Developing a tool to support diagnostic delivery of dementia

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Thesis Abstract

Current political drivers are set to increase the volume of people receiving a dementia diagnosis. However, there are problems with how diagnoses are being delivered, with people reporting it to be confusing, anxiety provoking, and being generally dissatisfied. Limited guidance exists that could help improve the delivery and steps are required to address this. Research has begun to explore the components of a good delivery of a diagnosis of dementia, however interventions to support clinicians to deliver diagnoses are limited. This project's overarching aim was to develop a prototype tool that has future potential to be used by clinicians, patients, and companions who are involved in the delivery of diagnoses of dementia.

A two-phase sequential design was undertaken. Phase one explored four Memory Assessment Service (MAS) clinicians', five patients', and five companions' perspectives of what makes a good delivery of a diagnosis of dementia via 10 semi-structured interviews. Thematic analysis of this data produced four overarching themes relevant to a good delivery of a diagnosis of dementia: overcoming barriers; navigation of multiple journeys; and completing overt and covert tasks. Two paper based tools were devised from these themes. One tool for service deliverers to support reflective practice and skill development; and the other for service recipients. This contained three elements: an information guide containing an overview of MAS appointments and outcomes, introduction to choices, bringing a relative or friend; a notes sheet which supported consideration of main concerns and choices, provision of space to record answers; and a prompt sheet to use during appointments to prompt question asking, and recording information discussed.

Phase two assessed the tool's acceptability across four focused group discussions with seven service deliverers and six service recipients. Thematic analysis was used to explore the preliminary acceptability of the tools, as perceived by the participants, and guided revisions to improve the design of both tools. Overall feedback was positive and both tools were deemed to be acceptable. The tools were modified to remove the prompt sheet and

incorporate the principles into the service deliverer's guide. Some minor adaptations to improve acceptability of phrasing were also made.

This project developed a novel tool for supporting clinical practice in the delivery of dementia diagnoses. It also contributes towards the knowledge of dementia diagnosis and provides an alternative narrative of quality diagnostic delivery, rather than diagnostic volume. The tool uniquely articulates clinicians' experiences of diverse and changing emotional responses to the process of diagnosis delivery and of their management of this to prevent impact on the recipient. It is suggested that by mastering these skills clinicians can facilitate cohesion with, rather than distancing from, the attendee's emotions. It also highlights barriers to good practice and the management of power within diagnostic appointments, both considered to potentially extend previous guidelines.

The next steps are to take the tools into further development work and then to evaluate the tools. This may include completing further focus groups to establish acceptability of the tools and contribute to further development. Formal evaluation of quality and usability could include field testing to assess feasibility.

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Mostly, I would like to thank all the participants who gave up their time to take part in the study.

Statement of Contribution

I. **Systematic Review:**

Claire Bennett completed the review with supervision from co-authors Nima Moghaddam and Danielle DeBoos

II. **Journal Paper:**

Claire Bennett with supervision from co-author Nima Moghaddam

III. **Project design:**

Claire Bennett (with supervision from Danielle De Boos and Nima Moghaddam, and advice from clinicians at the hosting service)

IV. **Applying for ethical approval:**

Claire Bennett (with supervision from Nima Moghaddam and the clinical director of the hosting service)

V. **Recruiting participants:**

Claire Bennett arranged with the clinical director and service managers of the hosting service that MAS clinicians would disseminate information about the project to patients and companions, and gain consent for contact details of people who were interested to be shared with Claire Bennett.

Claire Bennett arranged with the clinical director of the hosting service to contact clinicians by email, sent out by the hosting MAS service managers.

VI. **Data collection:**

Claire Bennett

VII. **Transcription:**

Nina Douglas, Typing Services

VIII. **Data analysis:**

Claire Bennett (with supervision from Danielle De Boos and Nima Moghaddam)

IX. **Write up:**

Claire Bennett (with supervision from Danielle De Boos and Nima Moghaddam)

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Systematic Review

Patient experiences of communication preference-matching by professionals in medical encounters: A systematic review with narrative synthesis.

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Abstract

Objective: To perform a systematic review of current published articles on patient experiences of communication preference-matching by professionals in medical encounters.

Methods: A systematic search of Medline, PsychINFO, Embase, and Cumulative Index to Nursing and Allied Health Literature was conducted. 11 studies meeting the inclusion criteria were assessed for quality and synthesised by a narrative review.

Results: Poor preference-matching was linked to negative patient experiences. There was an indication of an association between patient communication preference-matching and patient outcomes. Preferences were frequently matched for information but least often matched for emotional support. The occurrence of communication preference-matching was increased by assessment of preferences prior to the encounter.

Conclusion: Patients' communication preferences are not being fully met in current medical encounters. When patients' communication preferences are not matched there are potential implications for patient choice and autonomy within medical encounters.

Practice Implications: The current state of the evidence prevents any definitive conclusions about the effect of matching patient preferences. Future research needs to address the methodological weaknesses, especially the quality and cohesion, before any conclusions relating to patient outcomes can be made. Clinically, physicians should extend their focus beyond information transaction to include patients' emotional needs within medical encounters.

Keywords: Physician-patient communication; Patient experience; Patient preference; Communication preference matching; Communication in medical encounters.

1. Introduction

Communication is arguably the most essential component of all medical encounters [1,2]. As such, the quality of the communication between physician and patient can be viewed as one of the most important elements of these interactions [3]. There are several meta-analytic studies which have linked improvements in physician communication with outcomes such as enhanced patient satisfaction [4], improved adherence to treatment [2], reduction in symptoms [5], and a decrease in anxiety [5]. Due to the evidence of the impact of good quality communication there has been a focus on developing and maintaining this skill in physicians. Communication training is a core component of undergraduate medical education [6] and high quality communication is expected in qualified practice by the General Medical Council [7]. There are also a range of protocols to support physicians to communicate well with patients (e.g.: [8–10]) and specific practice guidelines which make recommendations for communication related to specific diagnoses (e.g.: [11]).

Patients' preferences for medical information also varies, even within specific diagnoses. For example, in a sample of 2331 cancer patients, 60% absolutely wanted to know if they had cancer but 1.9% did not want to be informed at all [12]. Patients' preferences also vary with the way medical information is presented. For example, approximately 80% of patients wished to know if they would die from their cancer but only 50% wished to gain an estimate of how long they were predicted to survive [13]. It has also been indicated that patients' communication needs change over the course of their illness [14,15]. This suggest that physicians' communication should be tailored to the individual patient's needs within each consultation [16].

Adapting communication to meet patient preferences can at times come into conflict with modern healthcare expectations. For example, there is a potential dilemma when the preference of the patient is to not know specific information about their illness, yet is required to give informed consent which requires sufficient information to make the decision to be disclosed prior to the decision being taken [17]. A further dilemma could occur if a patient has a preference for the physician to make decisions on their behalf, which would require the physician to take a paternalistic stance to the consultation. In modern healthcare settings this stance has increasingly been overtaken by the expectation of an egalitarian patient-physician relationship

with high patient involvement [18]. Despite these dilemmas authors continue to advocate routine individual assessment of patients' preferences (e.g.: [19,20]). The current National Institute for Clinical Excellence (NICE) guidance for cancer services [21] and guidance for patient experience [22] highlight the importance of respecting individual patient's preferences. Therefore physicians should attempt to tailor their communication style to meet their patient's needs.

Tailoring communication appears a simple task, however many patients (26% - 95% [19]) report that their physician's communication was not in concordance with their own communication preferences [23,24]. One difficulty is that it requires the physician to have a repertoire of communication styles from which to select the most appropriate for each patient. In order to select the most appropriate, the patient's needs or preferences should be elicited prior to consultation [23,25]. Then, to gain optimal quality in patient-physician interaction, the physician is required to select the most appropriate communication style [19]. Despite the numerous potential styles physicians would require to achieve this desired flexibility, when matching is achieved there appears to be positive patient outcomes. In Kiesler and Auerbach's [19] review of 69 studies, improved patient outcomes were linked to; preference-matching for desired information, preference-matching of participation in treatment decisions, and a complementary match of patient and physician interpersonal behaviour.

Whilst Kiesler and Auerbach's 2006 [19] review had a significant impact on the current understanding of patient-physician communication preference-matching, there are potential limitations to its current clinical applicability. The review separated communication into three distinct areas based on Ong et al. [3] identification of communication in medical encounters: creation of a positive interpersonal relationship; exchanging information; and involving patients in treatment-related decisions. However, in clinical settings the physician is required to undertake a wider range of communication tasks including information provision, information seeking, provision of emotional support, facilitation of patient participation, and development of a responsive interpersonal relationship [26]. This resulted in a potential reduction in the ecological validity of the review, as arguably it was not able to capture all elements of actual patient-physician communication. Notwithstanding this technical

point, since the review was published, research and clinical practice have also developed. For example, there has been a research focus on; continuing the progress of physician communication training [27], development of communication aids for use before and/or within consultations (e.g. [15]), decision making aids (see [28]), and the expansion of a range of instruments to elicit patient preference and measure matching (see [29]). All of these research areas may have affected current clinical practice for eliciting patients' communication preferences and adapting physicians' communication styles. Therefore a review which updates and broadens Kiesler and Auerbach's review of preference-matching in medical encounters is required.

The purpose of this review is to explore patient experiences of communication preference-matching by professionals in medical encounters. To achieve this two aims have been set. The primary aim is to investigate the current evidence of patients' experiences of communication preference-matching in medical settings. The secondary aim is to identify the areas of communication where patient preferences are being elicited. Within this review, patient experience includes the incidence when preference-matching occurs, descriptive accounts of patient experiences of preference-matching, and measurements of patient outcomes relating to preference-matching. Communication will refer to a wide range of elements of communication which could include: information transaction, emotional support, patient participation, and development of an interpersonal relationship.

2. Methods

2.1 Search Strategy

Studies were identified by searching the online databases in Table 1.

Table 1. Databases included in the search strategy

Database	Start Date	End Date
Medline	1946	July, week 2, 2015
PsychINFO	1806	July, week 1, 2015
Embase	1980	2015, week 29
Cumulative index to nursing and allied health literature (CINAHL Plus)	1982	18th July 2015

Note: The end date of all searches was 18th July 2015.

To find relevant studies a search strategy was developed for Medline, see Table 2. The primary search concepts, used in conjunction with each other, were; physician-patient communication[1], patient preference-matching, and patient experience. Relevant synonyms, thesaurus entries and Medical Subject Headings (MeSH) headings were then adapted according to each subsequent database searched. Google Scholar was also searched using the keywords (Physician-patient communication OR doctor-patient communication) AND (Patient Preference) and the first 100 results checked. References for returned studies were then exported into a referencing management tool (Mendeley) and duplicates removed.

[1] Searches were run using both hyphenated and non-hyphenated terms and the same papers were returned for each search, therefore only hyphenated terms were used in remaining searches.

Table 2: Search strategy for Medline

Search Number	Keyword	MeSH (explode and focus selected)	Operations Completed
1	**Physician-patient[a] communication** OR doctor-patient communication OR provider-patient communication	Physician-Patient Relations OR Communication	
2	**Physician-patient[a] interaction*** OR doctor-patient interaction* OR patient-provider interaction*		
3	**Medical communication** OR medical disclosure OR medical information		
4	**Diagnos* communication** OR diagnos* disclosure OR diagnos* information		
5	**Breaking bad news**	Truth Disclosure	
6			1 OR 2 OR 3 OR 4 OR 5
7	**Physician-patient match** OR physician-patient concordance OR physician-patient fit	Physician-Patient Relations	
8	**Patient* preference*** OR patient* choice* OR patient* involvement	Patient Preference	7 OR 8
9			6 AND 8
10	**Patient* experience*** OR patient* perception* OR Patient* outcome*	Patient Satisfaction	9 AND 10

*Key: Bold denotes the key term of interest, [a] terms were also searched in reverse with patient at the start, *indicates truncation, Caps lock indicates Boolean terms*

2.2 Inclusion and exclusion criteria

Prior to searching, inclusion and exclusion criteria were established (see Table 3) and applied when searching the databases. Where this was not possible, due to technical restrictions or excluding potentially relevant papers, they were applied when screening the title and abstracts of returned studies. When the title and/or abstract provided insufficient information, full paper copies were reviewed to determine the relevance. Reference lists of each relevant article were then searched using the same criteria and Google Scholar to source the abstracts where necessary.

Table 3: Review of inclusion and exclusion criteria

Inclusion	Exclusion
Paper focusing on matching of patient preferences for physician-patient communication	Papers focusing on concordance of demographic characteristics, shared decision making, only information preference-matching, patient preferences for treatment/information/type of doctor, or effects of communication on patient outcome (without preferences assessed)[a]
	Not reporting data relating to patients [a]
Outcome for patient detailed	Non-medical setting [a]
	Not English language [b]
English language [b]	Papers focusing on children (up to 18) or animals
Participants aged 18+ inclusive	
	Papers such as dissertations or discussion papers [a]
Peer reviewed studies [a]	
Any date	

Key: [a] Applied when titles and abstracts were reviewed, rather than using the Boolean term NOT to maximise breath of studies returned. [b] Applied in databases with the 'Limit to' function.

2.3 Data Extraction

For each study the following was recorded: author(s); date of publication; study design; setting and sample; methods; type of communication and key findings. Due to the heterogeneity of study design, meta-analysis was not considered appropriate ([30]). Effect sizes were calculated were possible.

2.4 Data Evaluation

Studies were evaluated against a pro forma specifically adapted for this systematic review. This was selected as there is no single gold standard tool to aid critical appraisal of data [31]. It was also anticipated that the search strategy would return studies with heterogeneous designs and methods. Due to the range of critical appraisal tools published for each type of study design [32], selection of different tools for each design type would hinder cross comparison. As such, previously published critical appraisal tools [33–35] were drawn upon to develop a specific nine question pro forma for this review (see Appendix A).

2.5 Data Synthesis

Data extracted was organised and synthesised by narrative review, following guidelines set out by the Economic and Social Research Council (ESRC) Methods Programme [36]. The synthesis was completed in stages (see Table 4).

Table 4: Stages of Data Synthesis

Stage	Process
1) Developing a preliminary synthesis	Creating textual descriptions of each study, tabulation of the data (grouped by study design), transformation of statistical findings into effect sizes, and translation of themes reported in qualitative studies.
2) Exploring relationships within and between studies	Mapping the key findings to aid the review structure, identification of themes within results, and tabulating the occurrence of themes across the studies
3) Strength of evidence	Data included in the review was then assessed for quality and strength as detailed in section 2.4
4) Critical reflection	The review was then reflected upon critically

3. Results

3.1 Search Outcome

631 studies were identified via electronic searching and an additional three studies were identified via reference lists. 548 papers were rejected following review of title and abstract. Following review of full paper copies, 11 studies were included in this review (see Figure 1). Of the 11 included studies, two used qualitative methodology [37,38] and the remainder used quantitative methodology [39–47] (see Table 5). Studies were published between 1997 and 2014, with a total of 4,504 patients included in this review. Quality evaluation of the studies resulted in five studies being rated as good [38–40,46,47] and six studies rated as fair [37,41–45] (see Appendix B for full scoring). No studies were excluded on the basis of the quality evaluation. To improve reliability of the search outcome, triangulation of exclusion criteria and quality appraisal was completed with author DDB[2]. 10% of papers excluded following full text retrieval were reviewed and author CB[3] decision upheld. Quality appraisal triangulation was also in agreement with detailed notes displayed in Appendix B.

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[3] Claire Bennett

3.2 Synthesis of evidence

Full results of data extraction are reported in Table 5. In summary, studies identified by the review of the literature were predominately observational quantitative studies which identified the occurrence of patient preference-matching and/or linked preference-matching with patient outcomes [39–45]. Only one study included an intervention designed to improve patient preference-matching [47]. One other study investigated the effects of physician communication training. It intended to improve patient-physician communication preference-matching by teaching the physicians patient's communication preferences [46]. Of the two studies using qualitative methods, one used thematic analysis to explore patient experiences where preference-matching appeared to have not occurred [37], and the other used grounded theory analysis to explore the processes linking preference-matching and therapy adherence [38].

A review of the returned study content identified two overarching themes with regards to patient experiences of communication preference-matching. These were (i) preference-matching occurred or was improved, and (ii) preference-matching did not occur or was poor. As this review had a secondary aim of identifying the types of communication preferences that were being assessed, two further themes were identified: (iii) topic of communication, and (iv) delivery of communication. The overarching themes each had a number of sub-themes. The occurrence of these themes were identified across studies and reported in Tables 6 and 7 to aid cross-comparison. Each overarching theme will be discussed in detail below.

Figure 1: Flow chart of literature selection

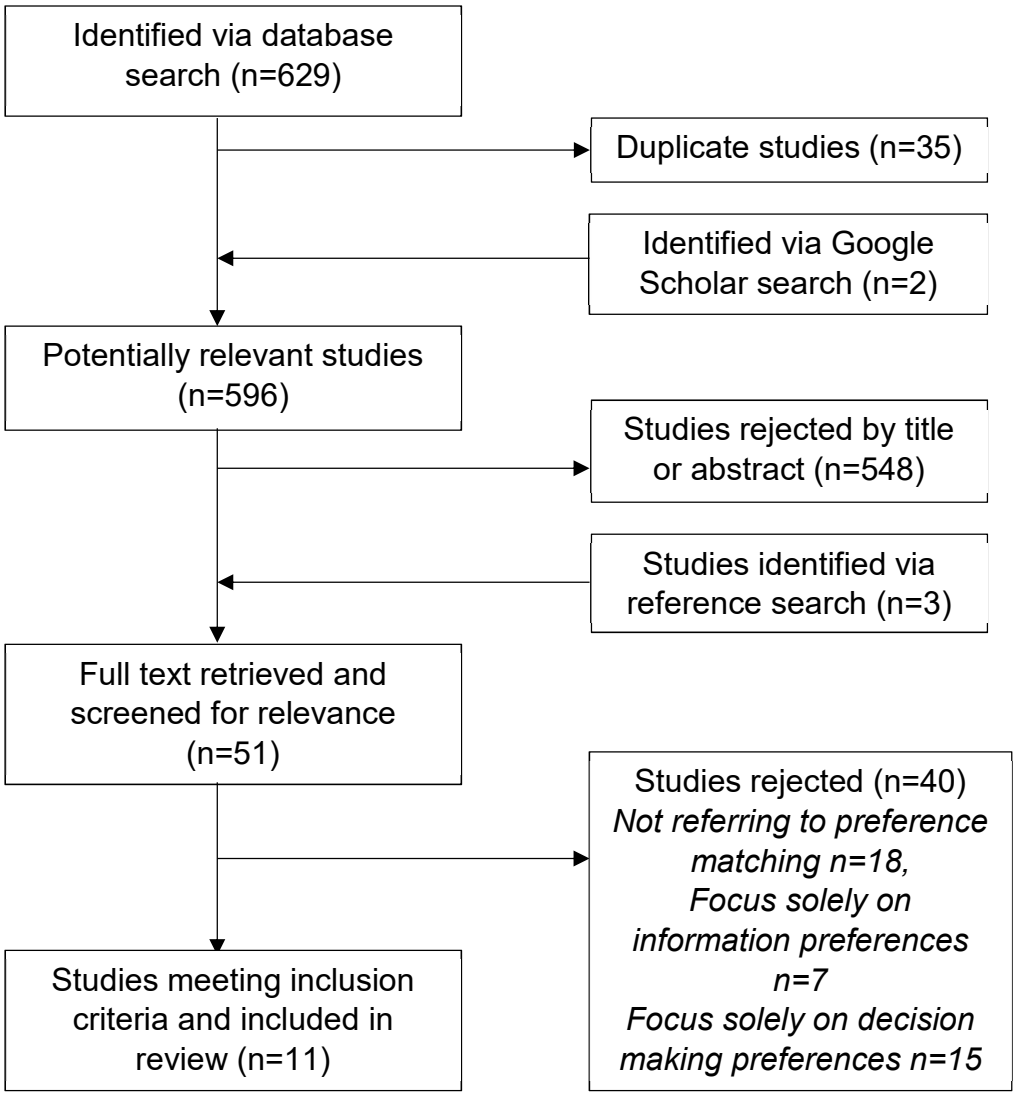

Table 5: Results

Author, Year, Quality	Methodology	Subjects	Methods	Type of Communication	Key findings
Brotherton & Abbott 2009 [37] Fair	**Qualitative** Thematic analysis, Descriptive study	16 patients with PEG feeding tube 27 carers Selection: 1 Hospital - North West England	Semi structured interviews appropriateness and adequacy of information provided regarding PEG placement	Information – appropriateness, adequacy and way delivered Involvement in decision making	Matching: Information matching was poor, patient's receiving none to very little, or very vague, not meeting their needs Too complex, rushed, issues overlooked, professionals failing to explain adequately or not allowing patient's questions to be sought and answered. Patient Experiences: Left feeing excluded, isolated and having no one to turn to. Perception of medical staff as being paternalistic and prescriptive
Mulder et al., 2014 [38] Good	**Qualitative** Grounded Theory Analysis, Conceptual study	28 HIV patients 5 Physicians 6 HIV nurses Selection: 2 university health clinics, Netherlands	Semi structured interviews: Patients' communication preferences and perceived determinants of therapy adherence.	Information exchange Relationship establishment	Patient Experiences: 'Matching information exchange preferences gave patients control by providing cognitive assurance, instrumental support and emotional relief.' 'Matching preferences for relationship establishment resulted in patients feeling satisfied, known and taken seriously'
Mackenzie et al., 2013 [39] Good	**Quantitative,** retrospective, cross sectional, survey	208 cancer patients Selection: 4 Australian hospitals	Post consultation: • Preferences for life expectancy disclosure • Experiences of life expectancy disclosure	Information giving of life expectancy e.g.: have you discussed life expectancy Physician's method of preparing for this information to be given e.g.: how did the discussion begin	Matching: 60% match of preference and experience. Not significantly different to chance. 86% of patients preferred their doctor to ask them before discussing life expectancy, 55.9% experienced a disclosure in line with this preference

Table 5 continued

Author, Year, Quality	Methodology	Subjects	Methods	Type of Communication	Key findings
Brown et al., 1997 [40] Good	**Quantitative,** cross sectional, survey prospective	105 cancer patients 5 oncologists Selection: One Sydney hospital	Pre-consultation: Patient Expectations Scale (six preferences of ideal doctor's communication style) Post-consultation: Patient Expectations Scale (actual experience) Patient satisfaction	Information about illness Emotional support Communication skills e.g.: used medical terms without explaining, listened to what I said Participation e.g.: I was able to talk as much as I wanted	Matching: 5.6% received a perfect match Mean number of aspects perfectly matched was 3.6 (maximum = 6) (most patients received exactly the doctor they wanted just over half of the time) Patient Outcome: No significant differences between mean number of matches and high or low satisfaction groups (median split).
Brown et al., 2009 [41] Fair	**Quantitative,** cross sectional, survey prospective	395 cancer patients 56 oncologists Selection: 14 medical practices in Ohio and Texas	Pre-consultation: Patient request for services schedule (expectations for 15 items) Post-consultation: Patient services received scale (matching of expectations, content of consultation, satisfaction, and importance of items of information and emotional support)	• Task orientation • Treatment • Prognosis • Risks • Lifestyle • Emotional issues • Miscellaneous	Matching: Median = 7 (of 15) expectations met 85 patients selected all 15 pre-consultation but only 15 (of 395) patients (4%) had all expectations met. Task orientation (86.1%), treatment options (90.1% - 96.5%) and risks (90.6%) were commonly met. Lowest match was emotional issues (8.6% - 29.6%) Patient Outcome: Satisfaction increased by 0.7 units for every one unit of patient expectations being met.

Table 5 continued

Author, Year, Quality	Methodology	Subjects	Methods	Type of Communication	Key findings
Cvengros et al., 2009 [42] Fair	**Quantitative** cross sectional, survey prospective	218 Diabetic patients Selection: Two medical clinics in Iowa	Pre-consultation questionnaires • Perceived health status • Krantz Health opinion survey • Patient practitioner orientation scale (PPOS) Post-Consultation • Provider behaviour questionnaire • Patient-satisfaction questionnaire short form • Self-reported diabetes adherence	Focus on: • Information sharing • Behavioural involvement and shared decision making • Socioemotional support	Grouped degree of matching into: (a) High preference and provider performed (b) Low preference and provider performed (c) High preference and not performed Patient Outcomes: Matching preferences and satisfaction Information sharing significantly predicted satisfaction (a) = 8.41, (b) = 8.64, (c) = 8.01 (*F(2,208)*=3.71, *p=0.03)* **Effect size** d=0.46 r=0.22 Behavioural involvement significantly predicted satisfaction (a) = 8.5, (b) = 8.5, (c) = 7.94 (*F(2,205)*=3.60, *p=0.03)* **Effect size** d=0.41 r=0.2 No overall significant predictors for socioemotional support, however difference between (b) = 8.52 and (c) =7.97 was significantly different (*t(211) = -2.30, p=0.02)* **Effect size** d=0.41 r=0.2 Diabetes Adherence No significant prediction of information or socioemotional preference matching on adherence Behavioural involvement significant predictor (a)= 3.7 (b)=3.7 (c)= 3.3 (*F(2,195)=3.39, p=0.04)* **Effect size** d=0.20 r=0.1
Farin et al., 2011 [44] Fair	**Quantitative** cross sectional, survey, prospective	342 chronic ischemic heart disease patients Selection: German patients in rehabilitation	Start of rehabilitation: KOPRA questionnaire about communication preferences End of rehabilitation: KOVA questionnaire about the perceived communication behaviour of the physician	Patient participation and patient orientation (PPO) Effective and open communication (EOC) Emotionally supportive communication (ESC) Communication about personal circumstances (CPC)	Matching: • PPO 61.70% • EOC 66.13% • ESC 66.07% • CPC 53.93% Patient Outcomes: No report of patient outcome

Table 5 continued

Author, Year, Quality	Methodology	Subjects	Methods	Type of Communication	Key findings
Farin et al., 2012 [43] Fair	**Quantitative**, cross sectional, survey prospective	703 chronic back pain patients undergoing rehabilitation	Start of rehabilitation: KOPRA questionnaire about communication preferences End of rehabilitation: KOVA questionnaire about the perceived communication behaviour of the physician	PPO, EOC, ESC, CPC	Matching: • PPO 64.22% • EOC 66.76% • ESC 65.55% • CPC 51.51% Patient outcomes: Correlations (r) *(p<0.001)*: Satisfaction Trust PPO 0.66 0.55 EOC 0.66 0.56 ESC 0.60 0.52 CPC 0.38 0.27 **r is effect size**
van den Brink-Muinen et al., 2007 [45] Fair	**Quantitative,** cross sectional, survey prospective	1787 Patient-GP consultations **Selection:** Dutch national survey of GPs	Pre-consultation: Questionnaire - Importance of aspects of communication Post-consultation: Rated GP performance on the aspects of communication	Affect-orientated: • Time • Attention • Listened • Empathic • Friendly • Frank • Took problem seriously Task-orientated: • Diagnosis • Explanation • Information • Advice • Helped Examination	Matching: (important and performed + not important and not preformed): Affect-orientated aspects range 63.5% - 95.9% Task-orientated aspects range 72.3% - 87.7%

Table 5 continued

Author, Year, Quality	Methodology	Subjects	Methods	Type of Communication	Key findings
Fujimori et al., 2014 [46] Good	**Quantitative**, Intervention, Randomised (by oncologist) control trial	601 patients (control n=309, intervention n=292) 30 Oncologist Selection: Two cancer centres in Japan	Control group: Consultation as usual Intervention: Oncologists attend communication skills training. The training was based on 4 studies of cancer patients' preferences (no reporting on representativeness of current sample) for information and communication style. Patient outcomes: • HADS • Satisfaction with consultation (single Likert scale 0-10) Trust in oncologist (single Likert scale 0-10)	Communication skills taught: • Setting up supportive environment • Considering how to deliver bad news • Additional information patient wanted to know • Reassurance Emotional and empathic responses	Patient Outcome: No significant differences between control and intervention for: • HADS Levels of anxiety, total distress • Satisfaction with communication Significant differences for • HADS depression (decrease from control 5.32 (n=309) to intervention 4.59 (n=292) *p=0.027*). **Effect Size** d= 0.18 • Trust (increase from control 8.87 to intervention 9.15 *p=0.009*) **Effect size** d=0.21
Murtagh & Thorns 2006 [47] Good	**Quantitative**, Intervention, non-randomised control trial (before and after design)	101 Patients with life threatening illness **Selection:** New admissions to 3 hospices in southeast England over 4 months	Control condition(n=40): Post-consultation outcome measure Intervention: Pre-consultation preference questionnaire, Post-consultation outcome measure Outcome measure: Satisfaction with: • Amount of information • Way information given • Information given to family Confidence about future decision making, matching their preferences	Information transaction Way of delivering information	Matching: Preference eliciting questionnaire significantly increased: • information delivery matching 80.3% control (n=49), 97.5% intervention (n=39) *p=0.041* **Effect size** d=0.52 • carer/family were kept informed in line with the patient's wishes 60.7% (n=37) control, 92.5% intervention (n=37) *p<0.001* **Effect size** d=0.82 No significant differences between control and intervention for the amount of information desired and confidence that decisions about care will be made within the patient's wishes.

Table 6: Cross-comparison of reported patient experience

Patient Experience	Brotherton & Abbott 2009 [37]	Mulder et al., 2014 [38]	Mackenzie et al., 2013 [39]	Brown et al., 1997 [40]	Brown et al., 2009 [41]	Cvengros et al., 2009 [42]	Farin et al., 2011 [44]	Farin et al., 2012 [43]	van den Brink-Muinen et al., 2007 [45]	Fujimori et al., 2014 [46]	Murtagh & Thorns 2006 [47]
Range of matching occurrence reported prior to any intervention			55.9% - 60%	5.6%	4% - 96.5%		53.93% - 66.13%	51.51% - 66.76%	63.5% - 95.9%		60.7% - 80.3%
Poor matching											
Emotional aspects lowest occurrence[1]					#				#		
Bad news delivery	#		#								
Outcomes detailed	#										
Improved matching											
Information highest occurance[1]					#						
Satisfaction		#		# NS	#	# SE		# SE, ME		# NS	
Trust								# SE, ME		# SE	
Anxiety										# NS	
Depression										# SE	
Adherence		#				# SE					
Mechanisms detailed		#									
Intervention improved matching occurrence											# ME LE

Key: # indicated reported in study, NS indicates a non-significant relationship between preference-matching and outcome, SE indicates a small effect size, ME indicates a medium effect size, LE indicates a large effect size, [1] when compared to other communication preferences

Table 7: Cross-comparison of reported type of communication studied

Type of Communication	Brotherton & Abbott 2009 [37]	Mulder et al., 2014 [38]	Mackenzie et al., 2013 [39]	Brown et al., 1997 [40]	Brown et al., 2009 [41]	Cvengros et al., 2009 [42]	Farin et al., 2011 [44]	Farin et al., 2012 [43]	van den Brink-Muinen et al., 2007 [45]	Fujimori et al., 2014 [46]	Murtagh & Thorns 2006 [47]
Topics											
Information (medical)	#	#	#	#	#	#	#	#	#	#	#
Emotional support/issues				#	#	#	#	#	#	#	
Personal circumstances							#	#			
Delivery											
Way information delivered	#		#	#			#	#	#	#	#
Participation/ facilitation of participation	#			#		#	#	#			
Relationship development		#					#	#	#	#	

Key: # indicated reported in study

3.2 Data Evaluation

As reported in section 3.1, studies were assessed as having either good [38–40,46,47] or fair [37,41–45] methodological quality (see Table 5 for summary and Appendix B for full results). Despite this assessment it is important to consider the comparative design strength of the studies included in this review. The Oxford Centre for Evidence-Based Medicine provide guidelines on the relative strength of differing designs of quantitative studies when considering the implications for practice [48]. Systematic reviews are viewed as the highest level of evidence, followed by randomised control studies at the second level. At the third level are cohort studies and at the fourth level are case reports. Out of the nine quantitative studies there were only two level two control studies; one randomised [46] and one non-randomised [47] relating to patient communication preference-matching. The remaining seven quantitative studies were observational cohort studies [39–44,49], providing level three evidence. As the Oxford Centre for Evidence-Based Medicine did not include qualitative studies into their levels of evidence, a separate comparable hierarchy of levels of evidence [50] was used to assess the two remaining studies. One study provided conceptual, level two, evidence [38] and one study provided descriptive, level three, evidence [37]. Overall this suggests that the studies included in this review mainly provided level three evidence.

