the Memory Assessment Service will not be affected if you choose to withdraw. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may still be used in the project analysis.

What will happen to the results of the research study?
This study forms partial completion of the researcher's thesis as part of a Doctorate of Clinical Psychology. It is anticipated that the results of this study will be available by February 2022. It is also planned that the research will be published in an academic publication in 2022. They will also be shared with Northamptonshire Healthcare Foundation Trust and the Memory Assessment Services within the trust. Participants will not be identifiable in any of these disseminations.

Who is organising and funding the research?
This research is being organised by the University of Nottingham on behalf of Health Education East Midlands and funded by Health Education East Midlands as part of the Doctoral Training of Annabelle Silvester, Researcher.

Who has reviewed the study?
All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Brighton and Sussex Research Ethics Committee.

Further information and contact details
If you have any further enquiries or would like to be sent a copy of the final report please contact:

Annabelle Silvester
Trainee Clinical Psychologist
Trent DClin Psy Programme
Division of Psychiatry and Applied Psychology
School of Medicine-University of Nottingham
B Floor, YANG Fujia Building
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB
Tel: 07746696691

Dr N Moghaddam
Research Clinical Psychologist

Dr Danielle De Boos
Trent DClinPsy Programme

Appendix N Participant Information Sheet. Companion-Intervention.

Trent DClinPsy Programme
University of Lincoln
Brayford Pool
Lincoln
LN6 7TS

Division of Psychiatry and Applied Psychology
School of Medicine - University of Nottingham
B Floor, YANG Fujia Building
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB

Appendix O Participant Information Sheet. Companion-Usual Care

Participant Information Sheet (Companion-Usual Care)
(Final Version 2.0 18.3.2021)

Title of Study: The acceptability and feasibility of a guide for the delivery of memory assessment outcomes
Name of Researchers: Dr Nima Golijani Moghaddam, Dr Danielle De Boos and Annabelle Silvester. **PI Northampton:** Dr Louise Birkett-Swan

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

This study is being conducted by a research team that is independent of the Memory Assessment Service to which you have been referred. It is important that you feel able to decide whether to participate in the study without feeling obliged. Memory Assessment Clinicians are impartial, and you will not be judged negatively based on your decision whether to take part in the study or not.

What is the purpose of the study?

A guide has been developed that aims to improve people's experiences of the communication of the outcomes of memory assessments. This guide requires evaluation to determine if it is effective in achieving this aim. The purpose of this study is to begin the process of evaluation by looking at how acceptable the guide is felt to be by the people who use it. This study will also look at some of the practicalities involved which will inform future research of the guide's effectiveness.

Why have I been invited?

You are being invited to take part because someone you support has been referred to a Memory Assessment Service and their initial assessment appointment is due to take place during the time period that this study is recruiting participants. We are inviting 48 participants like you to take part in the study.

Do I have to take part?

It is up to you to decide whether to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

If you choose to take part, at the initial assessment appointment, you will be asked to read and sign a written consent form. A 10-item questionnaire will then be given to you and the person you are attending the appointment with. This questionnaire asks for information on your views of the appointment you have attended and will be posted back to the research team without being seen by anybody in the Memory Assessment Service. Following the appointments with the Memory Assessment Service a member of the research team will contact you via telephone to remind you to complete the questionnaire and answer any queries you may have.

At the Memory Assessment outcome appointment, you will again be given a copy of a 10-item questionnaire asking for your views on the appointment. This questionnaire will also be posted back to the research team without being seen by anybody at the Memory Assessment Service.

We would like to audio-record the appointments with the clinician, so the researchers can evaluate how the clinician interacts with you and the person you support.

You will also be offered the opportunity to take part in a short interview about your experiences of the outcome appointment. Please see the separate information sheet titled "Participant Information Sheet- (Patient/Companion Interview)" for details of what this will involve.

Expenses and payments
Participants will not be paid to participate in the study.
What are the possible disadvantages and risks of taking part?
The possible disadvantages of taking part in this study are that it will require you taking time to complete questionnaires.

What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get from this study may help to inform future practice in the delivery of information in memory assessment outcome appointments and therefore there is potential for it to benefit others.

What happens when the research study stops?
There is no requirement for on-going participation in the study following the memory assessment outcome appointment.
What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting PALS on 0800 917 8505/ 01536 452070 or email complaints@nhft.nhs.uk

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.
Will my taking part in the study be kept confidential?
We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

We will ask you to share your contact information with us so that we can contact you regarding completion of the questionnaire and to arrange an interview where applicable.

Your contact information will be kept by the University of Nottingham for 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All research data will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. Care for the person you support by the Memory Assessment Service will not be affected if you choose to withdraw. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may still be used in the project analysis.

What will happen to the results of the research study?

This study forms partial completion of the researcher's thesis as part of a Doctorate of Clinical Psychology. It is anticipated that the results of this study will be available by Spring 2022. It is also planned that the research will be published in an academic publication in 2022. They will also be shared with Northamptonshire Healthcare Foundation Trust and the Memory Assessment Services within the trust. Participants will not be identifiable in any of these disseminations.

Appendix O Participant Information Sheet. Companion-Usual Care

Who is organising and funding the research?
This research is being organised by the University of Nottingham on behalf of Health Education East Midlands and funded by Health Education East Midlands as part of the Doctoral Training of Annabelle Silvester, Researcher.

Who has reviewed the study?
All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the ??? Research Ethics Committee.

Further information and contact details
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B Floor, YANG Fujia Building
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB
Study specific email and telephone number to be identified.