3.3.1 Occurrence of preference-matching

Across the 11 studies identified, seven reported the naturally occurring percentage of patients' communication preferences being met [39–41,43,44,47,49]. There was a considerable range in the percentage of preferences that had been successfully matched, ranging from 4% of exact (15 out of 15 areas of communication) matches [41] to 96.5% of patients' preferences for information about treatment options being matched [41]. The majority of studies reported preference-matching rates between 51.51% and 96.5%, which suggests that the method of recording only exact matches may have contributed to the lower rate. Only one study reported the comparison of occurrence of matching to chance, stating that the 60% of matching found was not significantly different to chance [39]. Comparison of different elements of

communication showed that patients' preferences for the amount and type of information given by physicians were being met most successfully [41].

Satisfaction was the most frequently reported patient outcome [38,40–43,46]. Qualitative data reported by Mulder et al. [38] indicated that feeling satisfied with the encounter was related to matching patients' preferences. This was supported by three quantitative studies which reported significant (small and medium effect sizes) improvement of patient satisfaction as preference-matching increased [41–43]. However, examination of the effect sizes suggests that preference-matching only marginally improved patient satisfaction. Also, inspection of the quality of the studies suggests that where satisfaction was reported to have increased, the study quality was only fair, level three evidence. Conversely, two studies reported the statistical frequency of preference-matching did not significantly alter satisfaction [40,46]. Both studies were quality rated as good and one was also level two randomised control trial [46]. When the quality and strength of the studies are considered the difference in the findings could indicate that lower quality and strength studies' findings should be treated with caution, to minimise the impact of potentially reporting a type one error. Therefore definitive conclusions about the presence and size of effect of the increase in satisfaction cannot yet be made. At best there is only a suggestion of the presence of a possible link between satisfaction and preference-matching.

Trust in the physician was also significantly related to an increase in patient preference-matching in two studies [43,46]. In an observational study, Farin et al. [43] reported significant, small and medium effect, correlations between increasing trust and increasing patient preference-matching. Due to the correlational design of the study it is not possible to make any conclusions about the directionality of the relationship. Therefore caution needs to be taken before accepting that an increase in patient communication preference-matching leads to an increase in patient trust in the physician. Fujimori et al. [46] also reported that patients who attended consultations with physicians who had undertaken communication training showed a significant increase (small effect size) on patient trust in the physician. The study assumed that as the

communication training had been designed on previously researched and reported patient preferences for communication, that physicians would be skilled to deliver consultations which met current patients' preferences. However it is not reported how generalizable the sample of patients which the training was based is to the current sample. Therefore care needs to be taken before accepting that this communication training improved or even achieved communication preference-matching in this study. This also casts doubt on the directionality of the link between preference-matching and patient trust.

Patient outcomes related to ongoing healthcare needs were also reported in two studies [42,46]. Fujimori et al. [46] reported that depression was significantly lower (small effect size) in the group of patients where the physician had attended communication training, when compared to the control group. In a separate study, adherence to diabetes management was also significantly associated (small effect size) with improvements to patient communication preference-matching [42]. For both these studies it is unclear how a change in preference-matching affected these outcomes following the one-off consultations examined in both studies. There is also no evidence reported as to the longevity of these patient outcomes, as neither study included follow up data.

Only one study attempted to increase the occurrence of communication preference matching. Murtagh and Thorns [47] reported that by administering a preference eliciting questionnaire prior to consultation, between 17.2% and 31.8% more patient preferences were matched, when compared to a control group. Despite reporting medium to large effect sizes and having a good quality rating, the study did not detail the process between the patient completing the preference eliciting questionnaire and the physician achieving an increase in preference-matching. As such, it is unclear what the intervention was manipulating or the mechanisms operating in this study, therefore conclusions about the patient experience are limited. However, a potential explanation is offered by Mulder et al. [38] where improved preference-matching enabled the patient to feel in control of their illness by provision of assurance, support and relief.

3.3.2 Poor occurrence of preference-matching

As all, except one, of the studies included in this review did not compare the rate of matching to chance it is difficult to establish a numeric value where preferences have been failed to be met (i.e.: significantly different to chance). Also due to the diversity in the methods employed to elicit preferences and the variety of preferences investigated, it would be misleading to generate a mean or median value to use as a threshold value for this sample. Despite this difficulty a visual inspection of the reported rates of preference-matching indicates that emotional aspects or issues are often the least well matched preferences [41,45].

Delivery of bad news was also reported in two studies as an area of poor communication preference-matching [37,39]. Mackenzie et al. [39] reported that preference-matching for information about cancer patients' life expectancy was not significantly different to chance. They also reported that only just over half of patients experienced their preference of the doctor asking if they would like to discuss life expectancy prior to disclosure of life expectancy. Brotherton and Abbott [37] reported that patients' who had a PEG feeding tube inserted found that generally communication was poor, but also that the physicians failed to meet patient's needs and preferences for the quantity, quality and type of information delivered. Patients reported experiencing physicians as paternalistic and prescriptive in their attitude to insertion of the PEG tube, and often rushed consultations or didn't allow for patient questions. Patients reported that this poor match of communication preferences lead them to feel isolated, excluded and that they had no one to turn to.

3.3.3 Communication topics

The inclusion/exclusion criteria specified that all studies were required to include preferences for a wide range of elements of communication. All 11 studies included information about the medical condition as a communication preference to investigate. However, studies then reported a wide variety of other topic preferences, mainly dependent upon the method or tool used to elicit patient preferences. Due to this variety, categories of emotional support/issues

and personal circumstances were developed to aid cross-comparison. Seven studies recorded preferences for emotional support/issues [40–46] and two studies recorded preferences for personal circumstances [43,44].

3.3.4 Communication delivery

All studies, except one [41], also reported patient preferences about the style of the physician's communication. The most common preference investigated was the way the physician delivered medical information [37,39,40,43–47]. Both preference-matching for patient participation during the encounter [37,40,42–44] and patient-physician relationship building [38,43,44,46,49] were reported by five studies. In this sample, patient participation included physician communication skills such as allowing the patient to voice their concerns [40], asking the patient what has helped and not helped in treatment [43], and encouragement of active self-management of illness [42]. Relationship building was deemed to be distinct from participation as it focused on development of a relationship between the physician and patient, as opposed to engagement of the patient in the encounter. Examples include showing empathy towards the patient [49], providing reassurance [46], and building a relationship where the patient is treated as an equal [38].

4 Discussion and Conclusion

4.1 Discussion

The primary aim of this review was to synthesise the evidence of patients' experiences of communication preference-matching in medical settings. Overall patients are experiencing differing levels of preference-matching both between physicians and areas of communication. Currently physicians appear to be more successful at matching patient's preferences for information than they are for emotional issues or offering emotional support. This suggests that patients' communication preferences are not being fully met in current medical encounters.

When patients' communication preferences were not matched, patients reported experiencing negative consultations which left them feeling isolated, excluded, and that they had no one to turn to [37]. Patients also experienced a

discordance between their preferences and actual experiences of disclosure of bad news, including how the disclosure was initiated and disclosure of information about life expectancy when this was not desired [39]. This suggests when patients' communication preferences are not matched there are potential implications for patient choice and autonomy within medical encounters.

The current state of the evidence prevents any definitive conclusions about the effect of improving the occurrence of matching patient preferences on patient outcomes. A first glace there appears to be an association between improvements in preference-matching and patient's retrospective satisfaction of the medical encounter. However the studies that reported a small positive effect [41–43], were appraised as being a lower quality and strength than the studies which reported no significant change [40,46]. It is also important to consider that there are measurement difficulties when attempting to retrospectively assess patient satisfaction. Previous research indicates that patients typically report high levels of satisfaction when completing self-report measures, yet express contradictory and complex opinions in subsequent interviews about their experience [51]. Therefore both quality and measurement issues suggest that there is a risk of an inflated reporting of patient satisfaction. In studies included in this review, levels of patient trust, depression, and treatment adherence were also reported to be connected with changes in preference-matching, however methodological flaws limit the conclusions that can be drawn. Therefore the methodological strength and measurement issues of included studies cast doubt on the strength of the reported findings. As such the current literature can only suggest that there could be a possible association between patient communication preference-matching and patient outcomes including satisfaction, trust, depression and treatment adherence.

Despite the limited conclusions of this review, the results can be formulated using existing theoretical models. The congruence hypothesis [19] can explain Mulder et al.'s [38] observation of the positive effects of preference-matching linking to patient's sense of control within the encounter. The hypothesis suggests that in situations thst are congruent with patient's beliefs about personal control (i.e. preference-matching is achieved), patients are more likely

to respond in a positive way [19]. Peters' Patient-Physician Match model [52] can explain Brotherton and Abbott's [37] finding that when preferences were not matched patients' experienced the physician as paternalistic and excluding. Peters' [52] model explains the finding as a failure of the physician to adapt their communication style to the patient's preference for autonomy within the medical encounter, which then impacts on patient outcomes.

A promising finding of this review was that not only was it possible to increase the frequency of patients' communication preferences being met [47], but patients also desired their preferences for receiving bad news to be established prior to disclosure [39]. Assessment of patient preferences prior to the encounter is something which has been previously suggested [23,25] and stipulated in Kiesler and Auerbach's 2006 review [19]. This is also in keeping with clinical guidelines [21] and the current expectation of patient focused care in the NHS [22]. Therefore, interventions or tools to improve the frequency of communication preference-matching potentially may aid physicians' improvement of the patient experience and possibly improve patient outcomes. However there is a distinct lack of research examining the effect of interventions in this area.

The secondary aim was to review the areas of communication where patient preference-matching had been investigated. Information provision was included in all studies included in this review. This could be due to the relative ease of assessing this preference as it is arguably simpler for patients to define, quantify, and report than an element such as development of a relationship. Studies then differed with respect to which additional areas of communication were included. The majority of studies selected questionnaires to elicit patient preferences, however there did not appear to be a consensus for which preferences should be assessed. This was perhaps due to a lack of a common tool used across all studies to elicit patients' preferences. Only two studies by the same authors [43,44] used the same method and tool, despite the availability of a range of previously published tools [29]. This heterogeneity in assessment method has limited the synthesis and conclusions that can be made about the elements of communication in medical encounters, and also the

effects of matching patient preferences for these elements on patient experience. At best the evidence reviewed suggests that communication in medical interactions is wider than just information exchange. This supports the suggestion that communication in medical encounters includes information transaction, provision of emotional support, facilitation of patient participation, and development of a responsive interpersonal relationship [26].

4.1.1 Limitations

There were methodological limitations of the evidence which have impacted on the robustness of the conclusions that can be made from the current literature. Despite all included studies being quality appraised as good or fair, the studies only provided level two and three evidence, which is less than ideal (see section 3.3). Most studies were level three, quantitative, observational cohort studies which lacked the ability to explore causation between occurrence of matching patient preferences and patient experience or outcomes. The two quantitative, level two, studies which included an intervention and control group [46,47] both had weaknesses linked to the way preference-matching was generated. Measurement issues have also impacted on the cohesion of the literature for assessing communication preferences. All these issues have impacted upon the conclusions that can be inferred about the effect of patient-physician communication preference-matching.

Additionally there were limitations to the methods of the review, which could have increased the bias of the findings. Although care was taken in development of the search strategy and inclusion of MeSH headings, there is always the possibility that it excluded potentially relevant studies. A strength of the search strategy was the heterogeneity of the studies returned, which enabled a range of data to answer the aims of the review. However, the inclusion of the studies and extraction of the data was, in part, subjective as only one researcher screened the results of the search against the inclusion criteria and extracted the data. This allowed both elements of the process open to the influence of the individual researcher's interpretation.

4.2 Conclusion

The occurrence of physicians matching patients' communication preferences in current medical encounters is highly varied. The appraised strength and quality of the current literature prevent definitive conclusions about the effect of matching patient preferences and benefits for the patient experience. At best there are only indications of a link with patient outcomes including satisfaction, trust depression and treatment adherence. There are suggestions that a failure to match patient preferences can lead to the patient feeling excluded, with no one to turn to, and being dissatisfied with the encounter. One promising finding of the review was that patient-physician communication preference-matching was shown to be improved by eliciting and sharing the patient's communication preferences, which is something that patients desired. If future research in this area aims to address the methodological weaknesses highlighted by this review, there could be the potential to impact on patients' experiences in medical encounters by matching patients' communication preferences.

4.3 Practice Implications

4.3.1 Research

This review has demonstrated that the state of the evidence for patient-physician communication preference-matching is less than ideal. To overcome this a number of recommendations are suggested. Future research should attempt to consolidate findings of the existing literature using intervention studies that aim to manipulate the rate of occurrence of preference-matching, with a controlled sample, to aid understanding of the effects on patient outcome. Longitudinal studies are also required to further understand the directionality of any changes in patient outcomes that could be linked to improvements in the occurrence of preference-matching. Research in this area also requires an effort to overcome the measurement issues in identifying communication preferences. This should include a broad understanding of communication in medical settings but should also focus on validating and adapting existing measurement tools to increase consensus in the topic area.

4.3.2 Clinical Practice

The state of the evidence has prevented identification of any clear clinical implications of improving patient-physician communication preference-matching in medical interactions. However, there are suggestions that patients' experiences are less than ideal when preferences are not matched. Clinical focus should be considered for the improvement of emotional support offered by physicians during medical encounters, as this was the least often matched communication preference. The review also suggests that if physicians desire to increase the occurrence of matching patients' preferences, then an assessment of the patient's preferences prior to the medical interaction could aid physicians in their successful adaption of communication.

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Claire Bennett is the primary contributor to this review and has undertaken the data collection, analysis and interpretation. Nima Moghaddam has contributed to the project by helping to shape the design and final write up of the review in his position of research supervisor to Claire Bennett. Danielle DeBoos completed independent review of exclusion criteria and quality appraisal criteria triangulation. All authors have approved the final version.

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Conflict of Interest

There are no known conflicts of interest that could inappropriately influence, or be perceived to influence, this review.

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Journal Paper

Developing a tool to support diagnostic delivery of dementia

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Abstract

It is increasingly recognised that there are challenges affecting the current delivery of dementia diagnoses. Steps are required to address this. Current good practice guidelines provide insufficient direction and interventions from other healthcare settings do not appear to fully translate to dementia care settings. This project has taken a sequential two-phase design to developing a tool specific to dementia diagnostic delivery. Interviews with 14 participants explored good diagnostic delivery. Thematic analysis produced key themes (overcoming barriers, navigation of multiple journeys, and completing overt and covert tasks) that were used to inform the design of a tool for use by clinicians, patients and companions. The tool was evaluated for acceptability in focused group discussions with 13 participants, which indicated a desire to use the tool and that it could encourage good practice. Adaptations were highlighted and incorporated to improve acceptability. Future research is now required to further evaluate the tool.

Keywords

Dementia; diagnosis disclosure; breaking bad news; qualitative

Introduction

Over recent years there has been a policy-driven shift toward identifying and diagnosing dementia at the earliest possible juncture[4]. It has been suggested that early diagnosis can: enable an advancement in the process of recognition and adaptation (de Vugt & Verhey, 2013); reduce feelings of uncertainty and anxiety (Dubois, Padovani, Scheltens, Rossi, & Dell'Agnello, 2015); and improve quality of life and relationships (Werner, Karnieli-Miller, & Eidelman, 2013). As such, over recent years the Prime Minister's Challenge on Dementia (Department of Health, 2012, 2016) and The Alzheimer's Society (Alzheimer's Society, 2014) have set targets for increasing rates of formal diagnosis for those affected by dementia. The most recent figures from National Health Service (NHS) England in January 2016, suggest 67.2% of affected people were

[4] See extended paper section 1.1 for details about dementia

receiving a formal diagnosis (Department of Health, 2016)[5]. Notwithstanding this increase, The Alzheimer's Society's continue to campaign for diagnosis rates to reach to 75% by 2017 (Alzheimer's Society, 2014a).

Although at first glance more people receiving a diagnosis sooner appears to be an improvement, there has been a lack of focus on the quality and experience of receiving a diagnosis. Also, it is becoming increasingly recognised that there are challenges affecting the current delivery of a dementia diagnosis with 'significant numbers of people reporting problems with how this is currently undertaken' (p39, British Psychological Society, 2014a). Furthermore, people with dementia and their caregivers have reported receiving unsatisfactory information and explanation at the time of diagnosis (Holroyd, Turnbull, & Wolf, 2002). In a recent exploration of people's experiences of the diagnostic process in United Kingdom (UK) National Health Service NHS) secondary care settings, diagnosis disclosure was reported to be confusing and anxiety provoking, with poor communication leading to general dissatisfaction (Samsi et al., 2014).

Attempts have been made to produce recommendations for dementia diagnostic delivery within the international research community including: the need for personalised delivery (Lecouturier et al., 2008; Werner et al., 2013); developing understanding of the diagnosis over time (Byszewski et al., 2007); and inclusion of carers and family (Grossberg et al., 2010)[6]. However, the current Department of Health (2009) practice guidelines merely suggest 'breaking the diagnosis well to the person with dementia and their family' (p37), and state that good quality information about the illness should be given at diagnosis. It is clear these guidelines lack sufficient detail to identify the constituents of good quality diagnostic delivery.

Alongside research recommendations and guidelines, clinical tools or interventions can also improve medical encounters. Despite a lack of dementia diagnostic specific tools, there are protocols and interventions relating to the

[5] Details of the UK dementia care pathway is presented in extended paper 1.6.1
[6] Extended consideration of current research is available in extended paper section 1.8

delivery of bad news[7] in other healthcare settings, which may have transferable concepts. Available clinician focused protocols (e.g., SPIKES, Baile et al., 2000; BREAKS, Narayanan, Bista, & Koshy, 2010) attempt to provide instruction via a series of chronological phases that include preparing to disclose the news, disclosure, and responding to reactions (Eggly et al., 2006)[8]. Specific patient focused interventions include patient coaching sessions (e.g. Finney et al., 1990), question prompt lists (e.g. Middleton, McKinley, & Gillies, 2006), decision making aids (e.g. Hess et al., 2012), and provision of audio tapes of the consultation (e.g. Ford, Fallowfield, Hall, & Lewis, 1995). Despite their potential clinical application, research outcomes show varying benefit of clinician focused protocols (COMFORT, Villagran, Goldsmith, Wittenberg-Lyles, & Baldwin, 2010) and patient focused interventions (Kinnersley et al., 2007; Stacey et al., 2017). It is possible that the varied clinical effect is due to the intervention focusing on only one participant in the interaction. Instead, to improve practice and patient experience both parties may need targeting as neither participant is acting in isolation (Butow et al., 2004; Furber, Murtagh, Bonas, Bankart, & Thomas, 2014).

Furthermore, breaking bad news protocols tend to view the process as a linear communication transaction between clinician and patient, which may not fully reflect the true complexities of actual clinician encounters (Villagran et al., 2010)[9]. Alongside these limitations, the Dementia Workstream of the British Psychological Society (BPS) Faculty of the Psychology of Older People (FPOP) is also cautioning against the direct application of guidelines developed in other healthcare settings to delivery of a diagnosis of dementia (BPS, 2014b). This is largely due to the increased importance of the companion in the context of dementia-diagnostic consultations (Murphy & Gair, 2014). During a consultation in dementia care settings companions often take on important dual roles as informant and advocate due to the cognitive impairment of the patient

[7] See extended paper section 1.2 for further detail and definition of breaking bad news. Section 1.3 outlines theoretical understanding of the breaking bad news encounter
[8] Details of breaking bad news in other areas and available protocols can be found in section 1.4
[9] Critical discussion of breaking bad news protocols is in extended paper section 1.4.1

(Robinson et al., 2011)[10]. Therefore, it is proposed that direct application of protocols developed for dyadic consultations would not capture or support the complex processes present within the dementia care triad in memory assessment services.

Due to the limited detail of the UK good practice guidelines and applicability of tools or interventions from other healthcare settings, it is critical that current research attempts to produce supportive tools for good practice[11]. As such, the overarching aim[12] of this study was to develop a prototype tool that has future potential to be used by clinicians, patients, and companions who are involved in the delivery of diagnoses of dementia.

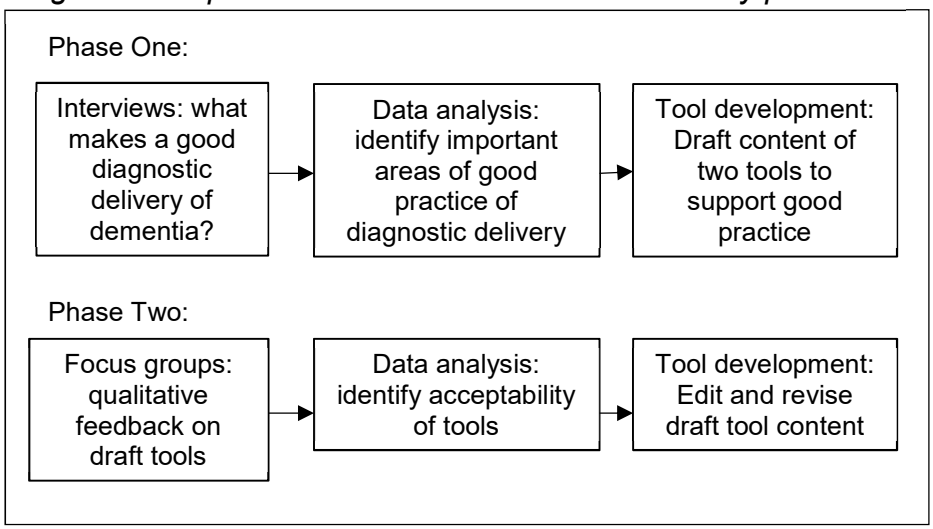
Methods

Study Design[13]

This study has taken a qualitative, sequential, two-phase design. Figure 2 presents the steps undertaken in each phase of the project, with the methods of each detailed below. An opportunistic approach to sampling was adopted in both phases to sample views from multiple stakeholders involved in delivery and receipt of a diagnosis of dementia. Participants were recruited from one NHS Trust that managed a total of seven Memory Assessment Services (MAS)[14] that covered a large UK city and the surrounding county. Ethical approval[15] for the study was obtained from East Midlands - Nottingham 1 Research Ethics Committee[16] (reference number 16/EM/0097) and all participants gave written informed consent, which included the use of anonymised quotes.

[10] Further information about difficulties with delivering a diagnosis of dementia is in extended paper section 1.7
[11] See section 1.9 of extended paper for the relevance to clinical psychology
[12] Primary objectives are outlined in section 1.10.1 of extended paper
[13] Extended methods outline the rationale for methods selection (2.1) and study design (2.3)
[14] See extended paper section 1.6.2 for overview of the hosting MAS
[15] Full consideration of ethical issues is in extended paper section 2.10
[16] See Appendix C for service access letter, Appendices D, E, F for REC correspondence, and Appendices G and H for R&D correspondence

Figure 2: Steps undertaken in each of the two study phases



Phase One

Sampling and Recruitment [17]

Clinicians[18] involved in the diagnostic delivery of dementia were recruited via email advertisement circulated by the MAS management team. Those who wished to participate were provided with the research team's contact details to express their interest in participating. Clinicians were only included if they were 18 years or older and could provide written consent. Interviews were arranged at a convenient time and location for those who wished to participate.

MAS patients and their companions were provided with study information by MAS clinicians at the end of their appointment across a selection of four clinic locations in the hosting site. This included inner city and rural clinics. People who expressed an interest in participating gave consent for their contact details to be shared with the research team. Only people who were over 18, had or supported someone with a diagnosis of dementia, and could provide written consent were included. Eligible participants were contacted after a minimum of one week following their appointment by the first author to further discuss the study and, if they wished, to arrange for an interview to be completed. Patients

[17] Further detail is available in extended paper section 2.4
[18] See section 1.5 for key term definitions, including a definition of clinician for this study

and companions who consented were offered the choice to be interviewed as a dyad of patient and companion or individually. Interviews were conducted in the participants' own homes. Overall, the aim was to recruit four clinicians, six patients and six companions.

Data Collection[19] and Analysis

Data were collected through ten audio-taped, face-to-face, semi-structured interviews[20] with the first author. Topics addressed included the process of the diagnosis, the person's experience of delivering or receiving a diagnosis, the experience of the MAS, and changes in practice. Interviews were transcribed verbatim by a transcriptionist[21]. The average length of interview was 27 minutes. Data were organised and managed using NVivo 11 Pro software (QSR International, 2016).

Following transcription each interview was analysed using thematic analysis[22] by the first author. All data were analysed as a single sample. Braun and Clarke's (2006) step-by-step guide and criteria for good quality thematic analysis was utilised[23]. Following familiarisation with the data, the first author coded each transcript. Initially, inductive coding was completed to ensure maximum retention of meaning in the data. Following this, deductive coding was applied to capture specific data relating to a good delivery of a diagnosis of dementia. All coding was focused at the semantic level and aimed to translate participants' experiences into good practice implications. The second author reviewed exerts of coded data to ensure rigorous and consistent coding. The first author developed initial themes and concept maps from the coded data. The themes and maps were then reviewed and adjusted in conduction with the second and third authors to identify the overarching themes and sub-themes. Finally, the first author defined and named the themes.

[19] Further information is available in section 2.5 of extended paper
[20] For detail about topic guide see sections 2.6 and 2.6.1 of extended paper
[21] More detail in extended paper section 2.7
[22] See extended paper section 2.2 for consideration of theoretical framework including TA (2.2.4)
[23] Full details of the stages of data analysis are in extended paper section 2.8, along with the steps for quality assurance (section 2.9), and researcher impact (2.11)

Tool Development

An initial draft of the tool was developed by the first author from the final theme structure of the constituents of good diagnostic delivery.

Phase Two

Sampling and Recruitment [24]

Four focus groups were held to critically review the draft tools, two for service deliverers and two for service recipients. The aim was to recruit a maximum of 12 of each participant type. Locations of the focus groups were selected to maximise recruitment by improving convenience, for example holding one service recipient focus group in a city centre location and the other in a rural location. An advert and details of all the focus groups were circulated via the hosting MAS management team to all staff members. Staff members were invited to contact the first author to express an interest in attending. As in phase one, clinicians circulated information about the service recipient focus groups to people attending MAS appointments in the two weeks prior to the focus group date. Information was also provided in letter form to participants in phase one who had given consent to be contacted in relation to the second phase of the study. People who were interested were required to contact the first author to reserve a place and to obtain further information.

Data Collection and Analysis

Each focus group was audio-recorded and facilitated by the first author. The topics addressed[25] included reviewing if the tools could meet their intended aims, if they were acceptable to use, and whether the tool was likely to be used in future practice. The focus groups were transcribed verbatim by a transcriber[26]. The average length of focus group was 61 minutes. Data were organised and managed using NVivo 11 Pro software (QSR International, 2016). Following transcription each interview was analysed using a mixed inductive and deductive thematic analysis by the first author. The inductive

[24] Further detail is available in extended paper section 2.4
[25] For detail about topic guide see sections 2.6 and 2.6.2 of extended paper
[26] More detail in extended paper section 2.7

approach coded data that related to opinions about the tool. Alongside this, three a priori themes were coded in deductive approach. These were: usage, barriers to uptake, and alterations. The remainder of the analysis was as described in phase one.

Tool Development

The draft tools were then adapted in line with the findings and feedback from the analysis of the focus group data.

Results

Phase One

Participants[27]

To preserve anonymity, the participants are described in aggregate terms. All 14 participants were White British and five were male. Recruited clinicians were three specialist nurses who deliver diagnoses of dementia and one support worker who is present in MAS appointments where diagnoses are delivered to provide additional information and on-going support.[28] Service recipients recruited were five patients and five companions. Overall, this recruitment represented four MAS clinic locations. Four of the patient-companion dyads were spouses and were interviewed as a dyad. One patient-companion dyad was a parent and child relationship and were interviewed separately. Patients were between the ages of 76 and 83. The length of experience of clinicians ranged from three to twenty years.

Themes

Four overarching themes were developed to represent the elements of a good delivery of a diagnosis of dementia as perceived by participants. Table 8 outlines the theme structure[29].

[27] A complete account of achieved recruitment and sample characteristics are in extended paper section 3.1

[28] Section 2.4.2 provides additional contextual information about the sample and 2.4.3 provides a comparison of the hosting MAS with other services that have MAS functions.

[29] The most salient themes are presented in this journal paper, for an account of all the themes in phase one see extended paper section 3.2

Table 8: Phase one theme structure

Overarching Theme	Sub-Themes
Overcoming barriers to good delivery	
Navigation of multiple journeys	Attendee's emotions Clinician's emotions
Overt tasks	Develop a supportive relationship Promote consent and choice Develop understanding Be patient centred Provide emotional support
Covert tasks	Overcoming power imbalance between clinician and patient Continual adaption Awareness and management of dynamics

Overcoming barriers to a good delivery[30]

Central to this overarching theme it is assumed that clinicians aim for a 'good' diagnostic delivery. However, to achieve a good delivery the clinician should be aware of, and attempt to mitigate against, a range of factors that could indirectly lead to a diminished patient experience including service constraints, high demand, and the aversiveness of delivering the 'bad news'.

The design of the service could place restrictions upon appointments and led to overfilling the appointment or rushing to deliver information. Quote 1 in Box 1 highlights how clinicians may have to balance the required elements of the appointment with the fixed appointment length (30 minutes in the hosting service). Alongside this, services and individual clinicians can also feel pressured by the volume of people waiting for appointments. In Quotes 2 and 3 in Box 1, Clinicians Jennifer and Louise are both conscious of the effects of high demands. Patient experience could be reduced if waiting times are long. Also, if clinicians are rushing or feeling pressured the quality of communication may decrease.

[30] Full discussion of theme available in extended paper section 3.2.1

Compounding these service level pressures, a diagnosis of dementia is a stigmatised, life altering diagnosis; therefore, the delivery can be difficult and stressful. Jennifer reports feeling like the grim reaper in Quote 4 in Box 1 when she delivers the news. These negative emotions are also experienced by the recipients, highlighted by Alan's quote (Quote 5, Box 1). Due to this, clinicians need to actively attempt to mitigate any temptation to shy away from delivering the news to ensure good quality diagnostic delivery.

Box 1: Quotes relating to overarching theme: Overcoming barriers to a good delivery

Quote 1
Pat (Clinician): *[discussing how to balance the necessary elements of the appointment]* there are time pressures, so it's getting the most in the time and about getting the basic information across.

Quote 2
Jennifer (Clinician): *[answering: what could be done better]* As a service, we've got an awful lot of referrals coming through. Sometimes people can be waiting and waiting.

Quote 3
Louise (Clinician): I think the problem with diagnosing dementia is sometimes about throughput and there's a lot on we need so many people diagnosed because there are so many people out there not being diagnosed but actually you can't start minimising, turning it into a conveyor belt.

Quote 4
Jennifer (Clinician): *[talking about her experiences of delivering a diagnosis of dementia]* in my own words, you feel like the Grim Reaper.

Quote 5
Alan (Companion): it's just a horrible thing to be told.

Navigation of multiple journeys[31]

During the appointment, the clinician will travel alongside the attendees in their emotional journey and travel through their own emotional journey. Good delivery enables both journeys to occur in the appointment.

[31] Full discussion of theme available in extended paper section 3.2.2

Attendee's emotions. During the diagnostic appointment participants reported feeling anxious, sad, embarrassed, frightened of the unknown, and shocked. There were also mixed emotions about receiving a diagnosis. A couple of the reactions of participants are highlighted by Quotes 1 and 2 in Box 2.

Clinician's emotions. The clinician is likely to develop an emotional connection with the attendees. This results in the clinicians also embarking on and managing their own emotional journey. Jennifer and Louise discuss their emotional experiences in Quotes 3 and 4 in Box 2.

Box 2: Quotes relating to overarching theme: Navigation of multiple journeys

Quote 1
Jane (Companion): *[considering the how the diagnosis has changed things]* it's nice to know, but I do get hurt sometimes when I think about it because I think, "Oh gosh, he's going to get worse" and I don't like to see him like that.

Quote 2
Mary (Patient): I wasn't shocked because I know there is something wrong. No, he was fine. I wasn't distressed. I mean, I am distressed but the day I don't remember John (husband and companion in the appointment) will be the worst day but not really, I know there's something wrong.

Quote 3
Jennifer (Clinician): *[talking about her experiences of delivering a diagnosis of dementia]* you still get a butterfly type feeling the minute you are about to deliver it.

Quote 4
Interviewer: Is there any particular part of it that you find to be the most difficult of the diagnostic appointment?
Louise (Clinician): You can't be frightened of the quiet [after diagnostic delivery] because I think that's about your own issues if you start filling it up, isn't it?

Overt tasks[32]

There are several overt tasks that the clinician should complete to achieve a good delivery of a diagnosis of dementia.

[32] Full discussion of theme available in extended paper section 3.2.3

Develop a supportive relationship. To achieve good practice a relationship must be built with the attendees to serve as the foundation for delivering the diagnosis. Louise - a clinician with 20 years of experience - highlights the central nature of the relationship (Quote 1 in Box 3).

Promote consent and choice. Good diagnostic delivery works with attendees to enable patients and their companions to make choices. Quote 2 in Box 3 is a discussion between Alan (companion) and Edna (patient) that indicates how some participants may differ in their desire for information. It also highlights how their MAS clinician (Louise) respected their choices.

Develop understanding. Understanding the diagnosis is perhaps a main aim when delivering a diagnosis. Primarily, being open about the diagnosis and using the term dementia is essential, referenced as particularly helpful by Ann in Quote 3, Box 3. However, introducing the word and concept of dementia requires careful management. The clinician needs to locate the attendee's current understanding of their difficulties and develop this. Pat (clinician) describes how he locates attendees' understanding in Quote 4, Box 3. Furthermore, good practice also identifies each person's informational needs and attempts to meet these in a range of ways, which was important for Kate (companion) and her mum Doris (Quote 5, Box3).

Be patient centred. Good practice involves placing the patient as the central focus of the diagnostic delivery. However, this must not be at the exclusion of either. Edna (patient) describes how Louise (clinician) managed the interactions with herself and her husband (Alan) who accompanied her (Quote 6, Box 3).

Provide emotional support. The clinician also needs to provide emotional support, alongside information, for the attendees and assess if heightened emotions are affecting the understanding of the diagnosis. Quote 7, Box 3, highlights how emotional reactions need support and consideration to prevent difficulties in comprehension.

Box 3: Quotes relating to overarching theme: Overt tasks

Quote 1
Louise (Clinician): relaying a diagnosis of dementia is not about relaying the diagnosis of a dementia, it's about the relationship that you've built up with them.

Quote 2
Alan (Companion): Well you need to know the facts and you need to know the prognosis and you need to know where we're going.
Edna (Patient): But people vary don't they and not, there are people who don't really want to know the facts, I suppose.
Alan: There are, yes.
Edna: I just think if you make it clear that you do want to know exactly what's happening then that should be respected and it has been.

Quote 3
Interviewer: Was anything particularly helpful?
Ann (Companion): she [clinician – Louise] had said to Michael quite early on, this is a possible dementia which gave us the chance then to talk. I think the directness of using the correct vocabulary has actually been very useful to us.

Quote 4
Interviewer: How do you judge the information to give?
Pat (Clinician): Partly from the assessment, so you kind of know what people's social and education background is, what experience of dementia they have so if, for people who have no exposure to dementia before it is about being more basic with the information … whereas people who have got more exposure/experience whether that's in healthcare themselves or family background, its taking that and building on it a bit really.

Quote 5
Interviewer: How did they [clinician] adapt so your Mum could understand?
Kate (Companion): Instead of using the medical jargon, she [clinician] tended to be the way my mum understood things. So she changed it into terms for mum to understand, so it was nice.

Quote 6
Edna (Patient): *[describing what happened in their appointment]* when she [clinician - Louise] asked questions, he [companion – Alan] answered her but she then turned back to me. I was always the main focus.

Quote 7
Interviewer: What is your perception of diagnostic delivery of dementia?
Susan (Clinician): […] Sometimes some people are in tears, so it's giving them a bit of comfort, bit of reassurance … it's very hard when somebody is crying because sometimes the more information you give them it's just an overload.

Covert tasks[33]

Alongside the overt tasks the clinician is also required to manage several tasks that recipients are less likely to be aware of to ensure that each person's experience is as good as possible.

Overcoming power imbalance between clinician and patient. Inherently the clinician holds a position of power during the diagnostic delivery as they are in control of how and when the diagnosis is shared. Clinicians need to manage this power imbalance and work towards a collaborative relationship with attendees. When clinicians can collaborate with attendees this can provide a positive experience as described by Ann (companion) in Quote 1, Box 4.

Continual adaptation. There is no one way to deliver a diagnosis. As such, in every appointment the clinician must constantly monitor and adapt to the attendees. In Quote 2, Box 4, Louise highlights how this adaptation requires effort and care. Supporting Louise's reflections, in Quote 3, Box 4, Ann (companion) describes positive experiences of how Louise adapted and delivered the news to her husband.

Awareness and management of dynamics. Many patients attend with a significant other, such as a family member or close friend. This can provide an important source of support to the patient, highlighted by Quote 4, Box 4. However, the clinician is required to actively manage the triadic relationship especially when there are differences between attendees in expressing concerns as discussed in Quotes 5 and 6, Box 4.

[33] Full discussion of theme available in extended paper section 3.2.4

Box 4: Quotes relating to overarching theme: Covert tasks

Quote 1
Ann (Companion): *[reflecting on the positive elements of their experience]* it was the collaboration. It was the working with us that seems to have come over so strongly, actually.

Quote 2
Louise (Clinician): *[reflecting on adapting her delivery of a diagnosis to each person]* I put a lot of energy into that, making it personal because you cannot predict, you cannot say, "This is the way to relay a diagnosis." You've got to check how you need to relay it. There are certain things you have to say. You have to say the words, don't you? But it's about how you reach that point and that's the personal bit.

Quote 3
Interviewer: Do you feel that you had the right about of information?
Ann (Companion): I noticed Louise [Clinician] pulled back the last time we went and she didn't give us any more information because your [Patient - Michael] body language had indicated that you'd had enough and I thought, "Oh, she's got this just right."

Quote 4
Interviewer: How does the carer or family member effect how you manage the appointment?
Pat (Clinician): […] Sometimes I have the service user with the carers in tears, the service user is saying everything will be fine we can manage. Sometimes the other way around in terms of the carer saying we will get through this.

Quote 5
Jennifer (Clinician): *[discussing tensions between attendees]* you're conscious of a family member that could be sat to the side that is saying, "Thank you" and quite grateful and, "We are aware" and giving you all the non-verbal because they don't want to speak in front of the patient.

Quote 6
Susan (Clinician): *[reflecting from her own personal experiences of supporting a family member about how it feels for a companion to divulge information the patient is not aware of]* it's like you're betraying somebody. This person that you've looked up to all your life, who has brought you up and then all of a suddenly you're wanting to betray everything that they're saying.

Tool Development

Many of the themes developed appeared to suggest the development of a tool specifically for use by clinicians. However, we decided on the basis that every diagnostic delivery is between at least two people, to also develop a tool for attendees to use as well. As such, the draft tool included two paper based tools; a service deliverer's tool, and service recipient tool for patients and

companions. Table 9 outlines which themes each tool targets and how the tool attempts to encourage each theme in clinical encounters[34].

The service deliverer's tool contained a description of the tool and the development process. It included ideas on its use, including as a tool to aid reflective practice or supervision and skill development of inexperienced clinicians. A specific section about clinician self-care preceded the main content of the tool that focused on the elements of a good delivery of a diagnosis of dementia. Each element of good delivery was explained and suggestions, developed from the study data, of how to achieve this were included. A section was included to suggest that the tool could be used as and when clinicians felt necessary, rather than a protocol or check list for every appointment.

The service recipient tool included: an information sheet about the service; a notes sheet to record concerns, questions and choices; and a prompt sheet to aid memory in the appointment. We envisaged that the tool would be sent to attendees with their appointment letter. Users of the tool are encouraged to review the information sheet and consider the questions in the notes sheet prior to attending their appointment. The prompt sheet was designed to be utilised during the appointment to aid memory recall. The information sheet contained: an introduction to the tool, an overview of the MAS appointments and assessment process, and information about the possible outcomes of the assessment. Attendees were also encouraged to bring someone with them to their appointment and the need to make choices in the appointment was also highlighted. The notes sheet was developed as a question prompt list with sections relating to current concerns, making choices including about information provision, and a free space to record other important information. Two copies of the notes sheet were included with directions for the patient and companion to complete one each to enable sharing of information or concerns in confidence. The prompt sheet included reminders to ask questions and provided space to record information shared during the appointment.

[34] See extended paper section 3.3 for extra information relating to themes that were unable to be presented here due to space limitations. Table 14 in extended paper (section 3.3) provides an overview of the representation of each theme across both tools.

Table 9 outlines how aspects of the tool specifically derive from the thematic analysis of phase one data.

Table 9: Development of Tools from Phase One Results

Phase One Results		Clinician's guide	Attendee's guide		
	Theme		**Information Guide**	**Notes Sheet**	**Prompt Sheet**
Overt Tasks	Develop a supportive relationship	In general introduction, emphasise importance of a good relationship Section about importance of engagement of attendees and some ideas about how to achieve this			Use the prompt sheet in appointment to remind of any questions and to encourage a two-way conversation
	Consent and Choice	Section about consent covering the importance of consent for a range of decisions and respecting choice. Include reference to the Mental Capacity Act 2005	Inform patients and companions that they will have some decisions to make	Provide examples of decisions and space to record them	
	Develop understanding	Specific section about using terminology including the importance of using the term dementia	Provide information about the Memory Assessment Service and Dementia	Include questions about problems that have been noticed about their memory and provide space to note answers	
		Remind clinicians to seek out patient's and companion's existing understanding and continually check out the development of understanding		Encourage patients and companions to consider the information they would like. Offer a space to record this.	
	Being patient centred	Section relating to the importance of keeping the patient as the focus	Include if two or more people attend, the clinician will still focus on the patient		
	Provide emotional support	Section about provision of emotional support as well as information and diagnostic outcome Encourage clinician to ask people about their feelings and to remain aware of their own emotions	Encourage patients to consider bringing someone to support them in the appointment		

Table 9 continued

Phase One Results Theme		Clinician's guide	Information Guide	Attendee's guide Notes Sheet	Prompt Sheet
Covert Tasks	Power imbalance	Section about engagement, remind clinicians to actively encourage attendees to ask questions, or invite attendees' own thoughts and observations		Encourage the patient and their companion to write any questions or concerns down prior to, and ask in the appointment	Encourage patients and companions to share concerns or questions verbally or in a written format
	Continual adaptation	Section about the importance of adapting practice to each person			
	Dynamics	Emphasise the need to manage complex dynamics actively and sensitively		Include two copies of the notes sheet and prompt that each can be completed in confidence by each attendee	
Navigate Journeys	Clinician's emotions	Highlight the personal impact of diagnostic delivery and the importance of self-care			
	Attendee's emotions	Section about providing emotional support to the attendees.	Information to support attendees to manage fear of unknown prior to appointment		
Overcoming barriers		Highlight to clinicians the personal impact of diagnostic delivery and the importance of self-care Encourage use of reflective practice and supervision Acknowledge the complexity and difficulty of delivering a diagnosis of dementia			

Phase Two

Participants[35]

To preserve anonymity, the participants are described in aggregate terms. All 13 participants were White British and three were male. Six service recipients contributed, including two people with diagnoses of dementia. Service recipients represented two MAS clinic locations, one inner city and one rural. In the seven participants who were service deliverers a range of roles were represented including service managers, specialist nurses, and support workers, all of who have direct experience of the MAS appointments where diagnoses are delivered. Two service deliverers represented two specific MAS clinic locations with the remaining four providing clinical time across all seven MAS clinics managed by the hosting NHS Trust. Four participants had previously participated in phase one. These were two service deliverers, one patient and one companion.

Themes[36]

Benefits[37]

For both tools, participants were positive. Service recipients indicated that they would have liked to have used the tool when receiving their diagnosis. A main benefit of the tool was the provision of information and opportunity to consider the appointment prior to attending.

Victoria (Service Recipient): I think it would be a very good tool because it would give you some guidance of what you're thinking and what you want to say but because you're so naïve you don't know what you want to say or what you want to think.

Usage[38]

Service managers felt that the content of both tools was in keeping with the hosting service's ethos and reflected what they felt would be good practice.

[35] A complete account of achieved recruitment and sample characteristics are in extended paper section 3.1
[36] Extended paper section 3.4
[37] For further details of Benefits see extended paper section 3.4.1
[38] Further details of Usage see extended paper section 3.4.2

Participants also acknowledged that the clinician's tool could be experienced as supportive of new and experienced clinicians.

Pat (Service Deliverer): especially when I was starting out, getting used to that delivery of the diagnosis and how to do it sensitively, some of that is just going to be by practice but having those pointers to start with would at least would point you in the right direction.

Hannah (Service Deliverer): It would also make you feel a bit justified if you felt just stressed or under pressure and may think actually, "Yeah look at all of these things that we have to balance, actually it is a lot that we do" and make you realise how much you are taking on when you do that.

Barriers to uptake[39]

A possible barrier for uptake of the clinician's tool was how acceptable a good practice guide would be to experienced clinicians. Some participants were concerned that people may feel patronised or fail to engage with the tool as it would be unnecessary. However, other people felt that if the tool was introduced well that this could be overcome.

Pat (Service Deliverer): It depends how it was presented. If it was in a "We've distilled down what makes a good diagnosis, what people think's a good diagnosis and here are some discussion points and things to maybe think about your own practice" then I think that would get a bit more attention than just another, "Here is something you need to read and do."

The main barriers identified by service deliverers for the service recipient's tool were the potential volume of paperwork sent out to patients, and the possible impact of the prompt sheet on appointment time.

Rose (Service Deliverer): although so far what I've read I like, it's how much information do you give people, how much paper do you-, when you're sending out an appointment letter, how much do you send people?

[39] Further details of Barriers see extended paper section 3.4.3

Alterations[40]

One main change was identified; the removal of the prompt sheet from the service recipient's tool and the concepts moved to the service deliverer's tool. This structural change was to reduce the volume of paperwork for service recipients and minimise the potential time impact for service deliverers in the diagnostic appointment. There were some alterations of wording and phrasing, and some additional areas identified for each tool, such as including a section in the service recipient's guide with details of where additional information or support could be accessed. These suggestions have been incorporated into the revised tools. Draft copies of the tools are available on request from the author[41].

Discussion

In response to the lack of best practice guidelines or interventions that could support good practice in the delivery of a diagnosis of dementia, we have developed a prototype tool. It has two elements, one for clinicians and one for people attending appointments, which can be used individually or in conjunction with each other. In feedback received during focused group discussions people felt that the tools could improve the experience of giving and receiving a diagnosis. Both tools were also judged to be supportive of all parties who may be present during a diagnostic delivery. To the best of our knowledge this tool is novel for dementia diagnostic settings[42].

A key strength[43] of this prototype tool is the development process. Other breaking bad news protocols, such as SPIKES (Baile et al., 2000), were not reported to have been developed with the inclusion of the patient's perspective (Ptacek & Eberhardt, 1996) or assessed for acceptability by clinicians who would use the tools. Therefore, by grounding this tool's content and design in the experiences and opinions of both deliverers and recipients, it is arguable

[40] For further consideration of theme 'alterations' see extended paper section 3.4.4. For an overview of the alterations made see section 3.5 and tables 15 and 16.
[41] Available to view in Appendices S and T
[42] Overview of findings, including how the results meet the primary objectives, are presented in extended paper section 4.1
[43] Extended paper section 4.6 further considers the strengths of this study, and section 4.7 considers the impact of the researcher and hosting service, and the scope of the study

that this tool is more likely to promote clinical encounters that are acceptable for clinicians, patients, and companions. This project has also enabled the voices of MAS patients, people with dementia, and their companions to share equal power with an 'expert' view. This goes someway to combat the common occurrence of professionals speaking on behalf of people with dementia that further marginalises and de-values those with dementia (Bartlett & O'Connor, 2010).

Despite the need for good practice guidelines and tools that can encourage better practice, there can be many barriers to their implementation including a lack of time, low priority, and difficulties accessing the research literature (Sadeghi-Bazargani, Tabrizi, & Azami-Aghdash, 2014). A positive of this study was that the focused group discussions highlighted that people held positive attitudes towards the tool. Negative attitudes were also articulated as people felt experienced clinicians may not see the tools as required, added burden of paperwork on attendees, and the prompt sheet may negatively impact on appointment length. In response, these potential barriers have been addressed in the tool's design, which is anticipated to improve the likelihood of the tool becoming adopted in current practice.

In the development of the tool is it possible that due to the low number of each type of participant, the themes developed may not fully represent the whole population. Despite this, themes that were developed are in some extent represented in other research[44]. For example, Lecouturier et al. (2008) previously advocated for an individualised approach to diagnostic delivery, and this was consistent with the study data. Another key concept was the development of understanding over time that is echoed by Byszewski et al. (2007) who emphasised how this approach can help the recipients prepare for the news. The importance of the companion in the diagnostic process and the complexities of triadic communication have been previously described by Laidsaar-Powell et al. (2013) and highlighted in the study themes.

[44] Further consideration of the theoretical understanding is in section 4.2, and a comparison to previous research can be found in extended paper section 4.3

A theme that is possibly unique[45] to this study and tool is the emotional journey of the clinician during diagnostic delivery. In guidelines about breaking bad news the stress of the encounter on the clinician has been noted (e.g. Baile, 2000), and in a review of the literature it was reported that doctors may struggle with emotions such as sorrow, guilt, identification, and feeling a failure (Fallowfield & Jenkins, 2004). However, there has been little focus on emotionally supporting or preparing clinicians for diagnostic delivery. In this study clinicians described how their emotions altered over the course of the diagnostic delivery and the need to remain aware of their own emotions to prevent a negative impact on the recipient. It is arguable that the skilful navigation of one's own emotional journey is a prerequisite for being able to attend to the more traditional essential tasks of a diagnostic delivery of dementia. Alongside this there is an increasing need to emphasise the role of emotions in clinical training and practice. Historically it can be argued that there have been various confusing and contradictory messages about the connection between professionalism and emotion (Shapiro, 2013). However, there is increasing recognition of the need to develop clinicians' emotional awareness and skills in negotiating their own and the attendees' emotions. It is suggested that by mastering these skills clinicians can lead to cohesion with, rather than distancing from, the attendees' emotions (Shapiro, 2013). This may well be especially important when negotiating the often highly emotive disclosure of a diagnosis of dementia.

The main limitation[46] to this study has been the recruitment of participants. Primarily the recruitment strategy has impacted on the views captured. It is possible that people who were ambivalent about their experience of diagnostic delivery would have been reluctant to participate. As such, it is possible that only a selection of important themes relating to good practice have been explored. Therefore, the results of this study and the content of the tools should not be viewed as exhaustive of all areas of good practice. It is evident that the

[45] Other areas unique to this study and extended consideration of the emotional journey are presented in extended paper section 4.4 and areas not included are discussed in section 4.5
[46] See extended paper 4.8 for further discussion of limitations

sampling procedure also failed to incorporate any participants with black and minority ethnic (BME) diversity. Incorporating and embedding the voices of these seldom heard groups is critical to meet the needs of BME communities (NHS Confederation, 2013). As such, this study has not been able to ascertain whether there are any unique differences in the acceptability of diagnostic delivery in these groups, thus representing a gap in this tool's development.

Continued development of excellence in dementia diagnosis requires a concerted effort in the production of good practice guidelines. This project contributes towards this effort and provides an alternative narrative of quality diagnostic delivery, rather than diagnostic quantity or volume. This considered, a major factor of the barriers to implementation of good practice guidelines are difficulties in understanding and navigating the research literature (Sadeghi-Bazargani et al., 2014). As such, care should be taken to continually bring the research field together. This could be via the use of systematic reviews, working groups such as Dementia Workstream of the British Psychological Society Faculty of the Psychology of Older People, or the production of published guidelines by the Department of Health or The National Institute for Health and Care Excellence[47]. Further research[48] is required to understand the feasibility and acceptability of both tools, and if they can promote better or more consistent diagnostic delivery of dementia.

In conclusion, this study has provided an insight into the experience of diagnostic delivery of dementia for clinicians, patients, and companions. By using thematic analysis to explore these experiences we have been able to develop a prototype of a tool that could support an improvement in the experience of the receipt of the diagnostic news, and support clinicians during a challenging task. Encouraging feedback about the tool has indicated the desire to use this tool in clinical practice and that it was likely to encourage good practice. The tool was also adapted following concerns articulated regarding some aspects of the design and this is envisaged to improve the acceptability of

[47] See extended paper section 4.9 for further discussion of clinical implications of this study
[48] Further discussion of future research can be found in extended paper section 4. 10

the tool in clinical practice. Future research is now required to further evaluate the tool and to continue to develop excellence in the clinical practice of diagnostic delivery of dementia.

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Declaration of Conflicting Interests

The Authors declare that there is no conflict of interest.

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Extended Paper

Extended Paper

This extended paper is intended to be considered in conjunction with the journal paper. It will provide additional information across all areas of the journal paper and includes my critical reflections on the research process.

Journal Paper Choice

I have written and prepared the journal paper for submission to Dementia: The International Journal of Social Research and Practice[49]. This journal was selected as it has previously published qualitative research and has a specific interest in research with direct relevance to improving the quality of care for people with dementia. This specific focus of the journal was in keeping with the main research aim of supporting improved practice and therefore appeared to be a good fit. In accordance with the publication style of Dementia, the journal paper is written in the third person. However, the extended paper is written in the first person as this helps demonstrate my accountability and acknowledges my role as an active participant in the research (Holloway & Galvin, 2016).

1.0 Extended Background

This section provides supplementary information to the introduction of the journal paper. It includes an overview of the terms referred to throughout the study and the importance of the encounter where a diagnosis is shared. It also provides detail of the UK dementia diagnostic pathway and a description of the service where the study was sited. Further areas of the difficulties of delivering a diagnosis of dementia are explored and an extended review of the current research literature is provided. A more detailed exploration of ways to support good practice is presented, as well as the rationale for clinical psychology's role. Finally, the primary objectives of the study are provided to serve as an expansion of the overarching aim detailed in the journal paper.

[49] Author guidelines available: https://uk.sagepub.com/en-gb/eur/journal/dementia#submission-guidelines

1.1. Dementia

1.1.1. Overview

The term dementia refers to a cluster of symptoms caused by disease of the brain, which is usually chronic or progressive in nature (World Health Organization, 2016). Symptoms can include disturbance of memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement (World Health Organization, 2016). Etiological subtypes can include, but are not restricted to: Alzheimer's disease, vascular disease, frontotemporal lobar degeneration, and Lewy body disease (American Psychiatric Association, 2013). People with dementia can have complex needs and, especially in the later stages, high levels of dependency and morbidity. Thus, the levels of care that can be required can challenge the skills and capacity of carers and services (National Institute for Health and Care Excellence, 2006). As the condition progresses, people with dementia can present with complex problems including aggressive behaviour, restlessness and wandering, eating problems, incontinence, delusions and hallucinations, and mobility difficulties (National Institute for Health and Care Excellence, 2006). Dementia is also considered a terminal disease, but people may live with their dementia for 7–12 years after diagnosis (Department of Health, 2011).

In this study, I have used the term dementia as this is most commonly used in clinical settings and by the participants of the study, therefore retaining the language most widely understood. However the current version of the Diagnostic and Statistical Manual of Mental Disorders (5th Edition; DSM-V) has adopted the term neurocognitive disorder (American Psychiatric Association, 2013). The reasoning of this alteration was to recognise recent alterations in terminology use in specific etiological subtypes, such as vascular disease that has moved from "Vascular Dementia" towards "Vascular Cognitive Impairment (Ganguli et al., 2011). The term dementia is also a direct derivative of the Latin 'dement', which means out of one's mind, or to be mad or insane. Therefore the change in terminology is also an attempt to move away from using terms that some view as pejorative (Ganguli et al., 2011) and socially stigmatised (Alzheimer's Disease International, 2012).

1.1.2. Prevalence

Dementia is common and increasing in the UK, therefore making this study highly relevant. It is estimated that in 2015 there were about 800,000 people living in the UK with dementia (Department of Health, 2015), and this is forecast to increase to over 1 million by 2025 and over 2 million by 2051 (Alzheimer's Society, 2014b). Dementia most commonly affects older people with 1 in every 14 of the population aged 65 years and over having dementia (Alzheimer's Society, 2014b). Alongside this, after the age of 65 the likelihood of developing dementia approximately doubles every five years (Alzheimer's Society, 2007). There are also over 40,000 people with dementia onset before the age of 65 years in the UK (Alzheimer's Society, 2014b).

1.1.3. Treatment

Currently, and only recommended for some specific types of dementia, there is medication that aims to maintain cognitive functioning, such as acetylcholinesterase inhibitors (National Institute for Health and Care Excellence, 2006). However, as there is no medical cure or treatment that can halt disease progression, the main treatments focus on symptom management to maintain or improve the quality of life of patients and carers (Overshott & Burns, 2005).

1.2. Breaking bad news

1.2.1. Definition

In medical settings, bad news often relates to terminal illness diagnostic delivery (Vandekieft, 2001), but can also be applied to a wider range of issues that includes a diagnosis of dementia (National Council for Hospice and Specialist Palliative Care Services, 2003). In broad terms, bad news can be used to refer to any news that considerably and negatively alters the person's view of their future (Buckman, 1992). Inherent in this conceptualisation is the person's perception of their future both before and after the news has been received. Therefore the impact of any news cannot be understood without an awareness of what the person already knows and expects (Buckman, 1992). An alternative definition extends this concept to also include references to information that communicates either: a feeling of no hope, a threat to a person's mental or

physical wellbeing, a risk to an established lifestyle, or fewer choices in the person's life (Bor, Miller, Goldman, & Scher, 1993). Therefore, the communication of a diagnosis of dementia can be understood within a framework of breaking bad news as it entails the transfer of information about a degenerative and incurable disease.

1.2.2. Aims of breaking bad news

In relation to the delivery of a diagnosis of dementia, the broad aims of breaking the news of the diagnosis are closely related to the rationale for diagnosing. Diagnosing dementia can: provide access to potential treatments, depending upon the dementia subtype; enable an advancement in the process of recognition and adaptation (de Vugt & Verhey, 2013); reduce feelings of uncertainty and anxiety (Dubois et al., 2015); and improve quality of life and relationships (Werner et al., 2013). Furthermore, it is considered a patient's moral and legal right to receive specific diagnoses unless they choose to waive it (Edwin, 2008; Etchells, Sharpe, Burgess, & Singer, 1996; Johnston & Holt, 2006). Therefore, a further aim would be to maintain ethical practice when the diagnostic process has been undertaken.

In a more detailed consideration of the specific aims of each 'breaking bad news' encounter in oncology care, Baile et al. (2000) highlight four specific goals:

1. Gather information to determine the recipient's knowledge, expectations, and readiness to hear the news
2. Provide intelligible information that meets the recipients' needs and wishes
3. Provide support to the recipient to reduce the emotional impact of the news
4. Develop a treatment plan in collaboration with the recipient.

Furthermore, there are specific aims for elements of the breaking bad news encounter that should be avoided. For example, it is acknowledged that bad news can trigger negative emotional responses and these can be worsened by the news being delivered abruptly, insensitively, bluntly or too quickly (Baile &

Parker, 2017). This suggests that *how* someone receives bad news could be experienced as aversive and care must be taken to avoid compounding negative responses, by attending to the manner of delivery.

1.3. Theoretical understanding of breaking bad news

It is argued that medical care, and the breaking bad news encounter, is essentially based on a special form of interpersonal interaction (Roter & Hall, 2006). It is also argued that the purpose of communication in medical encounters is to create good interpersonal relationships, which is a prerequisite for optimal medical care (Ong, de Haes, Hoos, & Lammes, 1995). Medical communications and especially the breaking bad news encounter, have a further specific purpose of information exchange between the clinician, patient, and companion (Roter, Hall, & Katz, 1988). Furthermore, in the breaking bad news encounter the clinician is tasked with communicating a specific piece of information and supporting the recipient(s) to comprehend, understand and begin to adjust to the information. This conceptualisation suggests that the breaking bad news encounter can be understood through application of known processes involved in communication and interpersonal relationships, information matching, and learning. Alongside this, it is important to consider the breaking bad news encounter within the context of the person's journey from initial symptoms to adjustment to their illness - and how receiving news that is likely to affect the recipient's emotions impacts on their ability to attend to that news. These areas will be explored further below.

1.3.1. Communication and interpersonal relationships

Communication is arguably one of the most essential components of all medical encounters (Roter & Hall, 2006; Zolnierek & Dimatteo, 2009), therefore there is also a need for high quality communication of diagnostic information. Improved empathic communication of bad news has been linked to a reduction in stress and anxiety for patients (Fogarty, Curbow, Wingard, McDonnell, & Somerfield, 1999) and improvement in levels of hopefulness (Sardell & Trierweiler, 1993). There are also several meta-analytic studies which have linked improvements in communication with outcomes such as enhanced patient satisfaction (Williams, Weinman, & Dale, 1998), improved adherence to treatment (Zolnierek &

Dimatteo, 2009), reduction in symptoms (Stewart, 1995), and a decrease in anxiety (Stewart, 1995).

Patient focused care is highlighted as one of the key values in the NHS Constitution (Department of Health, 2013). Patient focused care places particular emphasis on the personal relationship between the clinician and patient, which is based upon the psychotherapeutic concept of therapeutic alliance (Mead & Bower, 2000). Rogers (1957) defined the core conditions of the therapeutic alliance as the clinician having empathy[50], warmth and genuineness with, and towards, their patient. The importance of the patient-clinician relationship has been demonstrated through evidence that the quality of the relationship is associated with patient satisfaction, psychological distress and psychosocial adjustment (Lelorain, Brédart, Dolbeault, & Sultan, 2012). Therefore, a clinician's empathic understanding of their patient is fundamental to achieve patient focused care, and (by logical extension) is critical when delivering a diagnosis of dementia.

However, the mechanisms of how improved care and communication influence these outcomes it is not fully understood. A preliminary model of clinician-patient communication was provided by Ong et al. (1995) that highlighted the importance of background variables, such as clinician-patient relationship and disease characteristics, and actual content of communication, including instrumental and affective communication behaviour, for patient outcomes. Despite this preliminary model, the range of influencing variables on outcomes has only allowed for broad hypotheses that capture both direct and indirect pathways, both of which are modified by the relevant intrinsic and extrinsic contexts of the patient (see; Street et al., 2009). Although this is clearly an area for future research to explore, for this study it is sufficient to recognise the importance on patient outcomes of aiming for high quality diagnostic delivery.

[50] empathy is defined as 'ability to understand the patient's situation, perspective and feelings; to communicate that understanding and check its accuracy; and to act on that understanding with the patient in a helpful (therapeutic) way' (Mercer, Maxwell, Heaney, & Watt, 2004)

1.3.2. Information matching

Kiesler and Auerbach (2006) stipulate that any attempt to be truly patient-focused requires that patient's preferences for involvement are assessed prior to the interaction and then for the clinician to adapt their style accordingly. Preferences relating to a diagnostic delivery focus upon patients' preferences for the amount and kind of information and clinician's style of communication (Street, Elwyn, & Epstein, 2012). Preliminary studies have identified that an increase of patient-clinician communication matching can lead to patients being more satisfied with the clinical encounter (Campbell, Auerbach, & Kiesler, 2007; Krupat, Bell, Kravitz, Thom, & Azari, 2001). This suggests that there are important patient outcomes related to the process of eliciting patient preferences prior to clinical encounters, and then matching them.