Dr N Moghaddam
Research Clinical Psychologist
Trent DClinPsy Programme
University of Lincoln
Brayford Pool
Lincoln
LN6 7TS
Tel: 01522 837733

Dr Danielle De Boos
Trent DClinPsy Programme
Division of Psychiatry and Applied Psychology
School of Medicine - University of Nottingham
B Floor, YANG Fujia Building
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB
Tel: 0115 846 6696

Appendix P Participant Information Sheet. Interview Patient-Companion.

University of Nottingham
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Participant Information Sheet- (Patient/Companion Interview)
(Final Version 1.0 18.3.2021)

Title of Study: The Acceptability and Feasibility of a guide for the delivery of memory assessment outcomes
IRAS Number: 292410

Name of Researchers: Dr Nima Golijani Moghaddam, Dr Danielle De Boos and Annabelle Silvester. **PI Northampton:** Dr Louise Birkett-Swan

Further to your participation in our research study where you completed a 10-item questionnaire we would like to invite you to offer you the opportunity to take part in a short interview to discuss your experiences of taking part in this study and the outcome appointment you attended. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of the Memory Assessment Service clinicians will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

This study is being conducted by a research team that is independent of the Memory Assessment Service to which you have been referred. It is important that you feel able to decide whether to participate in the study without feeling obliged. Memory Assessment Clinicians are impartial, and you will not be judged negatively based on your decision whether to take part in the study or not.

What is the purpose of the study?
A guide has been developed that aims to improve people's experiences of the way outcomes of memory assessments are shared with them. This guide requires evaluation to find out if it is effective in achieving this aim. The purpose of this study is to begin the process of evaluation by looking at how acceptable the guide is felt to be by the people who use it. This study will also look at some of the practicalities involved which will inform future research looking into guide's effectiveness.

Why have I been invited?
You are being invited to take part because you agreed to participate in the study by completing a 10-item questionnaire. We would like to gain further information about your experiences of taking part in the study by asking you some questions. We are inviting 12 participants to take part in these interviews.

Do I have to take part?
It is up to you to decide whether to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?
If you agree to take part in an interview you will be approached by a member of the research team between 2-4 weeks after attending the outcome appointment. The interview will take place via telephone or video call or if this is not possible a face to face interview will be arranged, where restrictions allow. This will be arranged at a time convenient to you. The interview is expected to

last around 30 minutes. Two attempts to contact you will be made via telephone and if contact has not been possible a letter will be sent asking you to contact a member of the research team if you still wish to participate in the study. Interviews will be recorded and transcribed using a University of Nottingham approved, third party transcription service.

Expenses and payments
Participants will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?
Discussion of the outcomes of a memory assessment may feel uncomfortable, particularly at a time when you are still adjusting to what they mean for you and those close. Your emotional wellbeing will remain a priority throughout the interview and will be conducted by a researcher who has therapeutic skills to help manage this.

What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get from this study may help to inform future practice in the delivery of information in memory assessment outcome appointments and therefore there is potential for it to benefit others.

What happens when the research study stops?
There is no requirement for on-going participation in the study following your memory assessment outcome appointment.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting PALS on 0800 917 8505/ 01536 452070 or email complaints@nhft.nhs.uk

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?
We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you [and your medical records] during the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Where possible information about you which leaves the Memory Assessment Service will have your name and address removed and a unique code will be used so that you cannot be recognised from it, however sometimes we need to ensure that we can recognise you to link the research data with your medical records so in these instances we will need to know your name and date of birth.

We will ask you to share your contact information with us so that we can contact you regarding completion of the questionnaire and to arrange an interview where applicable.

Your contact information will be kept by the University of Nottingham for 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All research data will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information, we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. Your care with the Memory Assessment Service will not be affected if you choose to withdraw. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may still be used in the project analysis.

Appendix P Participant Information Sheet. Interview Patient-Companion.

What will happen to the results of the research study?
This study forms partial completion of the researcher's thesis as part of a Doctorate of Clinical Psychology. It is anticipated that the results of this study will be available by February 2022. It is also planned that the research will be published in an academic publication in 2022. They will also be shared with Northamptonshire Healthcare Foundation Trust and the Memory Assessment Services within the trust. Participants will not be identifiable in any of these disseminations.

Who is organising and funding the research?
This research is being organised by the University of Nottingham on behalf of Health Education East Midlands and funded by Health Education East Midlands as part of the Doctoral training of Annabelle Silvester, Researcher.

Who has reviewed the study?
All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Brighton and Sussex Research Ethics Committee.

Further information and contact details
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Dr N Moghaddam
Research Clinical Psychologist
Trent DClinPsy Programme
University of Lincoln
Brayford Pool
Lincoln
LN6 7TS

Dr Danielle De Boos
Trent DClinPsy Programme
Division of Psychiatry and Applied Psychology
School of Medicine - University of Nottingham
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Wollaton Road
Nottingham
NG8 1BB

Appendix Q Participant Information Sheet. Patient-Intervention.

University of Nottingham
UK | CHINA | MALAYSIA

Participant Information Sheet- (Patient-Intervention Group)
(Final Version 2.0 18.3.2021)

Title of Study: The Acceptability and Feasibility of a guide for the delivery of memory assessment outcomes
IRAS Number: 292410

Name of Researchers: Dr Nima Golijani Moghaddam, Dr Danielle De Boos and Annabelle Silvester. **PI Northampton:** Dr Louise Birkett-Swan

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of the Memory Assessment Service clinicians will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

This study is being conducted by a research team that is independent of the Memory Assessment Service to which you have been referred. It is important that you feel able to decide whether to participate in the study without feeling obliged. Memory Assessment Clinicians are impartial, and you will not be judged negatively based on your decision whether to take part in the study or not.