However, focusing on only the transfer of information in the diagnostic delivery of dementia risks forgetting the importance of the clinician – patient – companion relationship and the frequency of appointments where a companion accompanies the patient. As such, information matching and protocols that focus on the transfer of information rather than on the development of the relationship are not sufficient. Furthermore, it is important to note that many protocols have been developed from clinicians' own perceptions of good practice rather than empirical evidence. There is also limited evaluative research on the effectiveness of improving quality of communication in clinical practice (Wittenberg-Lyles, Goldsmith, Sanchez-Reilly, & Ragan, 2008). Therefore, research needs to focus on empirically based adaptations of existing protocols or the development of alternatives that can capture the intricacies and challenges of the communication of a diagnosis of dementia. These should draw on existing knowledge of the components of a good delivery of a diagnosis of dementia, and consider embedding the experiences of patients and their companions into research to overcome the dominance of the expert voice in the current literature.

1.3.3. Learning

Arguably breaking bad news encounters involve the clinician imparting knowledge of the patient's diagnosis to those present in the encounter. This

transfer of information or knowledge could, at a basic level, place the clinician in the role of educator or teacher to the patient.

One of the influential theories on formal and informal educational settings has been constructivism, which theorises how learning occurs. Largely associated with the work of Piaget, constructivism theorises how information from the environment and ideas from the individual interact to produce internalised structures within the learner (Wadsworth, 1996). The theory of assimilation proposes that new information can be understood by applying pre-existing information held in existing frameworks of knowledge. This requires minimal effort as the learner is able to incorporate the new information without any adaptation to the framework (Piaget, 1977). In contrast, accommodation is theorised to occur when the new information cannot be incorporated and requires existing frameworks to change, or new frameworks to develop. Although the original theories do not consider the emotional impact of either process, it is possible that accommodation of information such as a diagnosis of dementia may be more commonly associated with negative reactions to the news. In contrast, if the person receiving the news can incorporate the diagnosis into existing frameworks, they may be less likely to experience negative emotional reactions. This could be explained in more depth by the adjustment to illness literature (see section 1.3.4 for further discussion).

In addition to providing a theoretical understanding of how people may learn about their diagnosis, constructivism can develop understanding about how to present the information that forms the bad news. Here the principle of the zone of proximal development (Vygotsky, 1978) is useful in guiding clinicians in the way they present the diagnostic information. This principle describes a conceptual distance between what the learner (or recipient of the news) is able to understand via their own independent problem solving, and the level of learning that is possible for that person with support from more capable peers (e.g. clinician and/or companion) (Vygotsky, 1978). For clinicians in the breaking bad news encounter it is important to remain within this conceptual distance. Providing information that is beyond the person's zone of proximal development could risk overwhelming them or leading to misunderstanding.

However, providing information at a level that is similar to, or below, the learner's independent ability is unlikely to help them develop an increased understanding of their symptoms.

1.3.4. Adjustment to illness

Adjustment to illness has been defined in several ways. It is commonly defined by the outcomes associated with positive adjustment such as good quality of life, well-being, positive affect, life satisfaction and social role functioning (Sharpe & Curran, 2006). Considering the underlying cognitive processes behind these observable outcomes, it has been suggested that adjustment to illness involves regulation of self-identity to maintain a positive self and world view in light of the illness (Brownlee, Leventhal, & Leventhal, 2000). It is argued that the difficulty of the process of adjustment is influenced by the severity or consequences of the illness, individual characteristics, previous experiences of the illness, and whether helpful representations of the illness are forthcoming (Sharpe & Curran, 2006). This suggests that adjustment to a diagnosis of dementia may be a challenging task as it is a life-limiting, incurable, socially stigmatised illness. Therefore, it may be harder than some illnesses to draw upon positive illness representations.

The process of adjustment to illness can help explore why simply communicating the diagnosis does not achieve the aim of developing understanding. For example, Robinson, Clare, and Evans (2005) found that couples experienced multiple positive and negative effects of receiving a diagnosis, however the diagnostic news was not found to increase their understanding and acceptance of their circumstances. Pratt and Wilkinson's (2003) psychosocial model of understanding diagnosis disclosure from the perspective of the person with dementia indicates possible mediating variables between receiving the news and understanding and acceptance. This model suggests the variation in reaction depends upon the degree of both the person with dementia's desire or cognitive ability to know the diagnosis and the person's social context (Pratt & Wilkinson, 2003). The model represents these two concepts across two intersecting axes. The intersection of the concepts then creates quadrants that categorise reactions to the diagnostic news.

The first axis of the model represents the degree of the person's desire or ability to know the diagnosis and is linked to the concept of insight or awareness (Pratt & Wilkinson, 2003). This axis is based on observations of people with dementia where there appears to an inability to acknowledge their cognitive and functional impairments (Campbell et al., 2008). In a detailed exploration of awareness Clare (2003) proposed an ongoing reiterative cycle of developing awareness of changes with five interrelated processes of registering, reacting, explaining, experiencing and adjusting. Pratt and Wilkinson (2003) do not include these five processes, they instead capture desire or ability on a continuum from low to high; where high indicates that someone both wants to know and is able to understand their diagnosis. The second axis of Pratt and Wilkinson's (2003) model represents the contextual support received by the individual and is included to demonstrate that the person's context can be as active as psychological factors. Here the person's social context is understood as a continuum of negative to positive contextual support for the person with dementia.

The model explains the reactions to the diagnosis by intersecting the axes of the two variables to form four separate quadrants: detachment (categorised as low ability and negative social context); distress (high ability and negative social context); maximising coping strategies (high ability and positive social context); and denial and decline (low ability and positive social context) (Pratt & Wilkinson, 2003). This suggests that when and how people adjust to dementia is likely to vary across individuals. Furthermore, people may have already begun the process of adjustment prior to receiving the diagnostic news and may be able to more readily assimilate the diagnostic information (see section 1.3.3). For others, where they have not been able to begin their adjustment process, the diagnosis may present new or unwelcome news. In this situation people may have incorporate the diagnostic news by the more effortful process of accommodation that requires change or development of new frameworks of knowledge (see section 1.3.3). This highlights an area of complexity of breaking bad news where clinicians need to understand adjustment to dementia and

adapt to people in different stages to provide the best possible diagnostic encounter.

1.3.5. Emotions and processing the news

Although the way bad news is discussed can impact on the experience and recall of the information, the content of the bad news can affect how able people are to process all the information provided in the encounter. For example, people who received a cancer diagnosis reported feeling so stunned or shocked by the news that the rest of the conversation was lost (Ong et al., 1995). Furthermore, when provided with an audio recording to facilitate review of the encounter the participants reported it to be helpful in supporting understanding, comprehension of medical terms, compensating for loss of information due to the emotions experienced in the encounter, and preventing the information from unintentional distortion in memory (Hogbin & Fallowfield, 1989). This suggests that reviewing the diagnostic disclosure at a later time when emotional reactions are reduced, may aid understanding and information retention. This observation can be understood by considering in general how emotions affect memory.

In general, memories with emotional content tend to be vivid, lasting and selective, with good retention of the central features of the emotional event and poorer memory of peripheral features (Levine & Edelstein, 2009). It is theorised that this emotional narrowing is attributable to the effects of anxiety on cognition in emotionally arousing events. Attentional control theory (Eysenck, Derakshan, Santos, & Calvo, 2007) suggests that anxiety impairs attempts to attend to goal-directed information and instead increases attention for threat-related stimuli. In the bad news situation, diagnostic news could be a threat-related stimulus as, by definition, the news has the potential to alter considerably and negatively the person's view of their future. Here attentional control theory could explain why people may struggle to attend to information they may have planned to discuss, and instead focus upon the diagnostic news. However, it is also observed that for some people peripheral features of emotional events are retained, and for others highly important emotional information is forgotten. This suggests that attentional control theory may not fully explain the effect of emotion on information processing.

Goal-relevance theory (Levine & Edelstein, 2009) may advance understanding. This suggests that people's attention is both more easily captured and maintained by information that is relevant to their current goals. Therefore, information that is goal relevant gains more attention and memory rehearsal, thus promoting improved memory retention. As the goals that are activated at any one time are associated with the person's current emotions, these alter as emotional states change and differ from person to person and situation to situation. Furthermore, some events, such as receiving a diagnosis, may be experienced as emotionally overwhelming and the person's goal may change from developing an understanding of the event to managing the emotional response (Levine & Edelstein, 2009). Taken together, attentional control theory and goal-relevance theory appear to be able to offer an insight into the processes that could affect people's ability to retain information in the breaking bad news encounter.

1.4. Breaking bad news in other healthcare areas

Breaking bad news has been considered in other healthcare areas apart from dementia. A large proportion of the literature has focused on oncology and could be considered to have provided foundations for understanding the importance of the breaking bad news encounter. An overview is provided by Baile and Parker (2017) who suggest best practice for breaking bad news is 'good' communication that includes person centred communication and managing dyadic communication. Elaborating on 'good', they describe this to be communicating in ways that address the informational needs of the patient, as well as providing emotional support. They suggest that this is more likely to enable the development of trust, hope, respect, and willingness to collaborate with the clinician to achieve the best outcomes (Baile & Parker, 2017). Notwithstanding the face validity of recommendations developed in oncology, professionals have been calling for training about breaking bad news to extend to other healthcare areas (Hanratty et al., 2012). Despite this, caution is required as dementia diagnostic delivery has features distinct from diagnostic delivery in oncology settings. These include the requirement to consider how to adapt communication to people with cognitive changes and different

communication needs, and the increasing importance of the companion in the diagnostic encounter.

Due to these differentiating features, the literature from the fields of paediatric care and intellectual disabilities has increased relevance and potential transferability. Paediatric care could be considered comparable to dementia diagnostic disclosure as the child is usually embedded within a family or carer network that, like dementia diagnostic delivery, increases the importance of the companion. Despite this, many of the practice recommendations are focused on how to communicate news about the child to the parents, rather than to the child (Harrison & Walling, 2010). In this situation, it could be argued that these interactions are related more closely to oncology settings. Communicating bad news directly to the child is often only considered in relation to bereavement and supporting a child with a death of a parent or carer. Recommendations from this context that could be relevant to dementia diagnosis delivery include considering checking what the person knows (about the news to be broken), using truthful words, and explaining the information in chunks (Child Bereavement UK, 2011).

Breaking bad news to people with intellectual disabilities is heavily influenced by Tuffrey-Wijne (2013), and Tuffrey-Wijne and Watchman (2015). The principles outlined are based on the aims of building a foundation of knowledge, considering the person's understanding, identifying the support required, and supporting the people around the person with intellectual disabilities. The authors highlight how bad news is broken as a process may require the support of people important to the person with intellectual disabilities, rather than an expert in the area of news (e.g.: a medical professional for diagnostic news). This is based on maximising the person with an intellectual disability's capacity to communicate (i.e. with someone highly skilled and familiar with that individual's own communication), understand, and process the information. It is also acknowledged that understanding of bad news may take an undefined time and for some people full understanding may never be achieved for some types of news. In these situations the aim of communicating the bad news is finding an explanation within that person's own understanding (Tuffrey-Wijne, 2013).

Although elements of the literature from paediatrics and intellectual disabilities are relevant to dementia diagnostic disclosure, such as chunking information and adapting communication to the person, a person with dementia is experiencing skill loss rather than a lifelong disability or comprehension impairments linked to developmental stage. This suggests that an individual with dementia may still be able to access pre-morbid skills, concepts, and understanding necessary to comprehend the diagnostic news. If a dementia diagnosis was delivered only using recommendations from paediatrics or intellectual disability fields, people may experience feeling patronised and clinicians risk underestimating people's informational needs. This highlights the need for specific and careful consideration of breaking bad news in dementia care settings.

1.4.1. Breaking bad news protocols

Due to the evidence of the impact of good quality communication there has been a focus on developing and maintaining this skill in clinicians. Protocols have been developed that guide clinicians in bad news delivery, see Table 10 for overview. These include the SPIKES model (Baile et al., 2000), BREAKS Protocol (Narayanan et al., 2010) and the ABCDE mnemonic (Rabow & McPhee, 1999). Two literature reviews have examined the commonalities across 43 published articles with existing recommendations (Ptacek & Eberhardt, 1996), and between 14 published protocols (Ahmady, Sabounchi, Mirmohammadsadeghi, & Rezaei, 2014) for breaking bad news. The commonalities were presented in three main categories in both reviews. These were the setting of the interaction or the 'when', the delivery of the information; the 'what', and arrangement of the information or the 'how'. Specific elements of these three areas included: preparing the environment; identifying most appropriate people to be present at the disclosure; finding out what the recipient already knows; the use of clear language; giving empathic responses; and delivering the news at the recipient's pace.

Despite the best efforts of these protocols to support improved communication they are based on flawed assumptions that limit their clinical application. Initially

the protocols suggest that a clinician can plan the delivery of bad news. It has been argued that the definition of bad news is based on the person's perception rather than the clinician's judgement of what information is bad. Planning an encounter could lead clinicians to focus only on information they believe to be the most momentous and neglect information they assume trivial (Eggly et al., 2006). Alongside this, the protocols also appear to conceptualise bad news as a single piece of information, usually a diagnosis, imparted on a single occasion. However, observations of bad news interactions suggests that the diagnostic information is often followed by topics such as prognosis, treatment, and changing care or support needs, all of which could be considered as bad news (Eggly et al., 2006). Diagnostic delivery can be better conceptualised as a process where a variety of information is processed and space allowed for the possibility of repeated disclosure and question asking, if required (Werner et al., 2013). These assumptions that bad news delivery can be a planned, single event, can limit their usability in clinical settings.

A further consideration of the utility of the protocols is the areas they exclude. For example all the above mentioned protocols are based on dyadic interactions and exclude any guidance on triadic interactions (Eggly et al., 2006). Clearly this limits their applicability to dementia diagnostic settings and it is proposed that direct application of protocols developed for dyadic consultations would not capture or support the complex processes present, and clinical tasks required, within the dementia care triad in memory assessment services. Finally, most breaking bad news protocols have been written specifically from the deliverer's perspective with little or no contribution of the recipient's experience (Ptacek & Eberhardt, 1996). This limits the validity of existing protocols as they have the potential to overlook elements of the diagnostic delivery that are particularly important to recipients, rather than clinicians.

An additional criticism of the linear protocols outlined above is the lack of acknowledgement of adaptability in the clinician's approach. The sequential approach suggested arguably prevents, or limits, the opportunity for a clinician to truly adapt to the needs of the patient as they arise (Villagran et al., 2010).

One approach that could be drawn upon to improve adaptability is the attempt by clinicians to deliver medical and diagnostic information in line with patient preferences.

Table 10: Overview of breaking bad news protocols

Title & Authors	Overview	Strengths	Limitations
SPIKES Original book: (Buckman, 1992) Paper with model: (Baile et al., 2000),	Guideline for breaking bad news to patients about their illnesses: S – setting up the interview P – assessing the patient's perception I – obtaining the patient's invitation K – giving knowledge and information to the patient E – addressing the patient's emotions with empathic responses S – strategy and summary	• Suggests could be positive to include significant others. • Stage 'I' highlights patients have the right to decline to receive their diagnosis	• Developed by clinicians based on their own practices not via research • Process stated to be a series of steps to move through in a stepwise plan, encounters may need to move between the phases • Communication focused on the dyad of clinician-patient
BREAKS (Narayanan et al., 2010)	A six-stage protocol for systematic and easy communication strategy for breaking bad news: B – background (preparing) R – rapport E – exploring [what the patient already knows] A – announce [the news] K – kindling (deal with emotions and correct misunderstanding) S – summarise [the session]	• Inclusion of exploring what the person already knows is helpful	• Considerable overlap with previously developed protocols e.g. SPIKES and ABCDE. This could impact on BREAKS' contribution, and may offer limited incremental validity beyond existing frameworks. • Mnemonic letters are not fully understandable without some extra context. • Dyadic communication, no consideration of companions in encounters

Table 10: continued

Title & authors	Overview	Strengths	Limitations
ABCDE (Rabow & McPhee, 1999)	Techniques for delivering bad news well: A – advance preparation B – build a therapeutic environment/relationship C – communicate well D – deal with patient and family reactions E – encourage and validate emotions (reflect emotions)	• Claimed that the ABCDE framework was developed via review of the literature • Prompts to arrange for the presence of support for the patient	• Literature review claim is without references within the paper so not substantiated • Lacks consideration of communication beyond the dyad
How to break bad news to people with intellectual disabilities (Tuffrey-Wijne, 2013)	Central feature: Building a foundation of knowledge Features around this: Understanding – how or if the person can understand the news People – including everyone with significant involvement Support – for the person and those around the person	• Based on research with 200 people over seven years. • Section that considers the person's ability to understand the information could be relevant to dementia care settings.	• May risk patronising people with dementia as they are experiencing skill loss rather than life-long intellectual disability
Breaking bad news to children – information for staff (Child Bereavement UK, 2011)	Guideline for delivering news about the death of a family member to children. Key points include: When, Who, Where, Check what the child knows, use truthful words, Repeat information Consider developmental age as effecting understanding of death Discuss feelings	• Considers developmental stages and links to the child's concept of death and dying – could mirror the concepts of insight or awareness of disability in dementia settings	• Brief and only focuses on bereavement. May not apply to diagnostic information

1.5. Key terms

Within this study a range of people or terms are referred to. Table 11, provides an overview of the different roles or terms used. Within this study the product that is being developed is referred to as a tool. This term has been selected following consideration of the definitions of a tool, an intervention, and a guideline, which are discussed below.

Table 11: Definition of roles or terms

Term	Definition
Memory assessment service (MAS)	A specific service model developed to provide assessment and diagnosis of memory problems in the NHS, which includes dementia.
Patient	A person under the care of MAS, referred for an assessment of cognitive functioning; or who has recently received a diagnosis of dementia
Person with dementia (PWD)	Someone who has a diagnosis of dementia but who is not currently under MAS care.
Companion	The person (or people) who accompany the patient or PWD
Clinician	A healthcare professional including physician, or doctor. Selected because bad news is often delivered by specialist nurses in MAS settings rather than doctors.
MAS clinician	Any healthcare professional currently involved in the delivery of the MAS service. This includes specialist nurses, clinical psychologists, consultant psychiatrists.
Service deliverer	Any person involved in a service as a professional, which delivers dementia diagnoses or supports people who have a diagnosis of dementia
Service recipient	Any person, including patients and companions, who access any service or services for people with suspected or formally diagnosed dementia.
Attendees	Any person, including patients and companions, who attend an appointment where a diagnosis of dementia is delivered.

An intervention in a clinical setting has been defined in a range of ways. The broadest of definitions states that an intervention is anything that has an intention to change the course of events for a person, which could include a range of items and actions from surgical procedures to providing information leaflets (Segen, 1992). In public health, interventions are specified as planned actions that aim to prevent or reduce particular health problems (Lorenc, Oliver, Pattenden, & Doi, 2014). Both these definitions suggest that for something to be classed as an intervention it should contain a predefined intention to actively alter an element of a particular patient's experience. The output of this research is anticipated to remain within provisional or prototype development phases. Therefore, referring to the product as an intervention appears to be premature at this current stage. However, it is possible that with future development and research that the product developed could be utilised within an intervention to alter how diagnostic delivery is undertaken.

Clinical guidelines have been defined as statements that include recommendations intended to enhance patient care, which are based on systematic reviews of evidence (Francke, Smit, de Veer, Mistiaen, & Committee, 2008). Furthermore, the National Institute for Health and Care Excellence (NICE) state that guidelines change the process of healthcare and can be used to: assess clinical practice against; train clinicians; support patients to make informed decisions; and improve communication between patients and clinicians (NICE, 2012). Again, as this current study is focusing on the initial stages of development it would be premature to consider any output as a clinical guideline.

A more appropriate term for the product likely to be developed by this study is a tool. A tool has been defined as any resource that is designed to help a clinician improve their competence, knowledge or skills (Venes, 2017). More specifically a clinical tool has been described as an instrument, such as a survey or checklist, that helps users accomplish a specific task (Agency for Healthcare

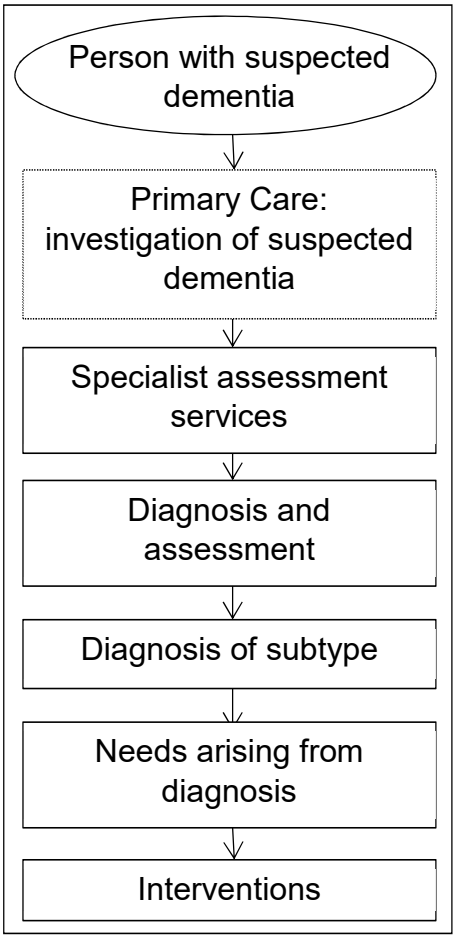
Research and Quality, 2016). These descriptions of a tool provide a narrower scope that is in keeping with the aims of this study and will be used to refer to the product.

1.6. Dementia Diagnosis

1.6.1. UK care pathway

In 2009 the UK government set out an aim for the development of specially commissioned services to take responsibility for the diagnosis of mild and moderate dementia (Department of Health, 2009). The aim was to increase the number of people receiving a diagnosis of dementia, and to also increase access to diagnosis as early as possible in the disease course (Department of Health, 2009). This has resulted in the development of specific services referred to as memory assessment services. As defined by the Royal College of Psychiatrists (Royal College of Psychiatrists, 2015) “A memory clinic/service is defined as a multidisciplinary team (either NHS or private) that assesses and diagnoses dementia, and may provide psychosocial interventions for dementia. This can include Community Mental Health Teams for Older People.” (p10). These services are accessed by those people for whom a GP identifies have worrisome symptoms and refers on to the specialist service for definitive diagnosis (Department of Health, 2011). As such, the current care pathway for dementia diagnosis (NICE, 2015) recommends an initial basic memory screen in primary care and then referral to specialist assessment services for comprehensive assessment and diagnosis (see Figure 3 for care pathway). As the guidelines do not specify how the specialist memory assessment services should be designed, there is large variations both between NHS trusts and, on occasion, within NHS trusts (Royal College of Psychiatrists, 2016). Therefore, an overview of the specific hosting MAS is provided below.

Figure 3: Dementia diagnostic pathway



1.6.2. Hosting MAS service design

The study was located with a single NHS Trust that managed seven MAS clinic sites, provided as a specialist service in dementia diagnosis assessment and communication. The services were accessed by patients via a GP referral, and patients were then invited to a 60-minute assessment led by a specialist nurse. In most cases, patients were then required to have a brain scan and additional tests accessed in outpatient hospital settings, before attending a 30-minute diagnostic appointment. The diagnostic decision would be made by a specialist consultant psychiatrist, but would be communicated by the specialist nurse. A follow-up appointment would also be offered to patients and their companions. At the time of the study in the hosting Trust and across the seven MAS sites there were approximately 12 weeks between a patient's initial assessment and their diagnostic delivery appointment. Patients were then followed up in clinic

four to eight weeks post diagnostic appointment. Wherever possible the appointments were with the same specialist nurse.

This service encouraged people to bring with them a family member or close friend to support them during their appointments. The service also had access to funding that enabled a support worker from the Alzheimer's Society to be available at all diagnostic appointments across all MAS site locations. The service aimed to be able to provide this extra support in a separate room after the diagnostic appointment. However, accommodation differences across the geographical area sometimes prevented this in certain MAS clinics and resulted in the support worker being present in the same room as the MAS clinician.

1.7. Difficulties when delivering a dementia diagnosis

1.7.1. Ethical dilemma – To tell or not to tell

Much of the research effort around the year 2000 focused on the dilemma of whether a diagnosis of dementia should be disclosed by the clinician. Whilst many were advocating that a diagnosis should be shared as this respects the patient's autonomy, some also viewed the diagnosis as potentially harmful to the patient as it was assumed to lead to the possibility of depression, anxiety, and suicide (Bamford et al., 2004; Carpenter & Dave, 2004). Therefore, the diagnosing clinician was faced with an ethical dilemma of how to balance the need to be truthful, yet do no harm (Maguire, 2002). Compounding this dilemma, it has also been suggested that due to the cognitive effects of dementia the clinician must regularly assess the patient's mental capacity (Cornett & Hall, 2008). Following this clinicians should then decide if patients whose mental capacity is compromised would benefit from receiving a diagnosis, as for it to be meaningful, the patient must have the capacity to comprehend and process this information (Cornett & Hall, 2008). Clearly these factors pose a significant ethical dilemma for the diagnosing clinician.

A now historical approach adopted to resolve this dilemma was for the diagnosing clinician to weigh up the potential benefits and risks of diagnostic disclosure and then decide if it was appropriate to disclose. However, this paternalistic approach has been heavily criticised for denying the patient their

moral and legal right to receive a specific diagnosis unless they choose to waive it (Fisk et al., 2007). The traditional paternalistic stance had also been heavily criticised in other medical settings (Peters, 1994). As such, medical encounters have shifted towards a collaborative approach of patient-centred care aimed to promote patient autonomy (Kiesler & Auerbach, 2006). Although it was somewhat delayed, this move has started to be mirrored for dementia diagnoses. Research has begun to highlight that patients and caregivers wished to have the news disclosed (for a systematic review of this literature see; Bamford et al., 2004). Alongside this researchers were recommending the need to disclose any diagnosis to the patient and family or caregiver in a way that is consistent with the patient's wishes (e.g. Fisk et al., 2007). These factors have also been reflected in clinical guidelines. For example, within the European Federation of Neurological Societies guidelines for the diagnosis and management of Alzheimer's Disease it is recommended to disclose the diagnosis, but to ensure that this is tailored to the individual (Hort et al., 2010).

This movement away from the ethical dilemma and towards the focus of how to deliver a diagnosis suggests that, at a conceptual level, the dilemma appears to be somewhat resolved (Werner et al., 2013). However, it is evident that there remains variation in clinical practice with a study showing only 49% of patients had been informed of their diagnosis (Holroyd et al., 2002), and a report showing that 60% of community mental health teams included did not always disclose a diagnosis to the patient (National Audit Office, 2007). Alongside this there is a lack of intervention studies aimed at improving the diagnostic disclosure in dementia (Lecouturier et al., 2008). Therefore, it is imperative that research focuses on how to support clinicians in diagnostic delivery to improve practice and potentially also improve patient outcomes.

1.7.2. Effects of Dementia

As outlined in section 1.1.1, symptoms of dementia can include disturbance of memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement (World Health Organization, 2016). These symptoms have the potential to impact upon the processes involved in receiving a diagnosis of dementia discussed in section 1.3. For example, if a person was

experiencing difficulties remembering information due to the process of dementia it is possible that they have difficulties acknowledging or appreciating their cognitive and functional impairments and experience either detachment or denial and decline (Pratt & Wilkinson, 2003), as well as the diagnostic information being difficult to remember. This forms part of the rationale for the MAS clinic to recommend that patients bring a companion with them to all appointments. In such instances, the companion may be relied upon as an informant of the difficulties to guide accurate assessment and to support the person, and those around the person, to understand and retain the diagnostic information. Despite this, many people who present in MAS services are in the earlier stages of the disease course, so any impairments may be able to be overcome by adapting information via chunking, providing written information, and with support from companions or other family members.

Furthermore, different etiological subtypes of dementia have different cognitive profiles that may have specific effects. This can be demonstrated by comparing the two most prevalent subtypes, Alzheimer's Disease and vascular dementia. Specific to the cognitive profile of Alzheimer's Disease are: more consistent impairments in immediate and delayed memory, even for structured information and when information is cued (Green, 2000); language deficit (Woodford & George, 2007); and impairment in recognition of previously presented information (Green, 2000). In comparison, vascular dementia is more likely to cause a patchy profile with a broader range of deficits dependent upon the location of vascular damage (Woodford & George, 2007). Despite the variability in profile, vascular dementia is more likely to show impairment of executive functions such as planning and sequencing; improved recall when structure and cues are provided; and greater emotional lability (Green, 2000). This suggests that in general terms people with a diagnosis of Alzheimer's Disease may struggle more to retain diagnostic information than those with a diagnosis of vascular dementia. Whereas people with a diagnosis of vascular dementia may experience more variation in their abilities and readiness for information, requiring assessment and adaptation from session to session or moment to moment. This suggests it may be harder for clinicians to take the presentation of a person with vascular dementia at assessment, as being indicative of their

later presentation at diagnostic delivery. Furthermore, for someone with a diagnosis of vascular dementia, there is potential for a greater emotional reaction to the delivery of the diagnostic news, which may also have a secondary impact upon the processing of information.

1.7.3. Individual differences

Tailoring a diagnostic delivery to each individual is a challenging task. One of the initial complexities is the difference between how patients would like to have their diagnosis delivered. For example, whilst most patients and family caregivers favour disclosure of the diagnosis of dementia (Werner et al., 2013), some people would have preferred to have had the possibility of a diagnosis of dementia discussed with them prior to delivery, to relieve some of the shock of the diagnosis (Robinson et al., 2011). There are also differences in how clinicians facilitate diagnostic delivery. Clinicians can struggle to balance providing an emotionally supportive relationship and delivering the bad news of the diagnosis (Dooley, Bailey, & McCabe, 2015). This can lead to avoiding explanations, not checking understanding and using fractured sentences (Karnieli-Miller, Werner, Aharon-Peretz, & Eidelman, 2007). Dooley, Bailey and McCabe (2015) suggested that if clinicians were to take a protective stance which could minimise patient's distress, this could also create barriers to patient focused communication and shared decision making. These two areas of variability highlight how challenging the communication of information about an incurable and stigmatized disease can be in clinical practice.

1.7.4. Triadic communication

During a consultation companions often take on important dual roles as informant and advocate due to the cognitive impairment of the patient (Robinson et al., 2011). However, observation of this triadic consultation demonstrated that it is a complex task to integrate the companion without marginalising the patient (Karnieli-Miller, Werner, Neufeld-Kroszynski, & Eidelman, 2012). Furthermore, diagnostic appointments where the patient is accompanied, also demands that the clinician consider the patient's consent about sharing the diagnosis. It should not be assumed that the patient wishes to share their diagnosis, instead clinicians need to respect that the diagnosis is the

property of the patient and they have the right to distribute or withhold that information, even from close family (Carpenter & Dave, 2004). Laidsaar-Powell et al., (2013) propose eight strategies for health care professionals to improve triadic communication. These include: encourage, welcome and involve companions in consultations; clarify and agree upon the role of preferences of patients and companions at commencement of the consultation; take opportunities to privately discuss sensitive information with patients alone; and reflect on your own behaviours towards companions (Laidsaar-Powell et al., 2013). Although these strategies were not specifically developed for dementia care settings, they may be applicable. However, clinicians in dementia care settings also need to provide specific support to companions, over and above acceptable inclusion into any appointment, because they face several unique challenges as dementia progresses. These include: taking on new tasks, both household and caregiving tasks; a changing relationship with the person with dementia; experiencing negative emotions such as frustration, impatience, anger, grief and doubts of competence; and facing fears about the future (Adams, 2006). This further exacerbates the specific challenges faced when delivering a diagnosis of dementia.

1.8. Current research for delivery of a diagnosis of dementia

The research field has started to respond to the clinical need for improvement in guidelines to support diagnostic delivery of dementia. In 2007, Karnieli-Miller et al. highlighted the need to support clinicians to cope with difficulties in diagnostic delivery of dementia and to manage the problems and pitfalls in practice. In relation to elements of a good diagnostic delivery they also suggested that clinicians need to assess individual's preferences, decision-making capability, and their needs for information and emotional support. Alongside this, there were calls for research efforts to focus on the development of educational programmes, and establishment of guidelines (Karnieli-Miller et al., 2007). This was later extended with recommendations including the modification of protocols from other diagnostic areas (Werner et al., 2013).