What is the purpose of the study?
A guide has been developed that aims to improve people's experiences of the way outcomes of memory assessments are shared with them. This guide requires evaluation to find out if it is effective in achieving this aim. The purpose of this study is to begin the process of evaluation by looking at how acceptable the guide is felt to be by the people who use it. This study will also look at some of the practicalities involved which will inform future research looking into the guide's effectiveness.

Why have I been invited?
You are being invited to take part because you have been referred to a Memory Assessment Service and your initial assessment appointment is due to take place during the time period that this study is recruiting participants. We are inviting 48 participants like you to take part in the study.

Do I have to take part?
It is up to you to decide whether to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights. If you decide not to take part in the study you may wish to look at the guide. Please be assured there is no expectation that you must then participate in the study.

What will happen to me if I take part?
If you choose to take part, you will be required to read through the enclosed information titled "Memory Assessment Services-A Guide" and answer the questions in the guide prior to your initial assessment appointment. You will also be encouraged to share this with someone who supports you such as a family member or friend.

At the initial assessment appointment, you will be asked to read and sign a written consent form. A 10-item questionnaire will then be given to you and, where applicable, the person attending the appointment with you. This questionnaire asks for information on your views of the appointment you have attended and will be posted back to the research team without being seen by anybody in the Memory Assessment Service. Following your appointments with the Memory Assessment Service a member of the research team will contact you via telephone to remind you to complete the questionnaire if you have not done so and answer any queries you may have. Information that has been collected about you by the Memory Assessment Service, including information held in your medical notes, will also be used in this study.

At your Memory Assessment outcome appointment, you will be encouraged to use the information guide provided at your initial assessment appointment. At this appointment you will again be given a copy of a 10-item questionnaire asking for your views on the appointment. This questionnaire will also be posted back to the research team without being seen by anybody at the Memory Assessment Service. We would like to audio-record your appointments with the clinician, so the researchers can evaluate how closely the clinician follows the intervention tool.
You will also be offered the opportunity to take part in a short interview about your experiences of the outcome appointment. Please see the separate information sheet titled “Participant Information Sheet- (Patient/Companion Interview)” for details of what this will involve.

Expenses and payments
Participants will not be paid to participate in the study.
What are the possible disadvantages and risks of taking part?
The guide that is being evaluated as part of this study has been developed in line with government guidelines on how to share the outcomes of memory assessments. It has also been developed using the views of others who have been through the memory assessment process. It is therefore felt that the risks of taking part are minimal. However, it is also unknown if taking part in the study will provide any benefits. Previous research suggests that communicating the outcomes of memory assessments with consideration to the wishes of the patient are viewed more positively by those taking part in them, further evaluation of the guide being used in this study is required to establish if it is helpful in improving this communication.

Whilst discussion of outcomes may feel uncomfortable this is something that your Memory Assessment Service will do with you, even if you choose not to take part in the study.

What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get from this study may help to inform future practice in the delivery of information in memory assessment outcome appointments and therefore there is potential for it to benefit others.

What happens when the research study stops?
There is no requirement for on-going participation in the study following your memory assessment outcome appointment.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers’ contact details are given at the

end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting PALS on 0800 917 8505/ 01536 452070 or email complaints@nhft.nhs.uk

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

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Where possible information about you which leaves the Memory Assessment Service will have your name and address removed and a unique code will be used so that you cannot be recognised from it, however sometimes we need to ensure that we can recognise you to link the research data with your medical records so in these instances we will need to know your name and date of birth.

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Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB
Tel: 07746696691

Dr N Moghaddam
Research Clinical Psychologist
Trent DClinPsy Programme
University of Lincoln
Brayford Pool
Lincoln
LN6 7TS

Dr Danielle De Boos
Trent DClinPsy Programme
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Appendix R Participant Information Sheet. Patient-Usual Care.

University of Nottingham
UK | CHINA | MALAYSIA

Participant Information Sheet (Patient-Usual Care)
(Final Version 2.0 18.3.2021)

Title of Study: The Acceptability and Feasibility of a guide for the delivery of memory assessment outcomes

Name of Researchers: Dr Nima Golijani Moghaddam, Dr Danielle De Boos and Annabelle Silvester. **PI Northampton:** Dr Louise Birkett-Swan

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

This study is being conducted by a research team that is independent of the Memory Assessment Service to which you have been referred. It is important that you feel able to decide whether to participate in the study without feeling obliged. Memory Assessment Clinicians are impartial, and you will not be judged negatively based on your decision whether to take part in the study or not.

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A guide has been developed that aims to improve people's experiences of the communication of the outcomes of memory assessments. This guide requires evaluation to determine if it is effective in achieving this aim. The purpose of this study is to begin the process of evaluation by looking at how acceptable the guide is felt to be by the people who use it. This study will also look at some of the practicalities involved which will inform future research of the guide's effectiveness.

Why have I been invited?

You are being invited to take part because you have been referred to a Memory Assessment Service and your initial assessment appointment is due to take place during the time period that this study is recruiting participants. We are inviting 48 participants like you to take part in the study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

If you choose to take part, at your initial assessment appointment, you will be asked to read and sign a written consent form. A 10-item questionnaire will then be given to you and, where applicable, the person attending the appointment with you. This questionnaire asks for information on your views of the appointment you have attended and will be posted back to the research team without being seen by anybody in the Memory Assessment Service. Information that has been collected about you by the Memory Assessment Service will also be used in this study. Following your appointments with the Memory Assessment Service a member of the research team will contact you via telephone to remind you to complete the questionnaire and answer any queries you may have.

At your Memory Assessment outcome appointment you will again be given a copy of a 10-item questionnaire asking for your views on the appointment. This questionnaire will also be posted back to the research team without being seen by anybody at the Memory Assessment Service.

We would like to audio-record your appointments with the clinician, so the researchers can evaluate how the clinician interacts with you.

You will also be offered the opportunity to take part in a short interview about your experiences of the outcome appointment. Please see the separate information sheet titled "Participant Information Sheet- (Patient/Companion Interview)" for details of what this will involve.

Expenses and payments
Participants will not be paid to participate in the study.
What are the possible disadvantages and risks of taking part?
The possible disadvantages of taking part in this study are that it will require you taking time to complete questionnaires and take part in an interview.

What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get from this study may help to inform future practice in the delivery of information in memory assessment outcome appointments and therefore there is potential for it to benefit others.

What happens when the research study stops?
There is no requirement for on-going participation in the study following your memory assessment outcome appointment.
What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting PALS on 0800 917 8505/ 01536 452070 or email complaints@nhft.nhs.uk

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.
Will my taking part in the study be kept confidential?
We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you [and your medical records] during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be

reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

We will ask you to share your contact information with us so that we can contact you regarding completion of the questionnaire and to arrange an interview where applicable.

Your contact information will be kept by the University of Nottingham for 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All research data will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. Your care with the Memory Assessment Service will not be affected if you choose to withdraw. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may still be used in the project analysis.

What will happen to the results of the research study?

This study forms partial completion of the researcher's thesis as part of a Doctorate of Clinical Psychology. It is anticipated that the results of this study will be available by Spring 2022. It is

also planned that the research will be published in an academic publication in 2022. They will also be shared with Northamptonshire Healthcare Foundation Trust and the Memory Assessment Services within the trust. Participants will not be identifiable in any of these disseminations.

Who is organising and funding the research?

This research is being organised by the University of Nottingham on behalf of Health Education East Midlands and funded by Health Education East Midlands as part of the Doctoral Training of Annabelle Silvester, Researcher.

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Brighton and Sussex Research Ethics Committee.

Further information and contact details

If you have any further enquiries or would like to be sent a copy of the final report please contact:

Annabelle Silvester
Trainee Clinical Psychologist
Trent DClin Psy Programme
Division of Psychiatry and Applied Psychology
School of Medicine-University of Nottingham
B Floor, YANG Fujia Building
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB
Tel: 07746696691

Dr N Moghaddam
Research Clinical Psychologist
Trent DClinPsy Programme
University of Lincoln
Brayford Pool
Lincoln
LN6 7TS

Dr Danielle De Boos
Trent DClinPsy Programme
Division of Psychiatry and Applied Psychology
School of Medicine - University of Nottingham
B Floor, YANG Fujia Building
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB

Appendix S Clinician Information Sheet-Usual Care

Clinician Information Sheet (Intervention)
(Final Version 1.0: 8.2.2021)

Title of Study: The Acceptability and Feasibility of a guide for sharing the outcome of a memory assessment

IRAS Number: 292410

Name of Researchers: Dr Nima Golijani Moghaddam, Dr Danielle De Boos and Annabelle Silvester

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

A guide has been developed that aims to improve people's experiences of the communication of the outcomes of memory assessments. This guide requires evaluation to determine if it is effective in achieving this aim. The purpose of this study is to begin the process of evaluation by looking at how acceptable the guide is felt to be by the people who use it. This study will also look at some of the practicalities involved which will inform future evaluation of the guide's effectiveness.

Why have I been invited?

You are being invited to take part because you are a clinician who delivers outcome appointments in a Memory Assessment Service who has agreed to help deliver the research project and has discussions with patients about the conclusions of their memory assessment.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

If you agree to take part in the study the initial phase will aim to gather baseline data and will require you to give patients a copy of a 10-item questionnaire looking at people's experiences of their outcome appointments. You will be required to give consent forms for the participants to read and sign and then give them the 10-item questionnaire which will then be sent to the research team by the participant in pre-paid envelopes. It is hoped that this will be done for 24 participants in total.

Once baseline data has been collected you will be required to read through a paper-based guide that has been developed to help clinicians think about their delivery of the conclusions of

assessments in Memory Assessment Services. You will be given help to familiarise yourself with this guide and will then use it to guide your practice in outcome appointments with patients who have consented to take part in the study.

You will also be asked to give information to participants about the study and help them to give written consent to take part in the study during their initial assessment appointment. The 10-item questionnaire will then be given to participants at this appointment once written consent is given. Participants will be given pre-paid envelopes to return these questionnaires directly to the research team. If you have any concerns about an individual's capacity to give informed consent, you will be asked to share this with the research team.

At the participants outcome appointment, they you will be required to use the guide to inform your communication of the conclusions of the participants assessment. You will also be asked to give participants a further copy of the questionnaire which they will again complete and send back to the research team via pre-paid envelope.

You will also be asked to take part in an interview to gain an understanding of your experience of using the guide. This interview will take place at a time and location convenient to you. We would like to audio-record your appointments for consenting participants so the researchers can evaluate any similarities or differences between clinicians in each arm of the study. Recordings of the interviews will be transcribed using an approved transcription service and transcripts will be anonymised. Once transcription of the recordings has taken place the recordings will be deleted.

Expenses and payments

Participants will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?

Taking part in this study may require some change in the way you deliver the conclusions of assessments. There will also be extra demands on your time in appointments when obtaining consent and answering questions about the research. Taking part in an interview will also place a demand on your time. However, it is expected that these time demands will be minimal, and the study has been designed to reduce the burden on participants where possible.