At a similar time, a behavioural intervention aimed at promoting three key elements of diagnostic disclosure was developed. The paper-based tool

targeted finding out what the patient already knows about their diagnosis, using the words ‘dementia’ or ‘Alzheimer’s Disease’, and exploring the meaning of the diagnosis with the patient (Foy et al., 2007). However, in a key publication Lecouturier et al. (2008) demonstrated that diagnostic delivery was broader than producing three key behaviours. Using a literature review, interviews with people with dementia and carers, as well as an expert consensus panel they produced a list of the key components of the process of disclosing a diagnosis (see Table 12). This was starting to evidence the complexity and enormity of good practice in diagnostic delivery.

Following these publications there has been the development of a number of recommendations of how to deliver a diagnosis well (see; (Grossberg et al., 2010; Manthorpe et al., 2011; Murphy & Gair, 2014; Royal College of Psychiatrists, 2016). Generally these include: the central areas of preparation; communication of the diagnostic information; provision of support for both patients and companions; and post-diagnostic care. All advocate for the clinician to adapt practice to meet the individual needs of each patient, as well as working with families and caregivers. It has also been recommended that the diagnostic delivery to be considered as a process (Werner et al., 2013).

Alongside these guidelines, the Memory Services National Accreditation Programme has developed a comprehensive set of quality standards to be met at all stages of dementia diagnostic care (Royal College of Psychiatrists, 2016). Although these guidelines are clearly a critical step in the development of what good practice is, clinicians require support to be able to implement these into their everyday practice. The journal paper highlights the role of a range of clinical tools and interventions in providing this support.

Table 12: Summary of key components of diagnostic disclosure of dementia, (Lecouturier et al., 2008) (p4)

Category	Sub-Category
Preparing for disclosure	• Plan disclosure meeting • Arrange post-diagnosis support • Establish rapport • Prepare the patient • Elicit preferences for disclosure
Integrating family members	• Identify and involve appropriate family members • Manage differing information needs of patient and family • Avoid collusion with family members
Exploring the patient's perspective	• Explore patient ideas • Elicit patient expectations
Disclosing the diagnosis	• Tailor information to patient preferences and ideas • Check understanding • Explore the meaning(s) of the diagnosis • Discuss prognosis
Responding to patient's reactions	• Explore the patient's emotional response • Elicit and address patient questions and concerns
Focusing on quality of life and wellbeing	• Foster hope • Explore coping strategies
Planning for the future	• Clarify follow up arrangements • Discuss support services available • Negotiate management plan • Discuss prevention and health promotion
Communicating effectively	• Develop rapport • Use appropriate verbal and non-verbal communication • Use active listening skills • Involve the patient • Structure and signpost the consultation • Consider issues of anti-discriminatory practice

1.9. Relevance for clinical psychology

It is argued that clinical psychology can provide a key role in the development of knowledge and practice in dementia diagnostic delivery (British Psychological Society, 2014a). Currently clinical psychologists are actively completing diagnostic assessment and delivery for a proportion of patients with complex presentations in MAS settings. They are often required to provide assessment due to their skills in neurocognitive assessment. Alongside this they have many

expert skills in positive communication and emotional support, developed in the provision of psychological therapies, that is transferable to the communication of a diagnosis of dementia. This skill mix and clinical experience arguably enables the profession of clinical psychology to hold a valid position to support the understanding and development of good practice. Alongside this, clinical psychologists have often supported colleagues via supervision, and developed training approaches in other areas of health care services. It is argued that this could enable the profession of clinical psychology to be well placed and accepted by healthcare providers to provide direct support or training regarding the communication of a diagnosis of dementia (British Psychological Society, 2014a).

1.10. Study aims

The overarching aim of this study is explained in the journal paper. Provided here are the primary objectives of the overarching aim.

1.10.1. Primary objectives

- To explore clinician, patient, and companion perceptions of what stands out as helpful and or challenging about their experiences of dementia diagnostic delivery within a local MAS.
- To identify key elements of practice to inform the design of a prototype tool with potential to support consultations in MAS clinics.
- To obtain preliminary feedback on the acceptability of the prototype tool.

2.0 Extended Methods

The following section is an extension of the method section recorded in the journal paper. It includes detail of the methods selected and provides rationale for the selection of the qualitative approach taken. Extended information about the study design, data collection and data analysis are provided. Alongside this consideration of ethics and researcher impact are also explored.

2.1. Methods Selection

The two main considerations of methods selection were my philosophical position, and guidelines on best practice in development of interventions in medical settings.

2.1.1. Philosophical Position

Historically social researchers have broadly positioned themselves along an axis of assumptions concerning reality (ontology) and how you discover that reality (epistemology) (Miller & Crabtree, 1999). Classically, and crudely for the basis of illustration, this axis has been partitioned into philosophical paradigms such as: positivism; post-positivism; critical theory; and constructivism (Lincoln, Lynham, & Guba, 2011). Members of each paradigm broadly share similar ontological and epistemological views, which maybe in contrast to other paradigms. For example; post-positivists hold a belief that the world exists apart from our understanding of it, while constructionists state the world is created by our conceptions of it (Morgan, 2014).

Rather than assume one of the more traditional paradigms named above, I chose instead to adopt the more recently proposed 'new paradigm[51]' of pragmatism. Pragmatism is underpinned by Dewey's (1938) concept of inquiry as the controlled and directed process of bringing together the elements of an indeterminate original situation to a determinate and unified whole. Therefore, scientific inquiry from a pragmatic stance sets out to attempt to not just gain knowledge but to gain knowledge for a desired reason or end point (Morgan,

[51] Pragmatism has been long established as a philosophical entity, the 'new' refers to the application of this to social research

2007). Furthermore, Morgan (2014) posits that the pragmatic paradigm does not need to rely on an abstract set of philosophical assumptions and can move away from defining ontological and epistemological stances. It does this by treating all research as a human experience, based on the beliefs and experiences of the researcher, which are directly connected to actions (Morgan, 2014). By taking this view, the focus of research conducted from a position of pragmatism is the identification of the research question that directs inquiry to unify inconclusive knowledge. The importance placed on the research question, rather than philosophical issues relating to specific methodology, allows the researcher to select the best methods to investigate the question (Teddlie & Tashakkori, 2010). Therefore, I felt by working with a pragmatic paradigm the aims of this study could become the influencing factors of method selection, rather than my philosophical positioning.

2.1.2. Developing tools and interventions

The design and methods have been heavily influenced by recommendations for developing decision aids and interventions. The Medical Research Council (MRC) has provided a four stage framework for good practice when developing interventions (Craig et al., 2008). The four main stages are: development; feasibility and piloting; evaluation; and implementation. This study is only focusing on the development stage. The specific guidance for this key element recommends that the intervention should be developed systematically, drawing upon existing knowledge and, if required, new primary data such as interviews with stakeholders (Craig et al., 2008). A more comprehensive model of the development of decision aids has also been drawn on to guide this study's design. Coulter et al.'s (2013) model highlights a staged process for the development of paper based decision aids. As the tools that are to be developed in this study are likely to be paper based, Coulter et al.'s (2013) model provides a transferable framework to specifically guide this study's design. The model specifies three stages prior to the first draft of the tool being produced. Alongside defining the scope of the tool, it also stipulates assessment of both patient and clinician views about the tool's target, reviewing existing evidence, and determining a format. Once a prototype has been developed, it is then recommended the prototype is reviewed in a phase named

alpha testing by patients to check comprehensibility and usability, and by clinicians to check acceptability and usability (Coulter et al., 2013). The model suggests that any subsequent changes should be made and then the revised tool taken into beta testing, which appears to parallel the MRC guidelines of feasibility and piloting.

Considering the above recommendations for tool and intervention development, I chose a qualitative methodological approach for this study. I felt that this methodology enabled the exploration of people's views of diagnostic disclosure of dementia, prior to any tool development. This is because a primary aim of qualitative methodology is to discover, understand, and describe people's experiences (Holloway & Galvin, 2016). In the review steps outlined by Coulter et al.'s (2013) model, qualitative methodology was also judged to provide the most valuable data about the prototype. This is an approach that has been recommended by other researchers developing interventions. Akard et al. (2013) state that qualitative approaches can provide data in support of the efficacy of the intervention, contribute to the intervention's refinement, and suggest potential outcomes. Alongside this it has also been suggested that this methodological approach can provide important information as to whether the target population view the intervention as relevant, acceptable, and beneficial (Meissner, 2011).

Quantitative methodology, that has a main objective of reducing phenomena to numerical values (Smith, 2015), was not selected as I felt it would be unable to provide the rich data required to understand patient and clinician views. The MRC framework recommends the use of a quantitative or mixed method approach, i.e. the combination of both quantitative and qualitative approaches, for the later phases of development, such as assessing feasibility or evaluation of the tool in a clinical trial.

2.2. Theoretical Framework

The pragmatic approach of this project required a theoretical framework that could develop a tool to improve the subjective experience of a diagnosis of

dementia. The framework needed to be able to do this by asking participants to make direct links from their experiences of dementia diagnostic delivery to perceived helpful and unhelpful processes within this event. I identified that thematic analysis would be suitable to meet this aim. The rationale for this choice is outlined below, alongside the consideration of other available theoretical frameworks.

2.2.1. Thematic Analysis (TA)

Broadly defined as a method for identifying, analysing, and reporting patterns within data, TA has been a widely used method for understanding data (Braun & Clarke, 2006). Historically TA has been viewed as a foundational approach for qualitative methods and its use has been advocated as process within most qualitative methods (Boyatzis, 1998). However, in recent years TA has become a widely used and recognised method in its own right (Clarke, Braun, & Hayfield, 2015). The most commonly adopted approach to conducting TA is set out by Braun and Clarke (2006, 2013). In this approach TA is presented as a method, rather than a specific methodology (Clarke et al., 2015), such as interpretive phenomenological analysis (IPA) or grounded theory (GT). TA's flexible approach to research also enables its use to address most types of research question, and can be applied to most types of qualitative data including this study's design of interviews and focus groups (Clarke et al., 2015). However, the flexibility and classification as a method has often lead to TA being criticised for being non-theoretical and historically lacking agreement on its completion (Braun & Clarke, 2006).

To attempt to overcome these criticisms, it is critical that a number of decisions are taken and made explicit during TA's use (Braun & Clarke, 2006; Clarke et al., 2015). The main decisions are regarding the type and level of analysis. There are largely two primary approaches to type of analysis in TA, inductive and deductive. Within a study the researcher can chose a unitary type of analysis or take a mixed approach of using both inductive and deductive analyses. Inductive approaches attempt to conduct analyses that are grounded in the data, rather than in prior knowledge or theories, and the themes generated are strongly linked to the data (Braun & Clarke, 2006; Clarke et al.,

2015). The alternative approach, deductive analysis, applies a theoretical lens to the data in a way that allows existing theory to inform the coding and theme development (Clarke et al., 2015). The level of analysis relates to the degree of interpretation of the data and is usually applied consistently throughout a piece of research (Braun & Clarke, 2006). There are broadly two levels of analysis; semantic and latent. At the semantic level the explicit or surface meanings of the data are identified; in a latent analysis the researcher is going beyond this and identifying the underlying ideas, assumptions and conceptualisations that underpin the semantic meaning (Braun & Clarke, 2006). The decisions taken within this study are documented in the journal paper, and in the data analysis section (2.8.2) of this extended method.

I selected TA for this study as its flexibility allowed the primary focus to remain on conducting analyses that could answer the research questions and meet the study aims. This flexibility also positions TA more as a set of tools or methods for researchers to draw upon, rather than a specific methodology. Therefore, TA was also deemed to be in keeping with my pragmatic stance.

2.2.2. Interpretive Phenomenological Analysis (IPA)

IPA (Smith, 1996) is an approach dedicated to the detailed exploration of personal meaning and lived experience. It is grounded in phenomenological philosophy and attempts to view things as they present in their own terms, rather than by already defined ideas or conceptualisations (Smith & Osborn, 2015). As such, IPA is predominantly concerned with a detailed understanding of how particular people have experienced particular events, and avoids generalisations (Smith & Osborn, 2015). Therefore, IPA could offer rich understanding of the experience of diagnostic delivery, and may support the development of areas of good practice. However, the priority of the study was the development of a tool, rather than more detailed idiographic accounts of diagnostic delivery of dementia.

2.2.3. Grounded Theory (GT)

Developed by Glaser and Strauss (1967), GT is a systematic, inductive, and comparative method that aims to develop theory (Bryant & Charmaz, 2007). It

allows for flexible methodology to build theory from inductive data, alongside promoting continued interaction with the data and emerging ideas (Charmaz, 2015). GT is best suited to subject areas with a lack of prior knowledge or theory relating to the research question. As evidenced in the background of this study this is not a claim that can be made in relation to the current understanding of a diagnosis of dementia and was therefore not selected for this study.

2.2.4. Conversation Analysis (CA)

CA is a naturalistic, observational science of both verbal and non-verbal behaviour (Drew, 2015). Unlike the other methods presented here, CA uses audio or video recordings of naturally occurring interactions as the primary form of data. Its principle aim is to discover how participants understand and respond to each other in their turns of talk, with a specific focus on how sequences of actions are generated (Hutchby & Wooffitt, 2008). It is also interested in how participants display for each other their understanding of what is going on (Hutchby & Wooffitt, 2008). CA would be a valuable method to develop detailed understanding of interactions within the MAS appointments. As such, it has recently been utilised to understand the use or neglect of diagnostic terms in MAS settings (Peel, 2015). However, the focus of this project was not the development of a rich description of interactions and instead to prioritise obtaining perceptions of 'helpful or challenging' processes within the diagnostic delivery from participants. Alongside this, CA may not be as able to depict which specific elements of the interaction are subjectively experienced as 'good' as other methodologies. Therefore, an approach using thematic analysis was prioritised with future potential to employ CA to understand if diagnostic interactions contain the processes participants identify as leading to a 'good' diagnostic delivery of dementia.

2.3. Study Design

This section explores the rationale and decisions taken for the study design for development and assessment of the tool.

2.3.1. Phase One: Tool Development

Identification and selection of the areas of good practice to be targeted by an tool can be completed in different ways. In a review of method strategies employed in healthcare settings, common techniques included; interviews, focus groups, and consensus panels using either the nominal group technique or the Delphi technique (Ryan et al., 2001). Consensus methods aim to determine the extent to which experts or lay people agree about a given issue (Jones & Hunter, 1995). Consensus methods were not selected for the development of a tool in dementia care settings as I felt it would risk excluding patients and their companions. This was due to the observation that often people with dementia have been marginalised and de-valued by others, and especially professionals, speaking on their behalf (Bartlett & O'Connor, 2010). In contrast, interviews and focus groups can gather specific information set out by the researcher(s) about any topic of interest, which can include the inclusion of the experiences of patients. These methods were preferable to a consensus group as a key aim was to incorporate the views of patients who were experiencing dementia. However, focus groups were felt to be inappropriate for the initial phase of the research as it has been suggested that interviews are preferable to focus groups when discussing topics of sensitive nature (Gaskell, 2000). Therefore, focus groups were deemed to potentially reduce the likelihood of participants feeling comfortable to disclose their experiences or views. As such I felt that conducting interviews would provide the best method to access to a range of views and encourage disclosure of experiences.

To maintain an audit trail and provide transparency, a table was maintained with how phase one themes were represented within the tools. This table is in section 3.3 (Table 14).

2.3.2. Phase Two: Tool Assessment

Focus groups were selected to assess the prototype of the tool as they have been suggested as a useful tool in the evaluation of early drafts of health promotions (Mitchell & Branigan, 2000). Furthermore, focus groups with the target audience assessing the acceptability of materials can be viewed as an essential phase for developing effective tools (Ayala & Elder, 2011). It has also

been recognised that focus groups can hold an advantage over interviews as they allow for the group members to engage in collective brainstorming of ideas, issues and solutions (Sussman, Burton, Dent, Stacy, & Flay, 1991).

It has been suggested that focus groups can produce more open dialogue when they are relatively homogeneous and group members are not well known to each other (Ayala & Elder, 2011). Therefore, to enable participants to feel most comfortable expressing their views, separate groups were chosen for service deliverers (i.e. any clinician involved in settings where a diagnosis may be delivered) and for service recipients. This also removed the potential for a service recipient to engage in a group alongside a potential current or past member of their care team, and vice versa. This may have resulted in both types of participant feeling less able to engage in open discussion due to concerns relating to how they would be perceived by the alternative category of participant. For example, it was possible that service recipients may be less likely to discuss negative experiences or opinions of their diagnostic disclosure experience if their MAS clinician was present. Small groups of participants were planned to facilitate the expression of more opinions and for people to be heard more clearly than is found in large groups (Holloway & Galvin, 2016).

As outlined in the journal paper, after phase two data were analysed, edits were made to the tool. To provide a record of the changes made and the rationale, a table was maintained for each tool. This detailed the location of the change, a descriptor, and the rationale. The completed tables are in section 3.5 (Tables 15 and 16).

To aid understanding of the results of this study, a further table was developed to compare existing breaking bad news protocols and recommendations specific to dementia diagnostic disclosure to the tools developed in this study. The comparators were: SPIKES (Baile et al., 2000), BREAKS (Narayanan et al., 2010), ABCDE (Rabow & McPhee, 1999), How to break bad news to people with intellectual disabilities (Tuffrey-Wijne, 2013), Breaking bad news to children – information for staff (Child Bereavement UK, 2011), Summary of key components of diagnostic disclosure of dementia (Lecouturier et al., 2008), and

other recommendations in research papers relating to dementia diagnostic disclosure (discussed in journal paper introduction and section 1.8 of the extended paper). The comparisons were completed by the primary researcher and made with the protocols or recommendations available in the published literature. The completed table is in section 3.5 (Table 17).

2.4. Participants

2.4.1. Sampling

Generally, sampling in qualitative research aims to identify the people who know and can talk about the phenomenon that is being investigated; and identifies the context where the phenomenon is likely to be visible (Holloway & Galvin, 2016). In this study, the area of under investigation are clinician, patient, and companion experiences of important features of dementia diagnostic disclosure. The context where dementia diagnostic disclosure is readily observable is within the MAS diagnostic appointment. To gain insights about clinician, patient, and companion experiences I used an opportunistic approach to sampling for both phases of this study. This approach was consistent with the aims of both phases where investigation of specific experiences (phase one) and potential user group feedback (phase two) was required.

Parallel homogeneous sampling schemes were undertaken within the opportunistic approach, that aimed to recruit participants who had similar characteristics or belonged to the same subculture (Holloway & Galvin, 2016). For both phases of this study, the two homogeneous schemes' criteria were to select participants who had received a diagnosis of dementia, i.e. MAS patients, people with dementia, and companions; and to select participants who were involved in the delivery of dementia diagnoses. Furthermore, participants were selected from a single NHS trust to attempt to limit the impact of the regional variations of service design and access. This strategy was deemed important as it enabled a targeted approach that retained a high degree of focus. However, homogeneous sampling that had highly restrictive selection criteria could have resulted in the development of a tool that had limited utility or application. To overcome this, efforts were established to ensure that some elements of heterogeneity were included in the sampling strategy, for example: selection of

participants from rural and urban locations; men and women; different clinical roles and responsibilities; and different dyadic relationships, such as spousal and parent-child. Compensation in the form of travel expenses was offered to all participants in phase two. However, all participants declined this offer.

The sampling strategy allowed people who had participated in phase one to participate in phase two. This strategy was developed following Coulter et al.'s (2013) model of developing decision aids. This includes repeated reviews of the tool by the steering group formed at the beginning of the process and that the tools should be tested by people directly involved in the development process. However, this has benefits and drawbacks that need to be acknowledged. The benefits include providing the opportunity for a degree of member checking. Where participants reviewed the tool developed from the data they provided in interview, they could provide direct feedback if the tool does or does not represent their view of good diagnostic disclosure. Alongside this, repeated participation may help participants to develop more confidence in engaging in the research process and how comfortable they feel expressing their views with the researcher. Despite these potential benefits, including people in both phases may increase the likelihood that participants will provide positive feedback or remain in agreement with tool when reviewing it as they have a degree of investment having previously participated. This was addressed by asking specific questions in the focus groups to attempt to elicit negative feedback.

2.4.2. Contextual information of the sample

Patients:

People who are expected to attend the MAS clinic are likely to be over 65 years as the hosting NHS Trust has a separate service, The Working Age Dementia service, that receives referrals from people over the age of 18 and under 65. The MAS service accepts referrals from the local general practitioners (GPs). Therefore, people attending the MAS clinics have been assessed by a medical practitioner as having one or more symptoms that may be associated with

cognitive changes present in dementia. Some people may have gone to their GP with concerns about themselves or their relative, or the GP may have raised concerns in the person's over 65 health check or other examination/testing situations. People who present in MAS clinics are likely to present with mild or moderate symptoms, with national statistics from 2014 suggesting that 51.7% of people diagnosed in MAS services are in early stages of dementia (Royal College of Psychiatrists, 2015). People presenting to the service could include people who go on to receive a diagnosis of a type of dementia, mild cognitive impairment, or no cognitive impairment that meets the criteria for dementia or mild cognitive impairment. People may be referred to other services if a more complex or other neurological condition, such as Parkinson's Disease, was suspected. This could include services such as the local older adult community mental health team, clinical psychology, consultant psychiatry or neurology services.

Companions:
Within the hosting MAS service, the companion's role is considered to support the patient and where appropriate to provide assessment information. They are usually a relative or a friend or a neighbour. People are encouraged to bring somebody with them to their appointments in the appointment letters, although this is not enforced and people could attend on their own. In these situations, it would be possible for the MAS clinician to gain consent to discuss the assessment and/or diagnostic information with a third party. This may be appropriate if family members reside in other geographical locations.

Clinicians:
Within the hosting MAS the patient's assessment, diagnosis and post-diagnosis appointments are all held with a Specialist Nurse. Where possible the same nurse is present for each appointment. In most situations, the Specialist Nurse is the first person to communicate the diagnosis, however for some people this may have been discussed by the referring GP, or clinical psychologist if additional assessments have been required. If the diagnosis is discussed by

other professionals the patient is still offered the standard diagnostic appointment.

Alongside the Specialist Nurse in the hosting MAS service all diagnostic appointments are supported by a support worker from the Alzheimer's society. They may not be directly informing the person what their diagnosis is, but they are providing information about what services are available, any further information or resources about the diagnosis and giving the person with dementia and their companion a contact point for future concerns. In some clinic locations, the support worker is present in the same room as the Specialist Nurse; in other locations, they are in a separate room and see the patient and companion after the Specialist Nurse. The hosting MAS service views the role of the support worker as a critical element in delivery of the diagnosis.

2.4.3. Comparison of hosting MAS and other services

The hosting NHS Trust managed a total of seven MAS clinic locations that covered a large city and the surrounding county. This represents 3.15% of services with MAS functions in the UK. It is not uncommon for NHS Trusts that cover large geographical areas to manage more than one MAS clinic. For the purposes of the national audit of MAS services each clinic area is considered as an individual MAS, and in 2014 it was estimated that there were a total of 222 MAS services in the United Kingdom (Royal College of Psychiatrists, 2015). Not all MAS services are run by NHS Trusts, following some commissioning decisions allocating service contracts to private providers.

The design of the MAS is decided by the managing organisation or NHS Trust. There is limited information about how other organisations have designed services that fulfil the MAS function. However available data suggests that in 2014 36% of MAS clinics were run as standalone services and 64% were run as functions of the older adult community mental health team (Royal College of Psychiatrists, 2015). The design of the clinics within the hosting NHS Trust of this study are standalone services. It is possible to consider standalone services as increasingly specialist services in diagnosing dementia.

Currently there is no data about how individual MAS services operate to make in depth comparisons with the hosting NHS Trust. However, NHS England has presented three models, one based within primary care, one mixed primary care and specialist service, and one standalone service, to support organisations to produce budgetary estimates (NHS England, 2015). These models differ from the hosting NHS Trust as although parts of the assessment are completed by nurses or eldercare facilitators, the diagnosis is communicated by a consultant psychiatrist. It could be argued that the hosting NHS Trust's design provides greater continuity for the patient as where possible providing the same specialist nurse throughout the contact with the MAS. Despite the differences in design the processes involved in the diagnostic disclosure are anticipated to be transferable across all MAS designs.

2.4.4. Sample Size

The size of sample that was set for the recruitment aim was guided by data sufficiency, rather than reaching data saturation. Data saturation is viewed by many as the 'gold standard' for determining the size of a sample (Guest, Bunce, & Johnson, 2006) and is generally conceptualised as a continuation of data collection until nothing new is generated (Green & Thorogood, 2014). However, achieving 'true' data saturation can be a problematic. There is limited guidance to show how to judge when saturation has been reached (Bowen, 2008), and as each person is unique, who is to determine that the next participant could not provide a new area to explore (Wray, Markovic, & Manderson, 2007)? Arguably, an approach that is more feasible for many studies, and one that fits with my philosophical position, is to aim for data sufficiency. This approach aims for an adequate sample size that can sufficiently answer the research question.

During the development of the sampling strategy there were some issues identified and related decisions made to decide the sample size. The first issue was the location of the recruitment. I chose to locate the study within a single NHS Trust where all MAS clinics have the same design. The purpose of this choice was to attempt to limit the impact of the regional variations of service design and access. However, this has implications for the potential

generalisability of the findings. Despite this, I felt that the phenomenon of diagnostic disclosure of dementia observed within the hosting NHS Trust was likely to have transferability to other areas where dementia diagnoses are delivered. Furthermore, the NHS Trust had granted access to services that were in both rural and urban locations, where a mixture of socio-economic and demographic diversity resided, thus providing a degree of heterogeneity. Therefore, on balance I felt that the limitations from recruiting within a single NHS Trust were likely to be mitigated against.

Another major decision was taken in collaboration with the hosting NHS Trust. This was in relation to the recruitment of the MAS clinicians, both as participants and as people who were supporting recruitment of service recipients. As detailed in section 2.4.4.1 below, the hosting NHS Trust placed restrictions on the number of MAS clinicians that could support the study, thus reducing the initial target for recruitment of MAS clinicians into phase one. Although this restriction limited my opportunity for sampling, I felt that it was appropriate to continue to recruit from the hosting NHS Trust as the service and individual clinicians had engaged with the study from the initial development and were familiar with recruitment into research projects. This enabled me to be more confident that I would be able to recruit clinicians and that they would support the project by enabling access to recruit service recipients.

During the decision-making process for the sample I was also considering how to maintain a manageable project. As outlined in section 2.1.2 the design of the study was influenced by Coulter et al.'s (2013) model for development of patient decision aids. To achieve the aims of the study I required a two-phase design that advanced the prototype tool to a stage where beta testing (Coulter et al., 2013) would be appropriate. This required assessment of both patient and clinician views about the tool’s target, reviewing existing evidence, and determining a format (contained within phase one). Once a prototype has been developed, it is then recommended the prototype is reviewed by patients to check comprehensibility and usability in a phase known as alpha testing, and by clinicians to check acceptability and usability (Coulter et al., 2013). This was the

aim of phase two. As such, I attempted to maintain a manageable sample size for both phases to enable both to be completed within this study.

Recruitment targets to reach data sufficiency were also influenced by several factors specific to each phase and are outlined below.

2.4.4.1. Phase One

The first phase collected data via interviews with clinicians, patients and companions. It has been suggested that the development of meaningful themes and useful interpretations can be achievable after six interviews and data saturation reached by 12 interviews for a homogeneous sample (Guest et al., 2006). When using recommendations for the sample size based on the findings of Guest et al. (2006) it is important to note that although it is empirically based, there are some further elements to consider to ensure data sufficiency. It is important to establish how comparable the sample analysed by Guest and colleagues is to the proposed study. Where similarities occur, the recommendations made by Guest and colleagues are more likely to provide good quality estimates. The following elements should be compared between the recommendations made by Guest and colleagues, and the design of this study.

- The information power the sample holds, for example a less extensive sample is needed where participants hold characteristics that are highly specific for the aims of the study (Malterud, Siersma, & Guassora, 2016), or where the information is easily obtained in interviews (Morse, 2000).
- The scope of the study, where the narrower the focus of the study aim the fewer participants are required (Morse, 2000)
- The degree of heterogeneity of the population, with populations with greater diversity requiring larger sample sizes (Ritchie, Lewis, & Elam, 2003)

The research aims of the study analysed by Guest et al. (2006) could be broader than the aims of this project. The aims were to ‘examine how women talk about sex and their perceptions of self-report accuracy in two West African

countries' (Guest et al., 2006) (p62). This is arguably a wider focus than the aims of the interviews in the first phase of this study, which was to explore clinician, patient, and companion perceptions of what stands out as helpful and or challenging about their experiences of dementia diagnostic delivery within a local MAS. This suggests that fewer participants than Guest et al (2006) recommend may provide data sufficiency to address this focused study aim. Alongside this, the narrower focus in this study is also combined with a relatively specific population of people who had experienced diagnostic delivery within MAS settings. This may also decrease the required sample, when compared to Guest et al. (2006) as the participants may hold greater information power. The degree of heterogeneity within the Guest et al. (2006) sample appears to be relatively low due to the inclusion criteria specified and the targeted populations. In comparison, it is likely that the sample in phase one of this study will have a wider degree of diversity due to targeting three classifications of participants, which could increase the required sample.

Overall, this study appears to have a narrower focus with participants who may hold greater information power, but may have a sample with greater diversity than the Guest et al. (2006) study. On balance, this combination of factors suggests that the recommendations set out by Guest et al. (2006) remain valid and could be used to guide the sampling schedule. Therefore, the initial aim was for six of each participant type, i.e. six clinicians, six patients and six companions. However, a primary factor in determining these subgroup targets was the size of the population, especially for MAS clinicians, which was limited by the size of the hosting service. This service held seven MAS clinics, each run by a specialist nurse with input from an Alzheimer's Society support worker. Due to this small population and guidance from the service management team, who advised that clinicians were heavily loaded with research recruitment from other projects, the recruitment aim was reduced to four clinicians. Despite this reduced aim, ensuring each clinician was located at a different clinic meant the data could still be sufficient as more than half the clinic areas could be represented. Therefore, the overall aim of this strategy was for a total of 16 participants.

2.4.4.2. Phase Two

The number of focus groups for one project can range from a single group to many (Wilkinson, 2015). More specifically it has been recommended that between three and four could be an optimum number (Holloway & Galvin, 2016), or even up to 12 groups (Miller & Crabtree, 1999). Four homogeneous groups were run with two separate sessions for both deliverers and recipients. Selecting two groups for each participant type would maximise recruitment as the provision of an alternative date and location would enable participants to select the most convenient group.

It is recommended that the size of the group should be determined by the number of people to give sufficient diversity in information without overwhelming participants with a large group setting (Onwuegbuzie, Dickinson, Leech, & Zoran, 2009). The numbers of participants for each focus group has been more consistently recommended as between four and twelve (Holloway & Galvin, 2016) or six and twelve participants (Miller & Crabtree, 1999; Onwuegbuzie, Dickinson, Leech, & Zoran, 2009). As such the aim was to recruit six people to each group, which resulted in a recruitment aim of 24 people.

2.5. Data Collection

2.5.1. Understanding sample characteristics

Prior to interview or focus group completion, each participant completed a brief demographic data form. This included gender, age, role (i.e. patient, companion), and contact information. The data were used to understand who had been recruited but was not intended to be included in any analysis.

Gaining an understanding of any variation in experience or emotional effects of receiving a diagnosis of dementia for patients was included in phase one. Attempting to obtain a quantitative indication of satisfaction about their appointment in the form of a questionnaire was considered. However, this was rejected based on questionable reliability/validity as previous research indicated that patients typically report high levels of satisfaction when completing these measures, yet express contradictory and complex opinions in subsequent interviews about their experience (Pollock, Moghaddam, Cox, Wilson, &

Howard, 2011). Instead the MAS clinician who led the appointment subjectively assessed the patient's reaction to the delivery of their diagnosis. The MAS clinicians could identify a range of different reactions due to their experience and regularity of diagnostic delivery. Furthermore, capturing observable patient reactions within the consultation could be achieved without adding further burden to patients by the completion of further assessments.