You may feel concerned that the 10-item questionnaire used in the study to understand people's experiences of outcome appointments will be used to evaluate individual practice. This will not be the case and no-one outside of the research team will be able to identify individual clinician, patient or companion's data. The aim of this study is to evaluate the potential use of further research of the intervention, not to evaluate individual practice of clinicians.

What are the possible benefits of taking part?

The understandings we gain from this research can be used to help inform future research and ultimately inform best practice to improve care for the people who use Memory Assessment Services.

What happens when the research study stops?

There is no requirement for on-going participation in the study following your interview.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Where possible information about you which leaves the Memory Assessment Service will have your name and address removed and a unique code will be used so that you cannot be recognised from it

Your contact information will be kept by the University of Nottingham for 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All research data will be kept securely for 7 years. After this time your data will be disposed of

securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may still be used in the project analysis.

What will happen to the results of the research study?

This study forms partial completion of the researcher's thesis as part of a Doctorate of Clinical Psychology. It is anticipated that the results of this study will be available by Spring 2022. It is also planned that the research will be published in an academic publication in 2022. They will also be shared with Northamptonshire Healthcare Foundation Trust and the Memory Assessment Services within the trust. Participants will not be identifiable in any of these disseminations.

Who is organising and funding the research?

This research is being organised by the University of Nottingham on behalf of Health Education East Midlands and funded by Health Education East Midlands as part of the Doctoral Training of Annabelle Silvester, Researcher.

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the ??? Research Ethics Committee.

Further information and contact details

If you have any further enquiries or would like to be sent a copy of the final report please contact:

Appendix S Clinician Information Sheet-Usual Care

Annabelle Silvester
Trainee Clinical Psychologist
Trent DClin Psy Programme
Division of Psychiatry and Applied Psychology
School of Medicine-University of Nottingham
B Floor, YANG Fujia Building
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB
Study specific email and telephone number to be identified.

Dr N Moghaddam
Research Clinical Psychologist
Trent DClinPsy Programme
University of Lincoln
Brayford Pool
Lincoln
LN6 7TS
Tel: 01522 837733

Dr Danielle De Boos
Trent DClinPsy Programme
Division of Psychiatry and Applied Psychology
School of Medicine - University of Nottingham
B Floor, YANG Fujia Building
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB
Tel: 0115 846 6696

Appendix T Clinician Information Sheet-Usual Care

Clinician Information Sheet (Usual Care)

(Final Version 1.0 8.2.2021)

Title of Study: The Acceptability and Feasibility of a guide for sharing the outcome of a memory assessment

IRAS Number: 292410

Name of Researchers: Dr Nima Golijani Moghaddam, Dr Danielle De Boos and Annabelle Silvester

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

A guide has been developed that aims to improve people's experiences of the communication of the outcomes of memory assessments. This guide requires evaluation to determine if it is effective in achieving this aim. The purpose of this study is to begin the process of evaluation by looking at how acceptable the guide is felt to be by the people who use it. This study will also look at some of the practicalities involved which will inform future evaluation of the guide's effectiveness.

Why have I been invited?

You are being invited to take part because you are a clinician who delivers outcome appointments in a Memory Assessment Service who has agreed to help deliver the research project and has discussions with patients about the conclusions of their memory assessment.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

Appendix T Clinician Information Sheet-Usual Care

What will happen to me if I take part?

If you agree to take part in the study the initial phase will aim to gather baseline data and will require you to give patients a copy of a 10-item questionnaire looking at people's experiences of their outcome appointments. You will be required to give consent forms for the participants to read and sign and then give them the 10-item questionnaire which will then be sent to the research team by the participant in pre-paid envelopes. It is hoped that this will be done for 24 participants in total.

Once baseline data has been collected you will be asked to give information about the study to a further group of patients about the study who will form the "usual care" group for comparison with the "intervention" group. You will help them to give written consent to take part during their initial assessment appointment. The 10-item questionnaire will then be given to participants at this appointment once written consent is given. Participants will be given pre-paid envelopes to return these questionnaires directly to the research team. If you have any concerns about an individual's capacity to give informed consent, you will be asked to share this with the research team.

You will also be offered the opportunity to take part in an interview to gain an understanding of your experience of outcome appointments. This interview will take place in at a time and location convenient to you. We would like to audio-record your appointments for consenting participants so the researchers can evaluate any similarities or differences between clinicians in each arm of the study. Recordings of the interviews will be transcribed using an approved transcription service and transcripts will be anonymised. Once transcription of the recordings has taken place the recordings will be deleted.

Expenses and payments

Participants will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?

Taking part in this study may require you to spend time speaking to participants during both initial assessment appointments and outcome appointments. Taking part in an interview will also place a demand on your time. It it is expected that these time demands will be minimal, and the study has been designed to reduce the burden on participants where possible.

You may feel concerned that the 10-item questionnaire used in the study to understand people's experiences of outcome appointments will be used to evaluate individual practice. This will not be the case and no-one outside of the research team will be able to identify individual clinician, patient or companion's data. The aim of this study is to evaluate the potential use of further research of the intervention, not to evaluate individual practice of clinicians.

Appendix T Clinician Information Sheet-Usual Care

What are the possible benefits of taking part?

The understandings we gain from this research can be used to help inform future research and ultimately inform best practice to improve care for the people who use Memory Assessment Services.

What happens when the research study stops?

There is no requirement for on-going participation in the study following your interview.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

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Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. If patients or their companions disclose serious concerns about individual clinician's practice during the process of participating in in the study, it may be necessary to share this information with the Memory Assessment Service.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may still be used in the project analysis.

Appendix T Clinician Information Sheet-Usual Care

What will happen to the results of the research study?

This study forms partial completion of the researcher's thesis as part of a Doctorate of Clinical Psychology. It is anticipated that the results of this study will be available by Spring 2022. It is also planned that the research will be published in an academic publication in 2022. They will also be shared with Northamptonshire Healthcare Foundation Trust and the Memory Assessment Services within the trust. Participants will not be identifiable in any of these disseminations.

Who is organising and funding the research?

This research is being organised by the University of Nottingham on behalf of Health Education East Midlands and funded by Health Education East Midlands as part of the Doctoral Training of Annabelle Silvester, Researcher.

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the ??? Research Ethics Committee.

Further information and contact details

If you have any further enquiries or would like to be sent a copy of the final report please contact:

Annabelle Silvester

Trainee Clinical Psychologist

Trent DClin Psy Programme

Division of Psychiatry and Applied Psychology

School of Medicine-University of Nottingham

B Floor, YANG Fujia Building

Jubilee Campus

Wollaton Road

Nottingham

NG8 1BB

Study specific email and telephone number to be identified.

Appendix T Clinician Information Sheet-Usual Care

Dr N Moghaddam
Research Clinical Psychologist
Trent DClinPsy Programme
University of Lincoln
Brayford Pool
Lincoln
LN6 7TS
Tel: 01522 837733

Dr Danielle De Boos
Trent DClinPsy Programme
Division of Psychiatry and Applied Psychology
School of Medicine - University of Nottingham
B Floor, YANG Fujia Building
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB
Tel: 0115 846 6696

Self-efficacy	[00:01:40] Speaker 1: Yeah, yeah, so it feels like it. It's not what you'd hoped it would be. [00:01:46] Speaker 2: Yeah. [00:01:47] Speaker 1: Yeah, um. [00:01:50] Speaker 1: Is there anything about the procedure, um, that you that comes to mind? What did you make of the procedure of the study? [00:02:01] Speaker 2: I think one of the things and we couldn't really make sense of it as a team was around where the paperwork went because we would find that, um, in terms of the procedure at our end, it felt pretty foolproof. You know we would. We were briefed by you know you you know, and the information that we had. We knew what we were doing. [00:02:24] Speaker 2: Administrator who sends out the appointment leaflet. She was also fully aware of what she was doing and she was also, you know, enclosing the paperwork for the study. All of that stuff was leaving our. [00:02:39] Speaker 2: Office and yet there is something went wrong and we don't actually know what happened, so I suppose like the procedure from start to finish. [00:02:51] Speaker 2: Has wasn't good, but um, I mean we've had. We've surmised on what, what, what, the challenges may have been. I think one one thing was around the the, the paperwork itself, and we thought perhaps people just take a glance and pop it in the bin. Or perhaps don't even realise what it's for. They might just assume that it's the kind of the leaflets that you get alongside an appointment letter and not. [00:03:21] Speaker 2: really think of it as well as relevant to them, so we kind of thought that. And then we wondered whether actually, um, the.	Issues with paperwork Study procedure felt manageable Barriers to participation Service users ignoring the paperwork Research not a priority

Appendix V Extract of Framework with quotes and linked emergent themes

Participant	Affective Attitude	
	Quotes	Emerging themes
C1 Emma	I found it. I found it quite useful actually. Especially the pack that you gave us	Clinician information was useful
	I thought it was a really good way in how best we can approach memory assessment services for people	Good approach to memory assessment
	I think it would have been actually really useful in the assessment process so I think overall it would have been such a good idea in practise	Guide could be useful for assessment
	It's hard because all the stuff that was on that you know on the information sheet was so relevant	Information was relevant to patients/companions
	But it's about I don't know because it's about condensing it down. But then obviously all the information is needed so it's really hard	Hard to decide what improvements could be made to shorten it
	I've actually found it beneficial in my practice to be able to contribute a better assessment or a better process of the MAS for everybody but it was actually good for, you know, sort of my learning and how, how I can improve for them as well	Beneficial to assessment process for clinician and patient/companion Good for learning
	Overwhelming for me, definitely because I I'm quite, you know, with my dyslexia. I'd rather have you know bullet points. You know, this is what you've got to do, whereas obviously within the guide it was paragraphs and stuff like that, which I did find quite difficult to manage	Clinician overwhelmed by the amount of information Need to condense the guide
	I think it it sort of gives us the confidence that we're actually, you know, we're actually asking the right questions. You know, we're making sure that we're not just focusing on the patient. We're focusing on the carer giving me a bit more confidence to actually say. Actually, I can see you by yourself if you want to know, but your mum doesn't want to know.	Builds confidence in being responsive to the patient/companion
C2 Nicole	so in that sense it was new and refreshing and it was also quite. I suppose it was quite reassuring in a way that some of what I was reading was the	Reassured existing practice is good

Appendix V Extract of Framework with quotes and linked emergent themes

	stuff that we were doing already because you think ah we're probably doing OK.	
	it feels a little bit reassuring. Then maybe that's the the standard or the the sorts of things that we should be doing.	Reassured existing practice is good
C3 Paige	As a clinician looking at the guide, I thought it was actually a good tool. A really excellent tool	The guide is good
	it's a good tool. It's a good guide	The guide is good
	~~I remember that that was quite informative for me just to break it down into, like you say, Layman Terms~~	~~Improved accessibility of language~~
	I love it because it it. You know it's certain things that we do daily and you don't think about it.	Increases awareness of own practice
	Yeah, I I quite like it. I really yeah yeah I know that that that tool I've saved it on my my computer	Liked it enough to save for future use
	~~It's quite nice that you acknowledge that it is very tiring process and we are only given an hour for it for disclosures.~~	~~Emotional toll of the work acknowledged~~
	but it's things that we already do, but you put it down on paper and broke it down for us. So it's quite nice just to read that because you think I already do that, but because you're just programmed to do it, just like that, you don't think this is what I'm actually doing, and it sounds so nice. It's like, Oh my goodness, this is nice. Actually I do. I do do a good job	Reassured existing practice is good
C4 Edie	I think that the um, the questionnaire that you've written, I think, would help it's really good to give them information on how to deliver a diagnosis, which can be have such an impact on some people.	Helpful to have information on giving a diagnosis
	I think it's really good idea.	Good idea
	I'll be happy to for that to be to go to every patient or every relative just to start the ball rolling.	Would be happy to use it in practice
	I think it would be very helpful. I can only see it as being helpful.	Guide is helpful