The system to classify patient's reactions was developed collaboratively with the hosting service to ensure that the system was suitable. Reactions were categorised along two intersecting axes, described below:

Axis 1: high emotion - low emotion

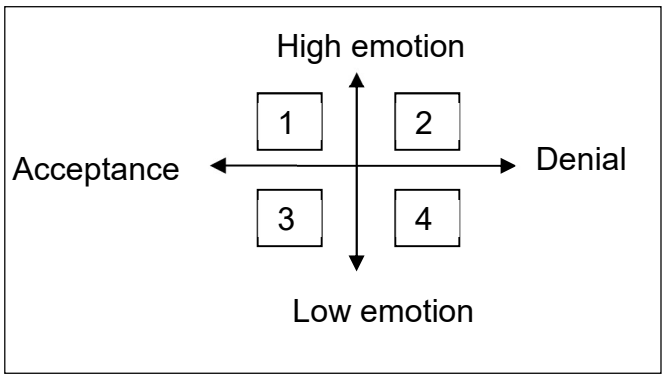
- 'high': any clear expression of a feeling (positive or negative) about what they have been told. This may be feelings of anger, sadness, fear.
- 'low': a person that seems numb or indifferent to what's being said. It may leave the clinician feeling unsure about how they felt.

Axis 2: acceptance - denial.

- 'acceptance': the person may verbally agree with what has been said 'Oh I knew it was something bad' and the conversation gives the impression they agree with what they have been told, even if they are upset by it.
- 'denial': the person may verbally disagree with the diagnosis or may continue to question it 'are you sure?' or ask for further tests or time to make sure. They may offer examples of the person getting better e.g. 'but he remembered his tablets last week and he never used to'.

The intersecting nature of the axes enabled categorisation into four quadrants, as shown in Figure 4.

Figure 4: Reaction classification



This information was only recorded for people who consented for their details to be shared with me. If this consent was obtained the clinician completed a contact form (see Appendix J) that enabled the recording of the patient's, and companion's if both recruited, name and contact details. The form also asked the clinician to identify the most appropriate quadrant for the patient's reaction. I then collected this data and contact information in either hard copy or via verbal report over the telephone.

2.6. Topic Guides

Topic guides were used in both phases of the study to ensure that similar data were collected from participants during the semi structured interviews and focus groups (Holloway & Galvin, 2016). Each guide contained key areas, or topics, to cover with each participant and a range of example questions that may elicit information for each area (see Appendix L). It included prepared opening and closing statements. During each interview and focus group, I adopted a flexible approach to ensure the key topics of interest were included and that relevant and interesting areas brought up by the participants could be followed up.

2.6.1. Phase one

Two topic guides were developed for phase one, one for interviews with patients and companions, and the other for interviews with clinicians. Although each guide contained prompt questions with a different focus, both topic guides contained the same key areas. For example; in the topic area relating to the experience of a dementia diagnosis, a question asked to clinicians included

‘what is it like to deliver diagnoses of dementia?’, whereas a question to patients and companions included ‘what was it like to receive your diagnosis?’.

The topics and questions included were developed to enable a broad examination of dementia diagnosis delivery, rather than to explore pre-existing ideas or assumptions. To achieve this I included questions relating to experiences, feelings and knowledge (see; Holloway & Galvin, 2016). Alongside this I also used open questions with follow-up enquiries to enable the participants to respond with the things that were most salient to them (Patton, 2015) (see topic guides in Appendix L for examples).

2.6.2. Phase two

The topic guides used in phase two had the same design as in phase one with each guide covering the same topics, but with slightly different phrasing. As the aim of the focus group discussions were to gain feedback about the acceptability of the tool, some a priori themes were included in the topic guide. A review of the MRC guidelines states the importance of assessing an intervention’s acceptability and cites problems of acceptability can seriously undermine interventions (Craig et al., 2008). Despite this the MRC fail to operationalise the term acceptability. A definition proposed by Ayala and Elder (2011) suggests an intervention’s acceptability is how well it is received by the targeted users, and the extent to which the intervention meets the user’s needs. Acceptability can also be more specifically applied to the materials included in a tool, whereby a judgement about the literacy level, content, presentation, and delivery can be obtained (Ayala & Elder, 2011). Most commonly considered in behavioural interventions in schools, another important conceptualisation is that of the social validity of an intervention. This seeks to judge an intervention at three levels; the significance of its goals, the appropriateness of its procedures, and the importance of its effects (Wolf, 1978). It is also important to recognise that acceptability has been assessed post implementation by numerically recording the uptake of the tool, dropout rates, and the degree of change influenced by the intervention or tool.

Drawing on the above conceptualisations, the important areas of acceptability to consider in the development of the tool and therefore included in the topic guide were:

- the degree that potential users felt it could meet its aims,
- the appropriateness of how it was attempting to meet the aims and if the tool would be usable,
- its reception by potential users that included an indication if they would use the tool in the future or would have used it in past appointments and any barriers to its uptake,
- the content in terms of the subject areas included and how the tool was written or presented.

Included in the focus group topic guides was a prepared statement of expectations of participating in the group that included respecting each group member's confidentiality. Participants were supplied with printed copies of the draft versions of the tool. Alongside this, each group was provided with a brief overview of each tool's aims and how we envisaged to be used. This provision also became a prompt for discussion.

Within the focus groups I took the role of group facilitator, using the topic guide to ensure that all key areas had been prompted or covered in the discussion. Rather than using prompting questions to encourage people to talk, I held back to enable the data to be generated from group discussion (Holloway & Galvin, 2016). I supported this with the use of non-verbal encouragement such as eye contact and head nodding, where appropriate, to encourage less confident group members to enter the discussion.

2.7. Transcription

Transcriptions of interview and focus group data were undertaken by a professional transcriptionist. I chose to use a transcription service as, although transcription can support immersion in the data, I felt the time saved would be more beneficial in data analysis and tool development. As a novice transcriber, I also felt that professional transcription services could help to avoid errors in the transcription process due to their expert level of training (Easton, McComish, &

Greenberg, 2000). To ensure consistency throughout the data set, the same transcriptionist was used throughout the study. To ensure that data were preserved during transcription all audio recordings were transcribed verbatim and in full. When a transcription service is used it is recommended that the transcript is proofread by the interviewer (McLellan, MacQueen, & Neidig, 2003). Therefore, on the completion of each transcript I reviewed it for accuracy by simultaneously listening to the audio of the interview and reading the transcript. Any data that had been misheard or incorrectly transcribed was corrected. I also ensured that each transcript was formatted in the same way and clearly identified each speaker. This supported ease of use during data analysis. To also ensure a quality service, the transcription service selected was based on recommendations and had previous experience of transcribing for TA data analysis. To ensure confidentiality the transcriptionist signed a confidentiality agreement.

2.8. Data Analysis

For both phases of the study I broadly worked within Braun and Clarke's (2006) framework for completing thematic analysis. All data were analysed as a single sample across participant groups rather than separating data into patient, companion, and clinician groups. There are alternative methods that could analyse the diagnostic delivery from the different participant groups, and then compare the developed themes between the groups. However, on balance I felt that single sample analysis was appropriate as all participant groups were involved in a common process of the diagnostic delivery. This common experience is also fundamentally an interactive experience between the participant groups, which may arguably reduce the degree of meaningful group-specific separation that could be achieved.

2.8.1. Phase 1: Data familiarisation

Transcription can be viewed as an excellent way of beginning familiarisation (Braun & Clarke, 2006), however as this was completed by a transcriptionist I did not have this opportunity. Instead, I began familiarisation when reviewing transcripts for accuracy. Once I was confident of the accuracy, I read and concurrently listened to the entire data set a further twice. Following this I then

read each transcript and completed a familiarisation memo for each transcript and the overall data set. This supported me to fully engage with the data and to capture my initial assumptions and ideas of the data.

2.8.2. Phase 2: Generating initial codes

Once I had immersed myself in the data I moved to generating codes. This process identifies a feature of the data that is interesting to the research question by the assignment of a code. Guided by the research aims and pragmatic position, I coded at the semantic level for both phases of the study to remain as close to the participants' meanings. (see Appendix N for an excerpt of a transcript with completed codes)

As I was completing a mixed inductive and deductive analysis of the data to ensure maximum retention of meaning and that specific data relevant to the research question for each phase was captured, I coded each data set twice. I started with an inductive approach to coding, to minimise any interpretive impact of the deductive framework. In this initial approach, I aimed to code the maximum possible areas of interest to avoid omitting data that may have been interesting at a later phase. I also attempted to retain a little surrounding data to preserve the context of each code and in some instances, assigned multiple codes to one unit of data. Noticeably, in phase two I felt it was critical to retain the group conversation in the coded data. This resulted in me coding larger sections of data and therefore retaining the different participants' contributions.

After I had completed the initial inductive coding, I then revisited the data set and completed deductive coding. For phase one of the study; the deductive coding focused on specific behaviours or elements of a good delivery of a diagnosis of dementia. For phase two, it required coding data relevant to the a priori framework of the acceptability of the tool. (See section 2.6.2 for discussion about acceptability.) I included three specific areas within this framework: usage, barriers to uptake, and alterations. Table 13 provides further information relating to the development of this a priori framework.

During the initial phases of coding I took sections of coded data to supervision to ensure the coding process was sufficiently embedded in the original data and had not jumped ahead to attempting to assign themes.

Table 13: A priori framework

A priori framework	Meaning	Link to definition of acceptability	Example
Usage	How people envisaged using the tool	How well people were receiving the tool (Ayala & Elder, 2011). Appropriateness of its procedures (Wolf, 1978)	If people were unable to identify how they would use it then the tool could be said to have an unacceptable design or inappropriate features.
Barriers to uptake	Any problems with the tool that would prevent it being used	If the tool was usable (Coulter et al., 2013) Make judgements about literacy level, content, and presentation (Ayala & Elder, 2011).	Where barriers are identified, this could provide information about how to improve acceptability, or if the barriers are significant enough, if the tool is fundamentally unacceptable
Alterations	Edits or changes to the tool's design or content	Comprehensibility of the tool (Coulter et al., 2013)	The degree of alterations required could provide information about the degree of acceptability, but also it can provide action points to improve acceptability of future design revisions.

2.8.3. Phase 3: Searching for themes

At the next level of abstraction, I began to cluster codes together around an organising concept. Practically, this resulted in systematically working through all the generated codes and sorting into collections or themes. The initial sort resulted in a large array of collections and a 'miscellaneous' theme where I was

initially unable to allocate codes to other collections. In phase one I undertook this first stage manually with each code printed and cut out. From this I then used a large work surface to cluster the codes. I used photographs to ensure a detailed audit trail was maintained. I then went through a process of attempting to describe each cluster to assess how much it overlapped with other clusters. Where overlap was noted I reorganised the codes until I had generated the first thematic structure of the data set. At this point I then took the structure to supervision to support the organisation of the 'miscellaneous' codes into other areas.

2.8.4. Phase 4: Reviewing themes

I initially reviewed the themes during supervision and began to identify areas of refinement. I also identified themes that were not sufficiently supported by the data to stand alone as a theme and were therefore merged into a closely related theme, or the codes were dispersed across numerous themes. Supervision also helped me to review themes that were capturing too much diversity and required splitting into sub themes. Throughout this process I referred to the criteria of internal homogeneity and external heterogeneity (Patton, 2015) to ensure that each theme was a coherent entity but also sufficiently distinct from other themes. To support this checking process, I wrote summarising memos of each theme and compared these descriptions for similarity. I also used thematic mapping to help visualise the organisation of the themes. In phase one this process of revision resulted in at least seven modifications of the theme structure captured in the audit trail by thematic maps.

2.8.5. Phase 5: Defining and naming themes

Once I felt I had sufficiently revised the themes and had the final theme structure in both phases, I produced a detailed analysis of each theme. This really helped me focus on exactly what each theme was conveying and how it fitted in the overall theme structure. In phase one this included an explicit consideration of how each theme linked to the process or practice of delivering a diagnosis of dementia. I felt this was an important stage in translating the experience and observations of the participants into ways would support that

good practice. During a review of these analyses in supervision, a final revision to the theme structure was made to remove any remaining overlap. I then produced names for each theme.

2.8.6. Practical considerations - NVivo

During the study, I developed and changed my approach to using Braun and Clarke's (2006) framework. One main area of change was my use of computer software package NVivo (QSR International, 2016). At the outset of data analysis, I completed coding 'by hand' whereby I annotated printed transcripts. I found this to be helpful for immersion in the data. However, I noticed that I was feeling overwhelmed by the task of managing and organising the data beyond this stage. I was aware of NVivo but as I had not previously used it I was unsure of how it could support my data analysis. Using online tutorials and technical manuals I began to understand how the programme could help me organise the data. Although, at first, the process of transferring the raw data and my handwritten codes into NVivo was time consuming, I quickly began to appreciate the flexibility it was offering. I noticed that I could easily code and annotate sections of data, and modify these if required. I also found it supported me to consider whether a section of data required a new code to be generated or if it was in keeping with an already developed code.

I also found NVivo supportive in the development and modification of the themes structures. Although at the beginning of phase one manually sorting codes and photographing the structure felt helpful, NVivo enabled me to manipulate the data into a structure, review the appropriateness with the raw data, and then re-organise easily and time effectively. I could also quickly and easily map the data and produce reports grouping all the raw data for a theme. I felt that this was critical to continuing to engage in the process and avoid 'settling' for an earlier version of the theme structure.

NVivo was also helpful for managing and organising memos, annotations and my reflective diary entries. It enabled me to clearly link specific memos to raw data, themes or to a transcript. This also prevented me from feeling unorganised and overwhelmed by the process.

2.9. Quality Assurance

There are a range of frameworks for assessing quality in qualitative research (see; Elliott, Fischer, & Rennie, 1999; Yardley, 2000). A large proportion has historically been judged against the concept of trustworthiness. Initially proposed by Lincoln and Guba (1985) this relates to the methodological soundness and adequacy, and can be viewed as adaptions of the concepts of validity and reliability applied to quantitative research (Bryman, 2012). Despite this concept having been widely adopted in qualitative research, it does not enable any evaluation of the impact or meaning of the study to the people who the research was intended to benefit. Therefore, Yardley's (2000) criteria of context, rigour, coherence, and the impact and importance have been used in combination with strategies of credibility, transferability, dependability, and confirmability for ensuring trustworthiness (Lincoln & Guba, 1985) to convey quality. Space restrictions have limited detailing of all criteria used, instead presented below are the quality checks that were most salient to this study.

2.9.1. Sensitivity to context (Yardley, 2000)

Prior to beginning the design of the project, I ensured that I understood the current service design in the hosting MAS by engaging with the service managers. I felt this was critical to understanding and being sensitive to the context during interviews and focus groups. I also spent time discussing and reflecting on the process or journey of gaining a diagnosis of dementia with MAS clinicians and other research colleagues. I felt this was a critical step to ensure that the study was sensitive to patient and companion needs. Due to MAS service management team's reflections that many found accessing clinic locations stressful, I chose to offer to meet people in their own homes. I also decided to offer to interview people as dyads (patient and companion). This was due to observations from MAS clinicians regarding the supportive role of companions. As such, an interview in a dyad may provide reassurance and the best possible environment to aid memory recall for patients.

2.9.2. Coherence (Yardley, 2000)

Methodological decisions were inherently guided by my philosophical position. I felt that the development of a usable tool fitted well with the pragmatic paradigm

that I have adopted. Although the rationale was omitted from the journal paper due to space, I felt that the methods selected for data collection and analysis have met both the aims of the study and maintained coherence within the pragmatic paradigm.

2.9.3. Credibility via Triangulation (Lincoln & Guba, 1985)

Data triangulation was a main element of the study design. By recruiting people who both delivered and received diagnoses of dementia, I could examine the research questions in each phase from these different perspectives. This helped to ensure that the tool was usable for both parties involved in a diagnostic delivery and ultimately enabled greater generalisability of the findings (Holloway & Galvin, 2016). During recruitment, I also coincidentally recruited all members of one diagnostic interaction, i.e. the MAS clinician, patient, and companion. This provided an unexpected area of data triangulation.

2.9.4. Credibility via Member checking (Lincoln & Guba, 1985)

I chose not to formally evaluate the agreement between my understanding and interpretations of participants' words or actions with participants within each phase via member checking. As member checking requires a substantial commitment from participants I felt it could be inappropriate and excessive at a time where patients and companions had received a life altering diagnosis. Also, as the second phase of the project enabled a process of ensuring key areas were included in the tool, I felt that including an extra check was over and above the necessary contribution required from each participant.

2.9.5. Confirmability via Reflexivity and Audit Trail (Lincoln & Guba, 1985)

To support reflexivity during the research process I utilised a reflective diary to critically consider my decisions, actions and conflicts. Furthermore, a critical reflection of this project is provided in section 5.0. During the study, I also maintained an audit trail of decision making, including methodological and analytical decisions. When writing up the study, care has been taken to report these decisions in a transparent way that provides the rationale for each decision, thus improving the rigor, comprehensiveness and credibility of the

research (Tong, Sainsbury, & Craig, 2007). I also engaged in periodic discussions with supervisors to ensure I was aware of and monitoring my own biases and interests.

Appendices N to R (which includes relevant extracts of my reflective diary) provide an example of the audit trail from transcript to initial theme titled 'emotions' and then to the final theme of 'clinician's emotional journey'.

2.9.6. Areas not described

A formal inquiry audit (Lincoln & Guba, 1985) that could evidence dependability was not completed, instead the process of submitting this DClinPsy thesis for formal examination via a viva voce was considered a method of establishing preliminary dependability.

Commitment and rigour (Yardley, 2000) has not been detailed. It is envisaged that the content provided within the extended paper provides evidence of the depth of engagement with the topic of diagnostic disclosure of dementia that space limitations in the journal paper prevented. Furthermore, impact and importance (Yardley, 2000) can be assessed by the potential clinical implications of the developed tools. This is discussed in section 4.7.

2.10. Ethical Considerations

2.10.1. Ethical Approval

Prior to commencing the study full ethical approval was gained from NHS Research Ethics Committee (see journal paper for details). Alongside this the hosting trust Research and Development (R&D) department approved the study. I also gained consent from the clinical director of the specific service within the hosting trust for the project, including the specific recruitment strategies utilised. The University of Nottingham acted as Sponsor for this study and approved all procedures and documentation prior to use. During the project, recruitment progress was reported to the hosting trust R&D department and the end of the study was reported to NHS research ethics committee following the final focus group. There were no major or minor modifications to the agreed proposal during the duration of the study. (See Appendix C for

service access letter, Appendices D, E, F for REC correspondence, and Appendices G and I for R&D correspondence).

2.10.2. Consent

For all participants, full written consent was gained prior to any involvement in interviews or focus groups. To ensure that participants could make a choice about participation, copies of the relevant participant information sheet and consent form were provided at least 24 hours before consent was obtained (see Appendix I for participant information and Appendix K for consent forms). For each participant type and for each phase, tailored information sheets were provided. Within all information sheets a description of the anticipated benefits and risks of participating were detailed, along with contact details for the research team, support agencies, and how to raise concerns. Discussions about the implications and expectations of participation were held with all prior to beginning any interview or focus group. This was to ensure that people could process and engage with all necessary information to consent and had the opportunity to ask any questions. Across both phases consent was gained on an ongoing and proportionate basis. For example, consent was first established to share contact details, prior to any consent to participate. Furthermore, consent was only obtained for each phase of the study, and therefore should any participant engage in both phases informed consent was re-established as if they had not had any previous involvement.

An inclusion criterion set for all phases was to have the capacity to consent. Capacity to consent is governed by the principles of the Mental Capacity Act (MCA; 2005) and relates to an individual's ability to understand and make choices. To decide if an individual has the capacity to make a decision, two questions must be fulfilled. 1. Is there an impairment of or disturbance in the functioning of a person's mind or brain? If so, 2. Is the impairment or disturbance sufficient that the person lacks the capacity to make a particular decision? As the disease process in dementia directly affects the functioning of a person's mind or brain that it is possible that some patients may not have capacity to consent to participating.

However, the first principle of the MCA states that people should be assumed to have capacity to make their own decisions, unless this is proved otherwise. It also states that a decision about someone's capacity to make decisions cannot be based purely on the presence of specific conditions. Also, mental capacity is established on a case by case, decision by decision basis, and as such a person may have varying capacity depending on the complexity of the decision. Therefore, it would have been inappropriate to assume a person lacked capacity to give full informed consent based on a diagnosis of dementia. Instead, recruiting clinicians were asked to complete an assessment of capacity to decide about participation for people where capacity was doubted. We deemed that the MAS clinician, rather than a member of the research team, would be the most appropriate person to undertake this assessment as they had formed a clinical relationship with the person. The MAS clinicians are also highly skilled with specific knowledge of the MCA and skills in assessing capacity.

2.10.3. Minimising distress - Recruitment

We recognised that patients and companions could experience receiving a diagnosis of dementia as distressing. Furthermore, it was possible that introducing the study and seeking consent to participate following the disclosure of their diagnosis could be experienced as overwhelming and increase any distress. To minimise this possibility, a flexible and compassionate approach to recruitment was required. Clinicians were advised to discuss the project with people who they assessed were not emotionally distressed, or were likely to become overburdened by the information. If people were receptive to discussing being involved in the project the clinician would provide a brief overview and copies of the participant information sheet and consent form. This was felt to be the minimum amount of information to enable informed consent to share their contact details, without overburdening with superfluous information at this stage of recruitment. Participation in the study was also clearly indicated to have no impact on their care received from the MAS clinic, or impact on any future treatment.

Where consent was given to share details, a minimum of one week elapsed prior to any further contact regarding participation. This was deemed sufficient to allow the patient and companion some time to emotionally process their diagnosis and study information. It also enabled people to have considered any questions about participation. At this point of contact a more detailed discussion of the study was held to ensure that all necessary information was provided to enable informed consent to be obtained.

2.10.4. Minimising distress - Data collection

Participants who were interviewed in phase one of this study were asked to talk about their experiences of receiving or delivering a diagnosis of dementia, and discussion may have cued upsetting memories relating to this provision. Participants were reminded at the start of each interview that they would be able to stop the interview at any time and/or ask not to discuss a question. We also anticipated that some participating health professionals may have experienced enquiries about their practices as threatening, construing such questions as challenges to their professional competence. However, participants will have often confronted issues of diagnostic delivery in their everyday provision of care. For those who would like to convey their views and experiences the study allowed them to do so confidentially – to an independent researcher.

It was also possible that sensitive and emotive subjects may have arisen during focus group discussions in phase two. Again, participants were advised that they could leave the focus group, and therefore choose to stop their involvement in that question. Alongside the topics of discussion, the group dynamics were also a potential cause of distress for example, a participant becoming worried or distressed by the opinions aired by other group members, an argument may have become unpleasant, or group members could exclude others (Wilkinson, 2015). To minimise the risk of these events occurring, the expectations of the members of the group were discussed prior to the start and were monitored during the group. In the event of the group dynamics becoming distressing to any members the group would have been terminated. Had there been a distressing event during interviews or focus groups, participants would

have been reminded of the service resources available to them to discuss these issues (i.e., clinical supervision, staff counselling service, support within the Carers Federation, or Alzheimer's Society, where appropriate to the role of the participant). Contact details of appropriate contact points were included in the participant information sheets. Also, the topic guides allowed flexibility in generating questions depending on the information participants discussed. This allowed for sensitivity in the level of depth of exploration and enabled continual adjustments to avoid prolonging any distress triggered by a question.

Despite the possible risk of increasing or revisiting distressing topics, it is also acknowledged that participants may have found participation to be beneficial. With the mitigating steps to minimise the risks, some participants may have appreciated the opportunity to convey their views and experiences to an independent researcher. Alongside this, as the main aim of the study was help improve practices and the experience of diagnostic delivery in the future, participants may have benefitted from an awareness that they were contributing to knowledge and future practice. Therefore, with the steps taken to minimise any negative impact, the potential benefits were deemed to outweigh any risk of harm to participants.

2.10.5. Anonymity and confidentiality

Participant anonymity was maintained by replacing real names with pseudonyms post transcription. Names of non-participants referred to were replaced with the role of the person such as 'son' 'MAS nurse'. Each participant was also given a unique identifier. I maintained a database of the contact details and relevant study information for each participant alongside their unique identifier. In a separate list, I maintained a record of the pseudonyms that related to each unique identifier. Identifiable data were entered on a case report form for each participant (see Appendix M) and stored with the completed consent form(s) in a locked filing cabinet at the University of Nottingham. Alongside the data management, I have also been selective with the reporting of the demographic information, the location of the hosting MAS service, and specific job roles. This was due to the small population, especially of MAS clinicians, making it relatively easy to identify participants.

For every interview and focus group the boundaries of confidentiality were discussed. Participants were informed that there were limits to the confidentiality that could be guaranteed within the study. The participant information sheet and consent form also stated that confidentiality may have been broken if there were any safeguarding concerns raised over the course of the study. We anticipated that had any concerns been raised and, after a discussion with the participant and within the research supervision team, the researcher may have consulted with the relevant safeguarding lead for the hosting MAS. All participants were made aware of the use of a transcription service and that quotations using pseudonyms would be used in the write up of the study.

In phase one where a patient and companion had been recruited in the same appointment, participants were offered a choice of being interviewed individually or as a dyad. For dyadic interviews and all focus groups it was not possible to ensure that confidentiality would not be broken by other participants. To minimise this risk, at the beginning of each dyadic interview or focus group the requirement of each member to respect confidentiality was discussed and agreed by each group member.

2.10.6. Data storage

All information and data has been handled in line with the Data Protection Act (1998) and the University of Nottingham's policy for research data. Anonymised data has been kept digitally on a secured computer. Audio files were transferred to a secure computer and were then erased from the recording device. Information has only been accessed by the research team, transcriptionist, supervisors and limited administration team. All research data will be stored for seven years after completion of the study and then destroyed securely. Identifiable data is stored in a locked filling cabinet at the University of Nottingham and will be destroyed three months after completion of the study.

2.11. Researcher Impact

As the main method of data collection and analysis is the researcher, it was important to consider my influence on the data. I was drawn to this topic area after completion of research relating to supporting people who care for a person with dementia. This highlighted the potential impact of the way in which people received their diagnosis. Thus, I developed an interest in understanding what a good delivery may be and how to encourage this to happen in clinical practice. This drive to support improvement has been the main influence on my philosophical position both in my research and clinical practice as a trainee clinical psychologist. I have noticed in my clinical practice that I am often drawn to finding solutions and this is likely to have led to a bias when designing this study. I may have been more inclined to progress the project to developing a prototype, where as another researcher, with different tendencies or philosophical positioning, may have chosen to explore phase one in more depth.

I also reflected on the inherent power imbalance between patients and medical professionals. Even though I was outside of all participants' care team, I was aware that some participants may view me to be affiliated with their healthcare practitioners, which may have impacted on how willing people were to openly criticise experiences or practices. I attempted to mitigate this as much as possible by working towards a power neutral position by meeting patient and companions in their own home and by clearly identifying the boundaries of confidentiality and anonymity.

3.0 Extended Results

3.1. Sample Characteristics

To ensure anonymity details have been reported with the minimum data required to understand the sample. Further information would risk identifying participants, especially clinical staff, due to the small population size. All participants had given consent for quotes to be used in the write up and were assigned a pseudonym to protect confidentiality. Also, omitted from the journal article, due to space constrictions, was the data regarding patient reactions to the diagnostic delivery (phase one only). None of the five patients were recorded as falling into the forth category of low emotion and denial. Two patients were recorded as having high emotions but seeming to accept the news, category one. A further two patients were categorised as falling into category three of having low emotional expression and accepting the news. Finally, one patient was categorised as having high emotional expression and to deny the diagnostic news.

3.1.1. Achieved recruitment

The recruitment aims for both phases were not fully achieved, as set out in the extended methods section. I decided to cease phase one recruitment after 14, rather than 16, people had participated to preserve the good will of the hosting MAS. I was aware that phase two recruitment was also reliant on MAS clinicians' good will and felt that further requests to gain one more patient and companion may have impacted on the degree of support for phase two. 14 participants were deemed to be able to give sufficient data. At the point of ceasing recruitment, the sample had a degree of heterogeneity as a variety of men and women, different roles and relationships, some variety of reactions, and a mix of participants who either worked or resided in city centre (n=5) or rural locations (n=9) had been recruited. Achieved recruitment also represented four of the total seven MAS clinics managed by the hosting Trust. At a national level, this represents 1.8% of all services with MAS functions in the UK. Alongside this, there were four occasions where all members of the diagnostic disclosure had been recruited (i.e. the clinician, the patient and the companion).

This triangulation and diversity improved the confidence that sufficient data had been collected to enable a range of views and opinions to be represented and sufficiently explored.

Phase two recruitment achieved 13 out of the intended 24 participants across the four focus groups. The data collected was deemed sufficient due to the range of participants that included service managers to front line staff; companions of people with dementia that had both working age and older age onsets; and people with dementia. I felt that it was beneficial to run each group despite not achieving intended recruitment, as rearranging may not have been convenient for the people who had already indicated they would be attending and there was no guarantee that further participants would be identified. Furthermore, it was not possible to continue to schedule further focus groups to increase the number of participants due to the timescale of the study.

3.1.2. Dropout rates

To minimise burden on MAS clinicians, figures on the number of people approached to participate in either phase were not collected. In phase one, one patient – companion dyad consented for their contact details to be shared but did not go on to participate. In phase two, one clinician who had wished to participate was then unable to attend the focus group. All other participants who gave consent to be contacted in either phase, went on to fully participate.

3.1.3. Recruitment of triads

Although not an aim of recruitment in phase one, there were four instances where all three members of the clinician – patient – companion triad present at diagnostic delivery were interviewed. Further details of these relationships will not be presented to protect the identities of the participants.

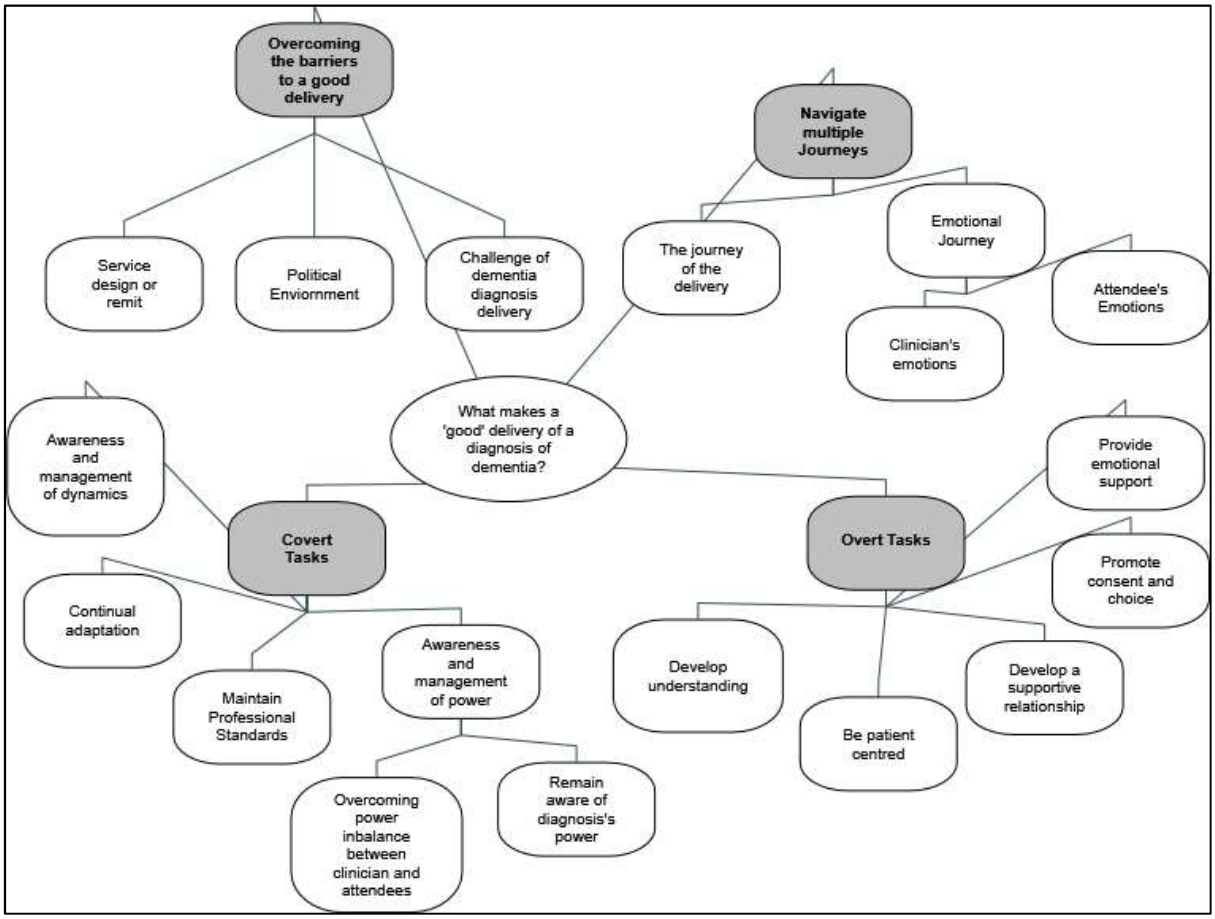
3.2. Phase One Themes

Theme development in phase one evolved across several revisions of the structure and content of the tool. The initial theme structure was developed by grouping codes that were referring to similar concepts. I initially completed this

outside of the NVivo programme to support the visualisation of the development of the themes. Photographs were taken of each theme and codes that formed the theme, examples can be viewed in Appendix O. This information was then inputted into NVivo where all future revisions were developed. During the development of the themes I utilised reflective practice and supervision. Extracts from my reflective diary relating to this process are presented in Appendices P and R.