Appendix V Extract of Framework with quotes and linked emergent themes

	It's a reference for people. I suppose it's a reference for people who've been in it for a while as well, because it's like almost saying that it's it's OK to feel upset yourself, although you can't show it because you're the professional and you're, you know, in the sort of your the supporting role. It's okay to feel those feelings you know, and it's what to do with them.	The guide provides validation for clinicians emotions
C5 Iris	what I liked about it was that it was, um, quite um. Sort of simple, really. I felt it was very user friendly.	Simplicity made it user friendly
	I liked the part. The section, um, about circling people being able to circle where they're having difficulties because on the BADLs there's no the the choices you've got there are quite limited and I end up scribbling at the side of them, whereas on yours with the ideas about what what they're finding, um, they're having difficulties struggling with um. Then you can elaborate on that with them, so I really liked that part.	Appreciated being able to elaborate on points
	The other part I liked was the making choices section. Um, yeah I liked that section, giving them ownership of their diagnosis and allowing them to discuss and explore what choices they have to make really and not being made for them	Liked that it encouraged an active role for patients/companions

Appendix W Development of initial themes

Acceptability

Affective Attitude

Theme: Positive opinion of the guide

Good approach to memory assessment
The guide is good
Good idea
Would be happy to use it in practice
Liked it enough to save for future use
Clinician information was useful
Guide could be useful for assessment
Guide is helpful
Helpful to have information on giving a diagnosis
Simplicity made it user friendly

Theme: The guide is positive for clinicians, patients, and companions

Information was relevant to patients/companions
Liked that it encouraged an active role for patients/companions
Builds confidence in being responsive to the patient/companion
Beneficial to assessment process for clinician and patient/companion
Good for learning
Reassured existing practice is good
Reassured existing practice is good
Increases awareness of own practice
Appreciated being able to elaborate on points
The guide provides validation for clinician's emotions

Burden

Theme: Low burden for clinicians

The guide flowed well
Clinician overwhelmed by the amount of information

Appendix X Thesis Poster

The acceptability and feasibility of a guide for sharing the outcome of a dementia assessment

Annabelle Silvester, Danielle de Boos, Nima G Moghaddam
Trent Doctorate in Clinical Psychology, Universities of Lincoln and Nottingham
Louise Birkett-Swan
Northamptonshire Healthcare Foundation Trust

Introduction

The quality of people's experiences of the diagnostic process for dementia has been questioned with individuals reporting dissatisfaction with information provided to them about their diagnosis (Low et al., 2019) alongside negative experiences of how diagnoses are delivered (British Psychological Society, 2014). The point of disclosure is key in the development of feelings of disempowerment experienced by people with dementia (Low et al., 2018).

Bennett et al., (2019) developed a prototype intervention that supports good practice. The intervention is based on clinician, patient, and companion experiences of the important features of an outcome consultation in Memory Assessment Services (MAS) in the UK and identifies key behaviours of good practice for consideration when communicating a diagnosis of dementia. Initial feedback from service users and their companions suggests this intervention has potential for improving practice.

Research Aims

- To determine the acceptability of a guide supported consultation for clinicians, patients and companions, in comparison to usual care using Sekhon et al., (2017) Theoretical Framework of Acceptability (TFA).
- To inform the feasibility of future research establishing recruitment processes and study uptake.
- To establish how well the chosen measurement strategy provides evaluation of the intervention (including completion rates, perceived relevance and burdensomeness).

Methodology

A mixed methods cluster trial design was used. Participants were clinicians, patients and patient companions recruited from two MAS. Clinicians working in MAS, responsible for sharing the outcomes of assessment, participated. Baseline measures of clinician empathy were collected from patients and companions using the CARE questionnaire (Mercer et al., 2004).