Presented in the journal paper were the themes that were most salient in the tool development. Discussed here are all the themes identified in phase one that answered the research question: what makes a good delivery of a diagnosis of dementia? Figure 5 provides a diagrammatic overview of the final theme structure, an earlier revision of the theme structure is presented in Appendix Q.

Figure 5: Phase One Final Theme Map



Key: Emboldened themes in grey background represent overarching themes

3.2.1. Overcoming the barriers to a good delivery

The central concept of this overarching theme is an assumption that clinicians aim for a 'good' delivery of a diagnosis of dementia but several factors present barriers that place the quality of the delivery at risk. To ensure the maintenance of good quality diagnostic delivery the clinician primarily needs to be aware of the existence of these factors and then take steps to mitigate against the effect on practice. Within this study, three main factors were likely to present a barrier to good practice.

3.2.1.1. Challenge of dementia diagnosis delivery

Not unsurprisingly, sharing a diagnosis of dementia is difficult[52]. Although breaking this bad news is a requirement of MAS clinicians, some people may not feel able to take on this challenging role. Here Susan, who is a support worker present in diagnostic appointments in the MAS clinics, reflect on her own feelings about the first instance of telling someone they have dementia.

> *Susan (Clinician, 3 years MAS clinic experience): I don't know how difficult that must be but I don't have to say those words and I don't know if I could.*

Although Susan's role in the MAS clinics is to be present within the diagnostic appointment to provide additional support and information about the diagnosis, her role does not include initially breaking the news, instead it is to continue to support people to continue to develop their understanding during and after the diagnosis. By remaining aware of her perception of her lack of ability to undertake the task, Susan could take steps or receive support to overcome this, if required. Also, it is at least possible that someone who did not feel able to deliver a diagnosis of dementia may not be able to achieve the same quality of interaction as a clinician who felt prepared. Therefore, it is important that clinicians are both aware of their own feelings and perceptions of delivering a

[52] See quotes from Alan and Jennifer in the journal paper

diagnosis, and that they also feel personally able to deliver a diagnosis to maximise quality practice.

Another inherent challenge when delivering a diagnosis of dementia is that the disease affects people's memory and cognitive abilities.

> *Pat (Clinician, 4 years' experience in MAS settings): We are dealing with people who have memory problems. It sounds flippant but there is a fair chance that some of the information we give will get lost.*

As such the clinician needs to be able to adapt communication and information in a way that supports recall. If the clinician has not considered this potential challenge and ways to attempt to overcome it, it is possible that the quality of the interaction is reduced.

3.2.1.2. Service design or remit

As well as being time limited, MAS is also limited in what it can offer as it is commissioned as a diagnostic service. As such, it can be personally difficult for clinicians who ultimately want to help people when they identify a person's need for support but there are no services to meet this need.

> *Susan (Clinician): sometimes I think, "What for?" When there's nothing at the other end. […] If they get offered medication they'll have a medication review in probably about five weeks time but not everybody gets offered the medication due to other medical conditions, so it's those people really that get left out.*

It can be challenging to deliver a diagnosis where there is no treatment.

> *Interviewer: Is there any part of the diagnostic process that you find the most difficult?*
> *Pat (Clinician): […] I feel I should be able to do something but I don't have an answer.*

It is also difficult when service restrictions limit flexibility in management of the triadic communication. Many people noted that ideally time and space would be provided for confidential discussions with the patient and companion, yet many were unable to provide this. Here Jennifer is talking about how hard it can be to manage an appointment where the patient and companion have different viewpoints and how she feels limited by the resources in the MAS clinic.

> *Jennifer (Clinician, with 9 years' experience): we don't have anybody to say to the carer, "Do you want to come outside for a couple of minutes [so] we can have a quick chat."*

In these situations, it is possible that the clinician could feel frustrated, hopeless or despondent about the task of diagnostic delivery. Should these emotions occur it is likely that they would impact on the quality of the diagnostic delivery. Reflective practice and supervision are potential ways of managing these and other emotions that result from diagnostic delivery.

Many MAS appointments are conducted in buildings that were not specifically designed for diagnostic delivery. This can impact on the experiences of the people attending appointments.

> *Kate (Daughter and companion of Doris): the room might have been a little bit more relaxing, that's my opinion, probably some comfy seats and a table.*

When clinicians consider the layout, it can be possible to adjust it to make it feel as welcoming as practical. For example, Ann, a companion, commented that it had helped when a clinician had ensured that the desk had been moved to one side to prevent any physical barrier being placed between them.

3.2.1.3. Political environment

MASs are situated within a wider political context of funding decisions within the NHS. Restrictions in funding and service availability can lead to waiting lists and

high volumes of referrals, that can put pressures on clinicians[53]. Some clinicians also felt that the wider political agenda of increasing the number of people receiving a diagnosis was risking the quality of diagnostic delivery. Here Susan is discussing if the service is person centred. She highlights how hard it can be to balance what she would ideally achieve with people but then goes on to comment on the constraints to this. In the following quote, she summaries this dilemma in her rhetorical question:

> *Susan (Clinician): it's like reaching targets. Sometimes I have four or five appointments in an afternoon, sometimes, is it quantity or quality?*

Alongside this, the MASs are viewed as being specialists in dementia diagnosis and therefore some felt concerned that the restrictions in funding had prevented people accessing specialist services. Here Louise is considering if there would be anything she would change and is considering how the limited capacity of MAS clinics might impact on the experiences of people who are able to attend.

> *Louise (Clinician, 20 years' experience): just sometimes you worry that not everybody gets that [the expertise and experience of MAS clinicians when delivering the diagnosis]. So you feel you're letting other people down because you don't have the capacity to see them.*

Also, some clinicians were aware of the variation in political funding between a range of medical diagnoses.

> *Susan (Clinician): if you've got cancer, the diagnosis of cancer, it's funded by the NHS, you've got support with your Macmillan Nurses. You get dementia, you fund it yourself and there is no support.*

It is important to remain aware of personal frustrations, such as those expressed by participants in this study, as this could impact on quality of individual appointments. Furthermore, it is within each clinician's power to

[53] See journal paper for quotes from Jennifer and Louise about service pressures

provide the best quality services they can, despite funding restrictions. As with other barriers to good delivery, reflective practice and supervision could be methods to attempt to mitigate any risks on practice.

3.2.2. Navigate multiple journeys

The diagnostic delivery of dementia is always situated within a context of the patient having experienced changes to their memory. Therefore, every encounter where a diagnosis is shared requires consideration of how the patient and companion arrived at that point in time, and what their future or next steps will be. This transition of the diagnosis is navigated, or facilitated by, the clinician. It is also multifaceted, with different concurrent journeys being taken. These different journeys are outlined below.

3.2.2.1. Journey of the delivery

A good diagnostic delivery is more than just telling the news. The clinician is required to support the attendees on their pathway to receiving the diagnosis. They must hold in mind the focus of the appointment, to relay this news, but also ensure that they have guided the patient and companion to be in the right place to be ready and prepared to receive this news.

> *Interviewer: What are your experiences of delivering a diagnosis of dementia?*
> *Louise (Clinician): It's not just about relaying the bad news, it's about the preparation of the person, moving towards breaking that bad news … So, at assessment, I'm on a journey with them towards the possibility of a diagnosis of dementia.*

Some people may arrive at a point on their journey where they feel ready to receive the news before others. For example, some people prefer the diagnostic news at the very start of the appointment.

> *Jennifer (Clinician): You can see it in their faces, "Can you just, come on."*

Therefore, the clinician may feel that they have a map of the appointments journey, but it is imperative that they understand where the patient and companion are on this map. Then the clinician's role is to walk alongside them to support the receipt of the news at a time when this is most appropriate. It is also important to note that some people may never be ready to receive the news, especially if there is limited insight into difficulties. In this case the clinician must attempt to find a place in the appointment where the emotional impact can be kept to a minimum. It can also include travelling backwards and forwards along the journey and revisiting the diagnostic news. Here Pat is discussing how people may react and how he manages this in appointments by going back and talking about the reasons for attending the appointment.

> *Pat (Clinician): some people have a very agitated, very defensive reaction to it [the diagnosis], "you can't tell me this," then it's about trying to explain it's there, you have come to this assessment, we have talked about some of the problems you are having such as x y z.*

The delivery of the diagnosis also marks a transition point where the ownership of the diagnosis is transferred from the clinician to the patient, and from attempting to understand what is wrong to how to live with dementia. Here Jane is describing her and Stephen's journey when receiving their diagnosis:

> *Jane (Wife and companion of Stephen, appointment with Jennifer): their words, they put you in the picture and so you know what to expect and things like that.*

Therefore, alongside traveling towards the news, the clinician also needs to support the patient and companion to begin a new journey after diagnosis.

3.2.2.2. Emotional journey

The diagnostic delivery is also an emotional journey for patients, companions and clinicians.

Clinician's emotions

Diagnostic delivery is a big responsibility for clinicians and this can present an emotional dilemma of being anxious about the delivery, yet also feeling a sense of being privileged to be present in people's lives at such a significant moment.

> *Interviewer: What it's like for you to deliver a diagnosis?*
> *Jennifer (Clinician): It's a huge diagnosis to give to anybody and it can be quite nerve wracking.*

> *Louise (Clinician): [considering if any elements of the diagnostic delivery are easy] it's not easy but the most enjoyable part is being on that journey with them. I know that sounds a bit fluffy and everything but it is, it is special.*

Clinicians also form emotional connections with attendees[54]. Therefore, good delivery requires clinicians to be open and aware of their own emotions to prevent any negative impact on the attendee's experience[55]. Overall, clinicians need to be aware that there will be emotional effects of diagnostic delivery and find ways, such as reflective practice, that help them to be open and aware of this experience.

Attendee's Emotions

Perhaps the more frequently considered journey in dementia diagnostic delivery is the attendee's emotional experience of receiving the news. However, the emotional journey begins prior to attending any GP or MAS appointments. People are often fearful of what might be wrong, of the implications of disclosing

[54] See journal paper and quote from Jennifer
[55] See journal paper for quote from Louise

problems, and if they suspected they have a dementia how this might affect them.

> *Susan (Clinician): [reflecting on observations about the older generation's beliefs and fears] I think it's a mentality that they fear that if they ask for help they're going straight into a care home.*

> *Ann (Wife and companion of Michael): I think for a lot of people it's extremely frightening because what you see on television is usually final stages.*

Many participants also highlighted the impact of negative associations of terminology.

> *Edna (Patient, attended appointment with Alan, her husband): Yes, the word itself…*
> *Alan (Companion): Has got connotations.*
> *Edna (Patient): I wish it had got a different word because we use the word demented as a throw away so it is a pity it's not got a different name.*

Most importantly people also described the experience of living with dementia as frightening, even prior to receiving a diagnosis. Two patient-companion dyads both described frightening experiences when driving prior to diagnosis and many expressed similar concerns to Mary of fears for the future.

> *Mary (Patient, attended appointment with her husband John): am distressed but the day I don't remember John will be the worst day.*

A good appointment will allow time for these fears, concerns and worries to be articulated and explored. It will also enable different emotions to be experienced, such as relief, as no two people experience the diagnostic process and news in the same way. Also, by conceptualising attendees' emotions as a journey, it is possible to be able understand how these can change over time

and during a diagnostic delivery, even when the change goes against clinician's or attendee's expectations[56]. It is also possible for clinicians to be able to contain worries and concerns, which can lead to an improved experience of the diagnosis.

> *Interviewer: How did your appointment feel?*
> *Michael (Patient, attended his appointment with his wife Ann, appointment with Louise): Well, it went surprisingly well and they were very skilled at putting me at my ease and giving me information.*
> *Ann (Companion): When he [Michael] realised, he felt safe … We felt safe, both of us.*

Good diagnostic delivery also considers the emotional effects of the service on the attendees. For example, many people reported anxiety waiting for results, or how well-timed appointments had reduced stress. Alongside this, discharge from MAS can be another junction in attendee's emotional journey as it can be experienced as an unwanted ending and the beginning of the emotional adjustment to life with dementia.

3.2.3. Overt tasks

A good delivery of a diagnosis of dementia requires clinicians to ensure several essential components have been completed. The recipient of the diagnosis is likely to be aware that the clinician has completed these tasks. Each component is considered below.

3.2.3.1. Develop a supportive relationship

As previously stated, good diagnostic delivery is greater than just delivering the news or information of the diagnosis. After the content of the diagnostic news, most participants referred to how they experienced the clinician as the influencing factor on the overall quality of their appointment.

[56] See journal paper for how a diagnosis can be a positive experience

Interviewer: What was good about your experiences?
Kate (Companion of Doris, her mother): She was very, very nice and my mum even came away and she said, "She's a nice lady, she made me feel comfortable." which was good. That's one of the things, you need to really don't you.

Clinicians were equally as concerned to ensure that people were getting the best experience possible. This is possibly due to the understanding that the way in which the news is delivered is so critical. The diagnostic encounter was described by Doris (Patient) as 'a person to person thing' and as such good delivery utilises the relationship between clinician and attendees as the mechanism for delivering the news[57]. However, the relationship is not instantaneous; it is something the clinician must develop and grow. The initial connection is key and a gentle introduction can help.

Interviewer: What do you do as a clinician that helps you to adapt to each different attendee?
Jennifer (Clinician): I tend to introduce myself at first and then I ask them how they have been and I try to get a bit of a conversation going, saying, "I've not met you, can I get to know you a little bit?"

Using open questions and gentle enquiry can encourage attendees to initially engage. They can also be useful to re-establish a relationship if people have previously met during the assessment appointment. The clinician can use this style of questioning to make the person receiving the news feel as comfortable as possible, to help facilitate acceptance of the news.

Interviewer: What was helpful about your appointment?
Michael (Patient, attended with Ann, appointment with Louise): […] she [Louise] has this skill of putting one at ease and accepting rather unpleasant information.

[57] Journal paper outlines the relationship as the foundation for delivering the diagnosis

This can be achieved in a range of ways that could include the manner of the clinician, how questions are asked, and use of welcoming non-verbal communication. The relationship can be extended beyond the face to face appointment via the use of clinical letters and arrangement of further appointments within the diagnostic appointment. It is also important to note that people identified that bad practice would be the disregard for this relationship building, citing that had the clinician had a dismissing manner they would not have felt so positive about their experience.

3.2.3.2. Develop understanding

Supporting someone to understand what their diagnosis means for them is critical and is greater than the terminology or diagnostic label.

> *Louise (Clinician): it doesn't matter what a person calls it. They can call it whatever they want. They don't have to call it anything, do they?*

It is important for the clinician to use the term dementia as this can reduce confusion as to the purpose of the appointments, and support understanding[58]. However, it is important that the clinician does not impose specific language use on patients and companions, as it is more important that the they understand the diagnosis rather than using the correct medical terminology.

A complexity to developing understanding is that people's understanding about their own difficulties, and what dementia is, is highly varied. Therefore, it is imperative that a clinician establishes, and does not assume, each person's understanding before attempting to develop it.

> *Louise (Clinician): establishing where is that person, are we on the same understanding, that we're on the same pathway.*

If a clinician has not established the baseline understanding, they are at risk of misjudging how best to grow each attendee's understanding in the time

[58] See journal paper for consideration of use of the term dementia in developing understanding

available. Pat's account below highlights how a diagnosis can be experienced by people with different understandings of their difficulties.

> *Pat (Clinician): People with prior experience might have had thoughts along that line already. People without any exposure before or don't think there is anything wrong, and I am saying there definitely is, they are kind of shocked by that.*

Pat's reflection is supported by the experiences of Mary and John. Pat was the clinician who delivered Mary's diagnosis:

> *Interviewer: How was the diagnosis discussed?*
> *Mary (Patient): Well he (Pat) was very, very kind.*
> *John (companion): He (Pat) gently led into it.*
> *Mary: Yes, I wasn't shocked because I know there is something wrong.*

Although Mary recognised that she was experiencing problems, for some people dementia can limit personal insight into difficulties. As such, the companion may developed a deeper understanding than the patient.

> *Edna (Patient, attended with Alan): it's the observers who see the game isn't it and I'm in the middle thinking everything is fine as far as I knew.*

In this case, it is not sufficient to simply inform someone that they do have difficulties. Instead, the clinician needs to sensitively support someone to be able to recognise their difficulties. It can help to review test results, and the rationale for attending MAS appointments.

> *Interviewer: How did he [clinician] explain the diagnosis?*
> *Alan (Companion and husband of Edna): he [clinician] explained on paper and some of the test results, what the norm was and what Edna was not meeting.*

Edna (Patient): Well, he went through each test that I'd done … he said, "You had problems here but so and so" and he went through it … and everything was as he said had happened and was confirming everything.
Interviewer: And do you think that was helpful going through what the test showed?
Enda: Yes, I think it was very helpful.
Alan: Oh yes, absolutely, I don't think he could've done it any other way.
Enda: I think it was very helpful.

Another important consideration is for the clinician to make links between the results and the effects for the individual. It can also help when clinicians use the results to share the diagnostic rationale and therefore reducing any doubts or disbelief about the diagnosis.

Once the basis of recognition of problems has been established there are some other important factors to consider when helping to develop someone's understanding. Outlined in the journal paper are the importance of the clinician's openness using the term dementia but with careful consideration of how this is done; and ensuring that clinicians attempt to discuss information in a way that is comprehended by the attendees.

For many people in this study, knowledge of the condition or their problems was their goal of the diagnostic delivery.

Edna (Patient): if I've got all the knowledge and I don't sit thinking, "I wonder if I've got something they haven't told me about."

However, care also needs to be taken to achieve the correct balance of information to achieve this knowledge and for it to be delivered at a suitable pace for each person. Here Jennifer is discussing how to provide the right amount of information in an appointment:

Jennifer (Clinician): the information you give in that half an hour is an awful lot and they've got to be able to digest it and walk out the door with what you've just said.

It is also important to recognise that developing understanding takes time. Even the best diagnostic delivery of dementia is unlikely to have fully developed a person's understanding and meaning in 30 minutes.

3.2.3.3. Promote consent and choice

People do not have a choice about having dementia but people do have choices in MAS appointments. These include if they would like to receive a diagnosis, who this can be shared with, and treatment decisions. Therefore, enabling choice and establishing consent before, during and after diagnostic delivery is critical. Consent is an explicit, dynamic process and cannot be assumed. It must be overtly established, or even re-established if previously discussed, prior to sharing the diagnosis.

Louise (Clinician): all that checking beforehand, checking that, are they ready to hear it, do they want to hear it. I check all that, 'Would you want to know?' Even at the diagnosis appointment, "Is this something that you'd want to know?"

Within the context of a good delivery of a diagnosis of dementia, consent not only applies to receiving the news, but also about who the news can be shared with, who is present, and who contributes during appointments.

Jennifer (Clinician): It's about gaining their [patient] permission, their acceptances to whether we can talk to family members.

At first glance, consent appears to be a simple task. However, there are critical steps before and after that ensure consent is meaningful. For someone to be able to consent, or to make a choice, about receiving a diagnosis they need to be fully informed. This means that a good diagnostic delivery will have established a clear and shared rationale from the outset of the assessment

appointment. It is also important for clinicians to use terminology such as 'dementia' from the beginning. Here Louise outlines why this is so important:

> *Interviewer: Does understanding change for people between the assessment appointment and diagnostic delivery?*
> *Louise (Clinician): The assessment appointment can be very emotional as well because you do have to use that word dementia. I feel it's very important to say, I always use the word dementia and if I bring you back to the second appointment and start using the word dementia, they haven't been allowed to get off the process. At least if you're saying that at the assessment, they have a choice.*

The 'getting off the process' as Louise describes it, or choosing to not attend or receive the diagnosis is within everybody's right and services should respect this choice. However, when discussing consent and choice with people, good practice involves exploring the reasons for decisions and possible outcomes, making the process meaningful. Again, Louise's account demonstrates how the simple concept of consent requires time to process with the patient and care from the clinician:

> *Louise (Clinician): if they say, "No, I wouldn't want to know," then they don't want to know, [but] you would explore that a little bit more. You wouldn't say, "Oh well, sorry, off you go, then, you don't want to know." You'd explore that, "Why, what does that mean? What does it make you feel?"*

Finally, the most important element of gaining consent or inviting patient choice is that these wishes are respected[59]. If all the above elements are achieved then the clinician, patient and companion can work together, which for participants of this study was a valuable experience.

[59] See quote from Edna in journal paper

3.2.3.4. Be patient centred

Alongside the clinician holding the patient as the focus, as outlined in the journal paper, it is important that the delivery of a diagnosis of dementia is made personal for each patient. It was acknowledged in this study, that working in a patient centred way was hard and effortful.

> *Louise (Clinician): you have to work very hard at keeping it personal. It would be easier to not make it so.*

As it is an effortful task, it is important that the clinician does not allow themselves to switch their focus to the companion. Clinicians also need to hold in mind that every attendee receiving a diagnosis is a person whose experiences are greater than medical concerns.

> *Interviewer: How do you know that you are being person centred, what are the things you do to make it person centred?*
> *Pat (Clinician): […] Not taking people out of the equation, not just talking to the carer, or just about the medical needs … Not really accounting for any of the other issues that are important to that person.*

Therefore, a good delivery of a diagnosis of dementia has a focus of the patient and, but attempts to ensure a boarder view of the patient, not just as medical problems, but as a person.

3.2.3.5. Provide emotional support

This is linked to the emotional journey of attendees, but is focused on the explicit provision of emotional support. This must be delivered alongside information about the diagnosis as heightened emotions can prevent the development of understanding[60]. Companions are often a source of great emotional support for the patient during the diagnostic delivery. Therefore, clinicians also need to explicitly support companions as well as the patient.

[60] See quote from Susan in the journal paper

Jennifer (Clinician): Sometimes it's comforting the partner because the person that's had the diagnosis maybe okay, it's the partner that can be quite upset.

As such, during a good diagnostic delivery of dementia the clinician is actively moving between information provision and emotional support. They also need to remain aware of all attendees and provide support as appropriate.

3.2.4. Covert Tasks

These are tasks that the clinician is required to complete to ensure a good delivery of a diagnosis of dementia, however the recipient is less likely to be aware of their completion than the overt tasks.

3.2.4.1. Awareness and management of power

During the delivery of a diagnosis of dementia is it important that the clinician is aware of power and where this lies. There is a need to be aware of the power imbalance between the clinician and the attendees, as well as the powerful nature of the diagnosis.

Overcoming power imbalance between clinicians and attendees

Outlined in the journal paper is the importance of working towards a collaborative as possible relationship between the clinician and attendees. How the clinician develops this is complex, but initially the clinician must recognise and understand the power they hold as a relative 'expert'. Ann's account reveals how attendees can value the clinician's expertise to manage the delivery of information about the diagnosis:

Ann (Companion and wife of Michael, appointment with Louise): [discussing if her informational needs had been enquired about] I'd want to trust the skills of the person who was doing it. They can't know us as such but if she's well-trained, she'll be able to read us and I think I'd want to trust those skills.

Later, Ann then described how, in her and Michael's appointment, they had not felt any fear in asking questions of the clinician. This demonstrates the intricate nature of the power balance, as at the same time as wanting the clinician to have the power, Ann felt equally able to openly engage with them. Although some attendees feel comfortable to actively take a more collaborative role, like Ann, it is the responsibility of the clinicians to work towards overcoming the power imbalance. Here Edna reflects on how there has been a shift in expectations of power over time:

> *Edna (Patient): They're not like the old days where my mother used to creep into the doctor's surgery and she was terrified and anything they said that was the gospel and she daren't ask them any questions and it's all changed. It's much better.*

Therefore, to achieve good practice, the power balance needs to be carefully monitored by the clinician. At certain points, they may need to take steps such as inviting questions, using open non-verbal communication, inviting shared decisions, and being open to challenges to attempt to re-balance the power.

The position of power also alters as the diagnosis is shared. Prior to the news being broken the clinician is arguably most powerful. However, once the diagnosis has been stated the power is held by the recipients of the news.

> *Interviewer: What is the most difficult part of delivering the diagnosis?*
> *Jennifer (Clinician): You don't really know the person and you go on your instinct but it's waiting for that response when you've just told them the diagnosis. You just never know, despite as many instincts as you hope work for you, you just never know what response is going to come back at you … you sit there thinking, "Oh, answer".*

Due to this shift clinicians also need to be able to tolerate a feeling of being powerless to enable to attendees the time to process the news.

Remain aware of diagnosis's power

As previously stated, a diagnosis of dementia is a life changing diagnosis with many negative connotations. Therefore, it is a very powerful diagnosis to both deliver or receive.

> *Interviewer: What it's like to deliver a diagnosis of dementia?*
> *Jennifer (Clinician): […] you are aware of the impact it's going to have on that family, that person.*

Here Edna and Alan's discussion about the diagnosis highlights the power the term holds for them:

> *Edna (Patient, attended with Alan her husband): it's not like measles which is you have measles and you start with measles and you finish with measles and you don't have measles again probably whereas dementia, it's a label almost, that you have forever.*
> *Alan (Companion): For life, yes. To my mind it's not a nice word.*
> *Edna: Yes, because it can get used in, "Oh, She's demented" as a sarcastic, not sarcastic but just as, not meaning it mental but meaning it as a criticism sort of thing, a nutcase like, that sort of phrase.*

Due to this the clinician needs to take care about the introduction of the diagnosis and manage this in a sensitive way.

Equally, providing a diagnosis can be a powerful way of providing understanding of someone's experiences. For some people, like Jane, the diagnosis delivered by Jennifer, MAS clinician with 9 years' experience, provided clarity on what had been happening for her husband.

> *Jane (Companion of Stephen): I came out of there, I was a lot clearer myself because I got to find out things which I didn't know and I felt more settled in myself.*

Jennifer's summary broadens out Jane's experience and discusses how many other people have similar experiences:

Jennifer (Clinician): I've often had from a patient, "you've given me a name to it now, there is something definitely wrong". So a lot of older people think they're losing it, they're getting older but you've actually given them a name now and they feel quite comforted by that, even though it is dementia but they've got a name and they've got something to work with.

However, the presence of dementia and its diagnosis can also have a negative impact on life. Here Stephen's diagnosis changed both his and Jane's life:

Stephen (Patient attended with Jane, his wife): They stopped me driving and things like that.
Jane (Companion): we've always been independent but now I depend on my son to come down or my daughter to come down and it's not us, is it? I put them out because she works, he works, and it is hard to rely on other people, when I've been independent all my life.

Therefore, the clinician must retain respect for power and the positive and negative implications that a diagnosis of dementia can have for individuals. With careful consideration, this power can be managed to ensure as good as possible diagnostic delivery is achieved.

3.1.1.1. Awareness and management of dynamics

This theme relates to the triadic nature of many MAS appointments and the extra complexity this brings. The triad can bring uncertainty of roles.

Interviewer: How did it feel to attend your appointment?
Ann (Companion and wife of Michael): I didn't know whether it was right for me to be involved or not and what people required in order to assess Michael, whether it would be better without me or with me or whatever.

Therefore, the clinician must actively manage the triadic relationship and interactions.

Interviewer: How do you manage tension between patients and companions?
Jennifer (Clinician): It's about acknowledging the person at the forefront but saying, "I'm listening to what you're saying but let me just hear what this person's going to say" acknowledging the family member as well and encouraging the patient.

When the interaction is managed, companions can often provide a source of rich information to aid diagnosis, as well as emotional and practical support during and after diagnosis. However, the clinician must be aware of the dynamics between patients and companions to ensure that the clinician does not negatively impact on either party. This can be especially difficult when provision of confidential time or space for each party is not available.

Susan (Clinician): you ask a question, "How are things at home?" and the service user, "Oh, yes, fine, fine, I'm doing all my washing, doing my ironing, doing my cooking." The daughter's sat at the side shaking her head and you just know that it's not happening but then it is very, very difficult for that daughter to discredit what her mum is saying.

One way to overcome this is via the disclosure of information in a written form. Here Ann describes how they managed to navigate the sharing of information that Michael had forgotten:

Ann (Companion and wife of Michael, appointment with Louise): I've been writing out things to take in with me of particular things that I'd noticed about Michael and that we'd talked about that he couldn't remember and that was accepted [by Louise] but we had also talked about not sharing those again because there were things I remembered that he didn't and didn't need to. So I just handed those over and they were accepted like that, which was great.

In this example, the sensitivity of the clinician enabled the least possible distress to be associated with the disclosure. Therefore, a good delivery of a diagnosis of dementia considers, and is sensitive to, the dynamics between attendees.

3.2.4.2. Continual adaptation

Adaptation to attendees perhaps underpins all other themes that form a good delivery. To successfully adapt practice to each person and throughout each appointment the clinician has to continue to complete 'mini assessments' and respond accordingly. This means that clinicians cannot adopt set expectations of how people should receive the news, or choices they make after the diagnosis.

> *Pat (Clinician): I try not to be, have an attitude of this is what you have to do. I have this information that can help but you need to tell me what I can do for you.*

3.2.4.3. Maintaining professional standards

Predominantly this theme relates to how the clinician continues to ensure their own quality of practice. A good delivery of a diagnosis of dementia relies on the clinician understanding the diagnosis, and having the most accurate and up to date information about treatment or support options. How this is achieved differs for each clinician but is nevertheless important. Here Pat is reflecting on how he overcomes some of the harder elements of diagnostic delivery and highlights the role of supervision from senior colleagues:

> *Pat (Clinician): MDT discussion and case formulation which is my opportunity to get it in my head. This person has x y and z, the scan says… and we are leaning towards x. I have a good relationship with the doctor to ask why is it Alzheimer's and not a vascular like that. They are happy to explain it. Once I have it in my head so I can explain it and pass it on.*

Having clinical experience of delivering diagnoses of dementia was also referenced as important in being able to achieve high quality diagnostic appointments. However, it was also suggested that it was possible to use of prompt sheets to guide less experienced clinicians in delivering good quality diagnoses.

3.3. Initial Draft Tool Development

The journal paper provides an overview of each tool and a rationale for the development of two paper based tools. Copies of the draft tools are presented in Appendices S and T. Table 9 in the journal paper provides an account of the incorporation of the most salient themes from phase one. Due to space limitations, only the most influential themes were reported in the journal paper. Table 14 below demonstrates the representation of all phase one themes across all elements of the tool.