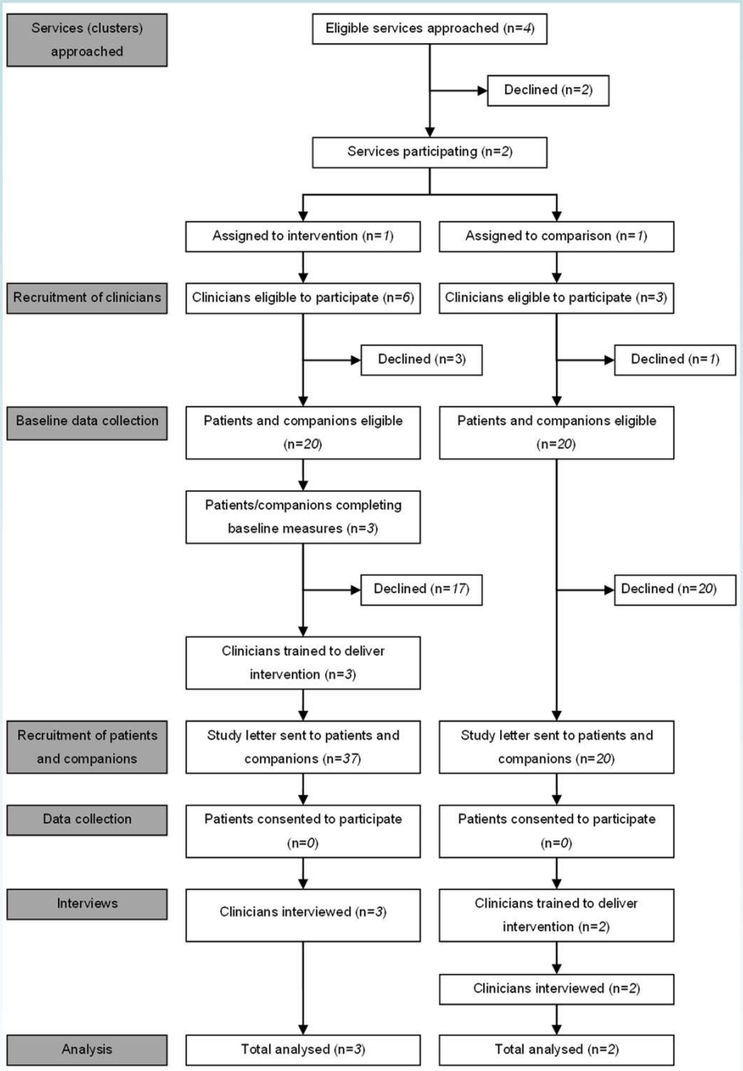
Clinicians in the intervention arm received training in how to use the guide to inform consultations. Patients and companions were sent the guide to complete prior to their initial appointments with the service. Patients and companions were asked to return completed CARE questionnaires to the research team. Clinicians, patients and companions were invited to take part in semi-structured interviews to assess the acceptability of the intervention and study procedure and feasibility of the study. Framework analysis was used to analyse interview data.

The Guide

The guide supports clinicians to provide consultations aligned with best practice when sharing the outcomes of dementia assessment.

The guide consists of two sections: the first is for clinicians conducting memory assessments and the second is for patients containing an additional section for their companion. The clinician section outlines good practice for the process of memory assessment and can be used to guide reflective practice and supervision. The patient and companion section helps both parties to identify their concerns and wishes prior to discussion with the MAS clinician.

Figure 1. Flow of participants



Results

Framework analysis identified themes relating to all seven constructs of the TFA (affective attitude, burden, ethicality, intervention coherence, opportunity costs, perceived effectiveness, self-efficacy). Inductive themes relating to acceptability and feasibility of the study procedure were also identified.

Participating clinicians reported good acceptability of the intervention and willingness to adopt the intervention into their practice but raised concerns that the patient and companion section was burdensome.

In total 3 (7.5%) of baseline measures were returned. A total of 57 patients (usual care *n=20, intervention n= 37)* and companions were invited to participate in the study of which none consented (0%).

Quotes

"As a clinician looking at the guide, I thought it was actually a good tool. A really excellent tool".

"I suppose it was quite reassuring in a way that some of what I was reading was the stuff that we were doing already because you think ah! we're probably doing OK".

"I'd rather have you know bullet points. You know, this is what you've got to do, whereas obviously within the guide it was paragraphs and stuff like that, which I did find quite difficult to manage".

Conclusion

The guide was assessed to be acceptable to participating clinicians working in a MAS outside of the service in which it was developed. However, low recruitment of clinicians means this finding may not be generalisable. Further evaluation of the effectiveness for the guide to change clinical practice is required.

The recruitment strategy was not feasible for patients and companions and therefore acceptability of the intervention was not assessed from their perspective. Levels of distress experienced by people who are being assessed for dementia is likely to have an impact on recruitment and should be considered in the design of future attempts to evaluate the guide.

References

Bennett, C. E., De Boos, D., & Moghaddam, N. G. (2018). Developing a tool to support diagnostic delivery of dementia. *Dementia*, *18*(7–8), 2505–2525 .https://doi.org/10.1177/1471301217750936 British Psychological Society. (2014). *Clinical Psychology in the Early Stage Dementia Care Pathway*. Karnieli-Miller, O., Werner, P., Aharon-Peretz, J., Sinoff, G., & Eidelman, S. (2012). Expectations, experiences, and tensions in the memory clinic: the process of diagnosis disclosure of dementia within a triad. *International Psychogeriatrics*, *24*(11). https://doi.org/10.1017/S1041610212000841 Low, L.-F., McGrath, M., Swaffer, K., & Brodaty, H. (2019). Communicating a diagnosis of dementia: A systematic mixed studies review of attitudes and practices of health practitioners [Article]. *Dementia (London, England)*, *18*(7–8), 2856–2905. https://doi.org/10.1177/1471301218761911 Low, L.-F., Swaffer, K., Mcgrath, M., & Brodaty, H. (2018). Do people with early stage dementia experience Prescribed Disengagement ®? A systematic review of qualitative studies. *International Psychogeriatrics*, *30*(6). https://doi.org/10.1017/S1041610217001545 Mercer, S. W., Maxwell, M., Heaney, D., & Watt Mercer SW, G. C. (2004). The consultation and relational empathy (CARE) measure: development and preliminary validation and reliability of an empathy-based consultation process measure. *Family Practice*, *21*(6). https://doi.org/10.1093/fampra/cmh621 Sekhon, M., Cartwright, M., & Francis, J. J. (2017). Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework [Article]. *BMC Health Services Research*, *17*(1), 88–88. https://doi.org/10.1186/s12913-017-2031-8