Table 14: Overview of phase one themes in draft tool

		Overcoming Barriers			Navigate Multiple Journeys			Overt Tasks						Covert tasks				
		Service design	Political Environment	Challenge of dementia diagnosis delivery	Journey of the delivery	Clinician's emotions	Attendee's emotions	Provide emotional support	Promote consent and choice	Develop a supportive relationship	Be patient centred	Develop understanding	Awareness and management of dynamics	Continual adaptation	Maintain professional standards	Overcoming power imbalance between clinician and attendees	Remain aware of diagnosis's power
Service deliverer's guide overall										**X**					**X**		
Sections of deliverer's Guide	Clinician self-care	**X**	**X**	**X**		**X**											x
	Terminology											**X**					x
	Patient as the focus										**X**		**X**				
	Consent								**X**								
	Engagement									**X**						**X**	
	Information and understanding				x							**X**					
	Emotional support						**X**	**X**									
	Adaptation													**X**			
Guide	**Attendee's guide overall**									**X**		**X**					
	Memory assessment service overview				x							**X**					
	Bringing support							**X**			**X**						
	Concerns and questions															**X**	
Notes Sheet	Choices								**X**								
	Current concerns										x	**X**	**X**			**X**	
	Making choices								**X**		x	**X**	**X**			**X**	
	Other important information										x		**X**			**X**	
Prompt Sheet	Concerns and questions									**X**	x					**X**	
	Choices								**X**	**X**	x					**X**	
	Results			x								**X**					
	Information			x								**X**					
	Next Steps			x								**X**					
	Contact information			x								**X**					

Key: **X** = displayed in Table 9 in Journal paper, x = present in tool but secondary aims and therefore not reported in journal paper

3.3.1. Service deliverer's tool

The first draft of the service deliverer's tool was designed to promote the elements of a good delivery of a diagnosis of dementia based on themes in phase one, wherever possible an attempt was made to represent each theme.

How the themes were represented in the tool varied, with some themes holding a specific section and other themes simply influencing the tool's development. For example, consent and choice was included as a specific section to highlight the importance of these concepts. However, the theme 'remaining aware of dementia's power' was not explicitly referenced. Instead this was woven into the tool with references in clinician's self-care to the impact a dementia diagnosis can have and in terminology of the utility of using the term dementia. Themes that appeared more specialised to dementia diagnoses and those less well represented in other protocols were prioritised. For example, a specific section relating to focusing on the patient and managing the dynamics of triadic relationships was included in the service deliverer's tool, as this is both highly relevant to dementia diagnostic delivery and was not as frequently discussed in existing protocols.

Overall, the main aims of the service deliverer's tool were to: attempt to encourage high and consistent standards of diagnostic delivery by outlining key elements of good practice; emphasise the importance of developing a supportive relationship during diagnostic delivery; and promote clinician's self-awareness via reflective practice. At the time of development this appeared to be a novel tool.

3.3.2. Service recipient's guide

This tool did not attempt to promote all the themes identified in phase one. For example, the themes of 'the clinician's emotional journey' and 'continual adaptation' would not have been appropriate to include in the attendee's tool as the responsibility lies with the clinician to act on these. Alongside this, themes relating to barriers that the clinician must overcome, such as the political challenges and service restrictions, would also be inappropriate for attendees

as this may have increased distress or discouraged people from attending appointments. Furthermore, care was taken to provide 'just enough' information and paperwork, to avoid overwhelming attendees.

Overall, the main aim of the attendee's tool was to provide information about the appointment; to reduce fears relating to not knowing what to expect; to encourage more active participation in appointment; and to support people to make, remember, and express choices in their appointment.

3.4. Phase Two Themes

The aim of the second phase of this project was to establish the acceptability of the draft tool. Three a priori themes were established prior to data analysis; barriers to uptake, usage, and alterations. One further theme was identified following the inductive analysis, which was titled benefits.

3.4.1. Benefits

Across all focus groups, participants provided positive feedback about the tool. The feedback was across a range of depths, from the tools in general to very specific areas or features. Here service recipients, Kate and Doris, are considering if both tools would be helpful:

> *Interviewer: Do you think that that they would be helpful?*
> *Doris (service recipient): Yes, very good.*
> *Kate (service recipient): Both of them, yes.*
> *Doris: It's ideal.*
> *Kate: I just think it's really, really good, everything is in.*

Here Emily, a senior service deliverer, considers the reasons she found the service deliverer's tool positive:

> *Emily (Service deliverer): What I would like to say is that the best thing for me about this is that this tool is based on the findings and feedback from the people that you've interviewed who are the members of staff or*

who have been through our service, so for me, this is great and that's a really good thing about this piece of work.

For the service deliverer's tool, the focus on relationships and the inclusion of the impact of receiving a diagnosis on the recipient were specifically appreciated.

Rose (Senior Service Deliverer): I like the bit about just maintain that relationship with somebody at the very beginning, not jumping straight into the diagnosis.

Emily (Senior Service deliverer): I think that's important in terms of that it does give you it from the other angle, so it isn't just about what we might expect nurses to consider taking into consideration in terms of how they deliver that but also of what might happen as a result of that person sitting in front of them and what they may need to take into consideration.

The provision of a notes sheet for service recipients was particularly welcomed[61]. Participants felt that the provision of two copies would be very helpful, as well as how it could help people to capture their thoughts and questions even if they were experiencing changes to their memory.

Laura (Service deliverer): it's [service recipient notes sheet] a very good idea because I think when people get that letter there will be a lot of thoughts going through and it might be that they want to write it down immediately or think about it for a few days and then look it again before they come to the appointment.

The positive feedback received is an encouraging indication that the tool would be deemed acceptable and desired.

[61] See journal paper for consideration of the service recipient's guide and quote from Victoria

3.4.2. Usage

When considering the acceptability of both tools it was important to consider how participants envisaged their use. If participants indicated that they would use the tool in a way that was in keeping with the original aims, this suggests that the tool's design was acceptable.

3.4.2.1. Service deliverer's tool

Interestingly, participants identified that the tool may serve different functions for clinicians with different levels of experience. For clinicians who are new to the diagnostic delivery of dementia participants suggested that the tool could be used to support their professional development and in preparing for the complexities of the delivery[62].

> *Annabel (Service deliverer): But for someone starting new into the service, I think it's to draw their attention to how complex it might be. I think that's helpful.*

Participants particularly noted the importance of the section relating to the emotional impact of delivering a diagnosis for supporting inexperienced clinicians.

> *Emily (Service deliverer): I do remember how, harrowing is probably the word that I would use, it is when you give a diagnosis because it's so devastating to that person and they may react in many different ways, from you may have a person who actually doesn't seem to almost bother at all to a person who is wracked with sobs and inconsolable.*
> *Rose (Service deliverer): And it's being prepared for that.*
> *Emily: And I'm being prepared for that, so this will almost help them to be prepared for it.*

However, Emily's use of the word 'almost' also indicates that it is perhaps also not entirely possible to prepare for delivering a diagnosis of dementia without

[62] Also see quote from Pat in journal paper

having the direct experience. This suggests that the tool's role should not be overestimated or replace the need for experiences such as shadowing other clinicians when developing as an inexperienced clinician.

For clinicians with more experience, participants indicated that the tool may be used as a tool for reflective practice or in supervision.

> *Pat (Service deliverer): what it could do is actually form the basis of some supervision as well in terms of discussing in clinical supervision or the MAS quarterly meetings and pick out, is that good, is that bad.*

Additionally, the service deliverer's tool was identified as capturing the hosting service's ethos.

> *Emily (Service deliverer): I feel you could use it as part of a philosophy of care really for our service, so yes it can be a tool but almost philosophises the whole service.*

This was a positive surprise that participants felt they could so strongly relate to the content of the tool, that it could encapsulate the whole service's ethos. This was unexpected as the original aim of the tool focused only on the diagnostic delivery, and its application to wider usages had not previously been considered.

Overall, participants' suggested usages of the service deliverer's tool indicated that they found it to be acceptable. Alongside this, they also identified usages not previously considered in the tool's development.

3.4.2.2. Service recipients' tool

An overall aim of the service recipient's tool was helping to alleviate fear and participants indicated that they felt the tool would be able to meet this aim.

Pat (Service deliverer): sometimes people don't know quite what it is that we're going to do, perhaps it will give them a clue to the sorts of things we're going to ask as well, so we're getting over that trepidation part .

Specifically, the inclusion of information about the service was designed to help structure thoughts and support attendees prior to and during their appointment. The notes sheet was highlighted as meeting this aim.

Victoria (Service recipient, wife of a person with dementia): I think it would be a very good tool because it would give you some guidance of what you're thinking and what you want to say but because you're so naïve you don't know what you want to say or what you want to think.

Kate (Service Recipient, daughter of a person with dementia): With this there's the opportunity to write down and then I can say look, "These are for you to read and this is what we can go over when you ask any more questions if you're unsure" and they are all written down what they suggested and what will help and I just think that's lovely.

As participants felt the tool was likely to be helpful, service deliverers suggested that it should be shared with attendees at the point of the GP considering referring to MAS, rather than with the MAS appointment letter.

Emily (service deliverer): This could be better used by the GP in that very initial appointment because a) it would prompt the discussion for the referral, b) it helps give the GP something to talk to in terms of, so that they know also what the patient might be expecting to do but they can talk them through that and then gives the patient something to take home with them after that appointment, so whilst they're awaiting their appointment from our service, they can be having a think about all of that and making some notes because I do really like the sheet here that says, what are your main concerns at the moment and what questions would you like to find out at the appointment and things like that, so it gives

them a prompt to think about that and they can then bring that with them, so I think that's really helpful, so this would better sit with the GP.

This was a further indication that the tool was deemed by participants to be acceptable as they were suggesting an extended application than previously proposed.

3.4.3. Barriers to uptake

It was important to explicitly consider if there were any perceived barriers to either tool being used in the future. Indication of a high volume or particularly significant barriers would indicate that the tool was not sufficiently acceptable.

3.4.3.1. Service deliverer's tool

A main barrier for any paper based tool is the level of engagement it can achieve with its intended user group. A potential barrier highlighted for the service deliverer's tool was whether clinicians perceived it to be necessary in their practice. Here Susan is expressing how she felt unsure if the tool would be necessary where good practice was already occurring:

Susan (Service deliverer): I certainly think that in some areas that all these things are being carried out and things are quite good and I don't know what you could do different really.

Laura also expressed concern about how clinicians would engage if they perceived their own practice to already be of a high quality:

Laura (Service deliverer): I think the only thing that concerns me is some of the clinicians might feel that they're a bit like sucking eggs.

Therefore, it is possible that when a clinician assesses their practice as already positive, they may not readily engage with the tool. Despite the risk that some clinicians may feel patronised by the tool, other clinicians felt comforted when they compared their practice to the suggestions in the tool. Here Rose

considers both how other clinicians may engage with the tool, but also how she felt when reviewing the tool in the focus group.

> *Rose (Senior Service deliverer): I would say that the majority of people are doing it this way anyway but yes, it would be something to read and think to yourself, because as I was reading it, I was imagining me giving that diagnosis thinking, "Yes, I do that, yes, I do that," so it's something a bit reassuring really.*

Potentially depending on how clinicians assess their practice may affect the way they engage with the tool. Some may find it a helpful tool for reflective practice or for building confidence, whereas others may disengage or disregard the tool. However, some participants felt this may be able to be improve engagement the tool's introduction[63].

> *Hannah (Service deliverer): Perhaps it's more about how, not whether it's there or not but how it's given … so perhaps it's less about whether it's there and how it's offered is probably the key in how people will take it, so if they don't want to look at it, they don't.*

Another area of consideration as a barrier to the tool's uptake was the more global barrier of the power of the tool to affect change. Pat here is reflecting on people's willingness or ability to be able to first engage with the tool, but then to be able to adjust their practice.

> *Pat (Service deliverer): people who perhaps are already either struggling or not as aware themselves of how to do that, how to control themselves, for want of a better way of saying it … but that's not necessarily anything that's perhaps going to be fixed per se by the tool.*

Therefore, it is important to recognise that no matter how acceptable the tools are, there is always the possibility that it may lack power to vastly change

[63] Also see Pat's quote in the journal paper

practice. Despite this, the barriers identified[64] were not felt to be sufficient to prevent the service deliverer's tool being a helpful addition to MAS settings.

> *Rose (Senior Service deliverer): I think that all of the staff in the clinics now would be interested to see it.*

Overall, it appears that participants were suggesting that the service deliverer's tool is likely to face inherent barriers to its uptake that any paper based tool may face. Alongside this, there are likely to be individual differences between clinicians to the degree that they chose to engage with the tool. However, participants thought that many clinicians are likely to be receptive to or interested in the tool, which is at least a positive starting position. Furthermore, participants highlighted how careful introduction of the tool may help other more hesitant clinicians to also engage. Therefore, the principle of a service deliverer's guide was assessed to be sufficiently acceptable and retained.

3.4.3.2. Service Recipient's tool

The journal paper outlines the major concern raised with the service recipient's prompt sheet. It is important to note that the concern about volume of paperwork was only expressed by service deliverers[65]. The quote below is the only direct consideration of the volume of paperwork by service recipients:

> *Interviewer: Would the paper work put people off?*
> *Kate (Service recipient, daughter of a person with dementia): Oh no, I don't think so, no.*
> *Doris (Service recipient and person with dementia): No, it's a guide isn't it. They don't have to read it; you don't have to do it but it's guiding the person making them feel as though they're caring.*

The lack of unprompted discussion about the size of the service recipient's tool by service recipients is an important consideration. Focus group participants

[64] See journal paper for the potential barrier of clinicians feeling patronised
[65] See Rose's quote in the journal paper

offered critical reflections on other aspects of the tool, and therefore it was unlikely that they were only providing positive feedback. As such, it is possible to consider the size of the tool as largely unremarkable.

Some participants suggested that the inclusion of the prompt sheet and the encouragement to use this in MAS diagnostic appointments may adversely affect appointments.

> *Emily (Service deliverer): I think my only problem with that is when it's saying, write down here what you've been told so that you can refer back to it. I suppose our appointments are time limited and what might happen as a result of that the patient might sit there and literally get that out at the end and sit writing and that may cause clinics to be late and things like that.*

> *Rose (Senior Service deliverer): We have half an hour in which to deliver, prepare somebody, deliver their diagnosis, discuss the treatment options, write them a prescription, but you literally have half an hour, so the struggle we have is that clinicians saying, "There's not enough time," so to add something into … to actually sit with somebody and then go through a form would take additional time then to do.*

This clearly requires important consideration as any tool that negatively impacts on appointment time and potentially adds extra burden on MAS clinicians is unacceptable. If the difficulties with the prompt sheet can be overcome, it is possible that the main barrier is the clinician's perception of user acceptability of the extent of the tool. This is noteworthy as the uptake of the tool will depend on MAS clinicians and services providing access to the tool. Therefore, it must be considered that even though the prompt sheet appears acceptable to the end user, the gatekeepers to the tool did not find it acceptable in its current format. As such, actions are required to modify this area to improve acceptability.

3.4.4. Alterations

All focus groups were directed to provide critical feedback about the content of the tool and to also make suggestions for alterations. This was to mitigate against any effect of social desirability leading to the provision of overly positive feedback.

3.4.4.1. Service deliverer's tool

There were some suggestions of alterations to the phrasing of some sections. This included changing the emphasis of some sections, such as emotional support, and including specific references to avoiding making assumptions.

> *Annabel (Service deliverer): I highlighted under emotional support 'at least some consideration.' I don't know, I'd take out 'at least' and I would add in something about directly asking for emotional reactions as part of the process. I think that's the best practice but being aware of it is fine but because people tend to minimise their emotional reaction to dementia diagnosis.*

> *Hannah (Service deliverer): check at the beginning, make sure you're not re-going over what they already know but you're also not missing out anything that they might not understand fully or might of thought they understood but actually wrongly understood.*

Participants also felt that the service deliverer's tool required additional sections relating to accessing appointments.

> *Annabel (Service deliverer): So could there be a section perhaps on accessibility even before, in thinking of your patients and the role of memory impairment on how they access those services.*

It was also suggested that a specific focus on the environment of the appointment would be beneficial to include and raise awareness about.

Victoria (Service recipient, wife of a person with dementia): I think the environment is important. I think it needs to be in a quiet, non-sterile environment.
Kate (Service recipient, daughter of a person with dementia): So maybe having something in specifically about making the space, because sometimes it's hard, you get given the room that you've got, about how you set the seats up if you can, making it…
Doris (Service recipient and person with dementia): If you could just make it less clinical.

The alterations offered by participants suggest that the tool's acceptability can be improved. It also highlights additional areas that are important for a good diagnostic delivery of dementia, such as supporting access to appointments, that did not feature in phase one.

3.4.4.2. Service recipient's tool

Participants identified that improvements could be made to the way dementia was explained in the tool. This included separating it out from an introduction of MAS, and altering the focus.

Victoria (Service recipient, wife of a person with dementia): You've listed two of the types of dementia. If they're given a different diagnosis, they may think they're only the two types there are, so that might be better left blank.
Matthew (Service recipient, husband of a person with dementia): There are several types.
Victoria: Because if you're coming away and you've not got Alzheimer's or Vascular you're going to think you're not, that this doesn't apply to you.

Service recipients also raised that references to professionals in the MAS appointments needed to be clarified to avoid confusion.

Victoria (Service recipient): You've just described them as the nurse. What kind of nurse are you thinking of because people may react to different types of nurses. If you say it's a psychiatric nurse that's going to be talking to you, they may react differently to a ward nurse.
William (Service recipient): When you've said specialist doctors and nurses, I mean that's not specialist doctors and nurses, it's specialist doctors and specialist nurses.

There was also discussion about the inclusion of information about the legal implications of receiving a diagnosis of dementia. People felt that it was important to particularly include information about power of attorney.

Matthew (Service recipient, husband of a person with dementia): If there's any mention of dementia you've surely got to mention power of attorney at the same time because if you once get to the stage where mental capacity has gone you will not get power of attorney. So the sooner you look at that problem, the better.
Ruby (Service recipient, person with dementia): It's horrible having somebody say it [dementia] to you and it's horrible suddenly having to accept it but I think the sooner, the sooner you start to try and cope and make arrangements for when it does hit and when you don't have capacity anymore because there could come a time when a person of the council or somebody in another authority could say what's going to happen to you" and this lasting power of attorney means that that decision would be taken by your next of kin.

In the notes sheet, participants felt that there could be extra support for people when completing the section relating to their current problems. Participants felt that by including specific areas of life this could help people to identify areas of concern more readily. It was noted that the focus appeared to be for older age groups.

Hannah (Service deliverer): it probably sounds less intimidating doesn't it when you're asking about each element. Rather than having to just say,

"Yes, I'm just struggling, full stop" they can say, "Well, this bit's been fine but actually, okay, I'm happy to admit that there has been a problem in appointments or banking" or that type of thing.
Laura (Service deliverer): Because it might be that they're fine with their banking but they can't remember to keep their appointments.

Victoria (Service recipient wife of a person with dementia who was diagnosed under the age of 65): looking at it from a younger person's point of view as well, it said there are no questions about how does it affect your work.

It was also raised that encouraging people to make decisions and record these on the notes sheet may give an impression of the choices being fixed or unchangeable. This was considered an area that may cause people to disengage from the tool. However, Hannah (service deliverer) felt that this could be overcome by including a short statement that choices could be altered later. Finally, participant raised that people may find it useful to have a contact number for additional help and support before attending their MAS appointment.

Overall, it appeared that some modifications to the service recipient's tool could improve its acceptability.

3.5. Tool revision and finalising the prototype

Overall, the feedback received was that the design was largely acceptable. Participants indicated that the tools were usable in current practice when considered with the proposed alterations and the removal of the prompt sheet. Therefore, the principle design of two separate tools and the inclusion of the notes sheet for service recipients were retained. However, to improve the overall acceptability of both tools, alterations were made prior to finalising the prototype tool. Tables 15 and 16 outline the changes made. The revised tools can be found in Appendices U and V. The tools were also compared to the existing literature, as shown in Table 17.

Table 15: Service recipient's tool: overview of modifications

	Description of the change	Why changed
Service recipient guide		
Introduction	Expansion of description of the tool to reflect additional sections. Additional explanation of why the guide has been received	Changes to other areas of tool required introduction. Original introduction did not clearly state why someone would have received it, this may have increased anxiety or confusion
Memory assessment service	Change of focus. Revised to provide a general overview of MAS settings, rather than an option for each area to insert information. Inclusion of specialist to describe MAS nurses Removal of dementia from this section	Feedback from Service deliverers regarding detail and clarity. Comments from service receivers about potential confusion about how dementia was introduced in initial draft, and around nurse's title
Bringing someone with you	No changes	
Main concerns and questions	No changes	
Making choices	Removal of prompt to write choices down	Replication of content in notes sheet, attempt to keep length of guide compact following service deliverer's feedback regarding volume of paperwork
What is dementia?	New section inserted. Brief overview of symptoms of dementia and common types. Provision of signposting to gain more detailed information	Feedback from both service deliverers and service recipients to improve description about dementia
Extra information	New section inserted. Signposting to Alzheimer's Society, National Dementia Helpline, and GP	Incorporation of 'who to contact' from prompt sheet

Table 15: Continued

	Description of the change	Why changed
Service recipient notes sheet		
Introduction	Insertion of prompt to write choices down from guide. Addition comment included highlighting the tool is for individual's own use, but this can be shared if they would like	Concern from service deliverers that people may feel they must complete the form, rather than as a supportive tool.
Main concerns	Re-ordering of questions. Inclusion of specific areas where difficulties may have been experienced	Feedback that starting with a closed question may not encourage people to continue to use the tool. Service deliverers and recipients both expressed that structuring how someone might identify areas of difficulty could be helpful
Making choices	Inclusion of prompt that choice can be changed	Feedback that people may not feel able to record decisions if they felt they would be final, or realise that they would be able to change their mind at a later point
Service recipient prompt sheet	Removed – topics combined into other areas	Service deliverers identified that this could put additional burden on clinicians and this was deemed to make this element of the tool unacceptable

Table 16: Service deliverer's tool: overview of modifications

	Description of the change	Why changed
Service deliverer's guide		
Introduction	Removal of reference to service recipient's prompt sheet	Removal of this element of the tool
Looking after yourself	No changes	
What make a good delivery	Formatting change – combination of two paragraphs into a single piece of text	Visual impact
Attending the appointment	New section. Inclusion of consideration of reminding people to attend and any transport support they may need	Service recipients indicated that people may need support to get to appointments. Service deliverer comment that a good delivery requires the person to attend an appointment and consideration about how clinicians can support this is important
Environment	New section. Prompt for clinicians to make changes to layout if required	Referred to in phase one results, but feedback in phase two from service recipients that this would be an important topic to highlight more explicitly
Terminology	Additional information included. Extra information about gentle introduction and assessing people's current associations with terminology	Service deliverers reported that the previous wording of this section failed to capture the care that is required
Patient as the focus	Inclusion of prompt to offer each attendee confidential time to help support difficult dynamics, and reference to the need for clinicians to hold each person's perspective in mind	Direct feedback from a service deliverer to improve clarity of discussion of dynamics and to explicitly remind clinicians they can be flexible with provision of 1:1 time
Consent	Changes to formatting – removal of paragraphs	Visual impact

Table 16: Continued

	Description of the change	Why changed
Engagement	Removal of three pointers of how to achieve engagement	Feedback from service deliverers that some elements were stating the obvious, so removed to prevent patronising readers
Information and understanding	Inclusion of a line that people may prefer a black and white explanation	Feedback that the previous version did not present this choice that some people may desire
Emotional support	Removal of the word ‘some’. Inclusion of reference to the life changing nature of the diagnosis	Feedback that the original version risked minimising the emotional impact of receiving a diagnosis of dementia
Adaptation	No changes	
Closing an appointment	New section. Transfer of elements from the service recipient’s prompt sheet. Includes leaving time to end the session well without rushing, informing people of the next steps, supporting them to write down any key information, discussing legal issues such as driving and lasting power of attorney, and providing contact information for local or national services	Removal of prompt sheet. Service recipient’s feedback of the importance to discuss legal issues as early as possible.

Table 17: Comparison of tools to existing literature

Title & Authors	Overview	Commonalities	Additional sections or areas	Exclusions
SPIKES Original book: (Buckman, 1992) Paper with model: (Baile et al., 2000),	Guideline for breaking bad news to patients about their illnesses: S – setting up the interview P – assessing the patient's perception I – obtaining the patient's invitation K – giving knowledge and information to the patient E – addressing the patient's emotions with empathic responses S – strategy and summary	Both have a 'tool' that can be easily used by clinicians Specific elements in both service deliverer's tools: • S relates to section: 'environment' • P relates to 'consent' • I can be found in 'Information and understanding' • E is comparable to 'Emotional support' • S is 'Closing an appointment'	Service deliverer's tool: • Looking after yourself as a clinician • Attending the appointment • Terminology • Patient as focus (but not excluding companions) • Engagement • Adaptation Service recipient's tool as a whole	None identified
BREAKS (Narayanan et al., 2010)	A six-stage protocol for systematic and easy communication strategy for breaking bad news: B – background (preparing) R – rapport E – exploring [what the patient already knows] A – announce [the news] K – kindling (deal with emotions and correct misunderstanding) S – summarise [the session]	Both have a 'tool' that can be easily used by clinicians Specific elements in both service deliverer's tools: • B relates to section: 'environment' • R compares to 'Engagement' • A can compare to 'terminology' and 'information and understanding' • K is 'Emotional Support' • S relates to 'closing an appointment'	Service deliverer's tool: • Looking after yourself as a clinician • Attending the appointment • Patient as focus (but not excluding companions) • Consent • Adaptation Service recipient's tool as a whole	• Exploring what the patient already knows is not represented as a standalone section instead located in Terminology. • Background in BREAKS also includes the clinician researching the patient's diagnosis and preparing for questions that may be asked. This is not specifically covered in the service deliverers tool

Table 17 continued

Title & Authors	Overview	Commonalities	Additional sections or areas	Exclusions
ABCDE (Rabow & McPhee, 1999)	Techniques for delivering bad news well: A – advance preparation B – build a therapeutic environment/relationship C – communicate well D – deal with patient and family reactions E – encourage and validate emotions (reflect emotions)	Both have a 'tool' that can be easily used by clinicians Specific elements in both service deliverer's tools: • A links to 'Environment' • B is comparable to 'Engagement' • C can be linked to 'Terminology', 'Information and understanding' and 'Adaptation' • D has some similarities with 'Patient as the focus' • E relates to 'Emotional support'	Service deliverer's tool: • Looking after yourself as a clinician • Attending the appointment • Patient as focus (but not excluding companions) in all communication not just in dealing with reactions. • Consent • Closing an appointment Service recipient's tool as a whole	None identified
How to break bad news to people with intellectual disabilities (Tuffrey-Wijne, 2013)	Framework Central feature: Building a foundation of knowledge Features around this: Understanding - how or if the person can understand the news People – including everyone with significant involvement Support – for the person and those around the person	Foundation of knowledge can be compared to 'Information and Understanding' in the service deliverer's tool Understanding is included in sections 'Terminology', 'Adaptation' and 'Information and understanding'. Support – 'Emotional support' is the section most closely related.	This is a framework rather than a tool. As such the service deliverer's tool offers more practical elements of how to complete the diagnostic delivery. Service recipient's tool as a whole	Focus on the people around the person receiving the bad news is not as strongly emphasised in either the service deliverer's or service receiver's tools. Nor does it encourage including everyone in the person's life. Understanding in the service deliverer's tool is not as extensive as this framework as it doesn't consider non-verbal methods of communication.

Table 17 continued

Title & Authors	Overview	Commonalities	Additional sections or areas	Exclusions
Breaking bad news to children – information for staff (Child Bereavement UK, 2011)	Guideline for delivering news about the death of a family member to children. Key points include: When, Who, Where, Check what the child knows, Use truthful words, Repeat information Consider developmental age as effecting understanding of death Discuss feelings	Both have a 'tool' that can be easily used by clinicians Specific elements in both service deliverer's tools: • Use truthful words is like 'terminology' • Repeating information relates to 'Information and Understanding' • Considering effects of developmental age is like considering the effects of memory difficulties located in 'Information and Understanding' • Discuss feelings related to 'Emotional Support'	Service deliverer's tool: • Looking after yourself as a clinician • Attending the appointment • Environment – i.e. making the clinic space the most welcoming, rather than choosing where to deliver the news. • Patient as focus (but not excluding companions) • Consent • Engagement • Adaptation • Closing an appointment Service recipient's tool as a whole • Looking after yourself within the service deliverer's tool is an additional area	• Consideration of when, who is best placed and where to give the news – the service deliverer's guide assumes the clinician is the best placed person and it will be delivered in the MAS diagnostic appointment • Exploring what the patient already knows is not represented as a standalone section instead located in 'Terminology'.
Summary of key components of diagnostic disclosure of dementia (Lecouturier et al., 2008)	• Preparing for disclosure • Integrating family members • Exploring the patient's perspective • Disclosing the diagnosis • Responding to patient's reactions • Focusing on quality of life and wellbeing • Planning for the future • Communicating effectively	Specific elements in service deliverer's tool that are comparable: • Preparing for disclosure – 'Environment' • Disclosing the diagnosis – 'Terminology' and 'Information and understanding' • Responding to reactions – 'Emotional Support' • Planning for the future – 'Closing the appointment' • Communicating effectively – 'Adaptation', 'terminology', 'Information and understanding'.	Service recipient's tool as a whole	• Focusing on quality of life and wellbeing is not captured within the tools or in the themes generated in phase one.

Table 17 continued

Title & Authors	Overview	Commonalities	Additional sections or areas	Exclusions
Other research papers relating to dementia diagnostic disclosure	Generally, these include the central areas of preparation, communication of the diagnostic information, provision of support for both patients and companions, and post-diagnostic care. All advocate for the clinician to adapt practice to meet the individual needs of each patient, as well as working with families and caregivers. Specifically: • finding out what the patient already knows about their diagnosis, using the words 'dementia' or 'Alzheimer's Disease', and exploring the meaning of the diagnosis with the patient (Foy et al., 2007) • diagnostic delivery to be considered as a process, the need for personalised delivery (Werner et al., 2013) • developing understanding of the diagnosis over time (Byszewski et al., 2007) • inclusion of carers and family (Grossberg et al., 2010)	General: • Preparation – section titled 'Environment' • communication of the diagnostic information -section 'Information and Understanding' • Support for both patients and clinicians – 'Emotional support' • adapt practice to each patient – 'Adaptation' section • working with families and caregivers relates to 'Patient as focus' (but not excluding companions) • Finding out what the patient already knows is referenced in 'Terminology' Specifically: • Using the words dementia – relates to section titled 'Terminology' • Process and developing understanding over time is referenced in 'Information and Understanding' • Personalised delivery is referenced in sections 'Information and understanding', 'adaptation', 'emotional support' and 'consent'	• Looking after yourself (as a clinician) and overcoming barriers to good practice are not considered in existing research or recommendations	• Post diagnostic support is not addressed as an action for the clinician. The service deliverer's guide prompts clinicians to signpost and provide information and contact details for further support • Exploring the meaning is not a specific element of the tools, but it could be translated into developing understanding

4.0 Extended Discussion

4.1. Overview of findings

This section considers the findings in relation to the original aims and objectives of the study.

4.1.1. Overarching aim: develop a prototype tool

A review of how this aim has been met is presented in the discussion section of the journal paper.

4.1.2. Primary objective: Explore clinician, patient, and companion perceptions of what stands out as helpful and or challenging about their experiences of dementia diagnostic delivery within a local MAS.

Phase one results explored clinician, patient, and companion perceptions of the diagnostic delivery of dementia. Thematic analysis enabled these perceptions to be developed into the constituents of practice in delivering a diagnosis of dementia. This included: overt and covert tasks; viewing the delivery as containing multiple journeys; and overcoming barriers.

Participants identified overt tasks involved in the delivery of dementia diagnoses, such as explaining test results to support development of understanding. Alongside this, participants also identified covert tasks that included management of power and dynamics, and continual adaptation to the attendees. Importantly, participants also expressed that the delivery of a diagnosis of dementia should be viewed as a process or journey. This journey does not begin and end within the appointment where a diagnosis had been discussed, nor does it only relate to the process of disclosing the diagnostic news. Participants referred to the delivery of the diagnostic news as one small junction on their wider pathway through life before the symptoms of dementia, to understanding the diagnosis, and then onto living with dementia. Viewing the diagnostic delivery as a journey also supported the emotional transitions that both clinicians and attendees experience before, during, and after the sharing of the diagnostic news. By placing the delivery within this wider context,

it was evident that participants viewed a good delivery as being greater than just the constituent parts or tasks completed by the clinician.

Participants also identified barriers that may prevent clinicians from being able to achieve ideal quality delivery. It was evident for the clinicians who participated in this study that they sometimes felt that issues, such as the design of the service or the political agenda, constrained their practice. Due to this, clinicians described a way of working to achieve the best delivery within the limits imposed on them and to buffer attendees from these challenges. It was also identified that there were some inherent barriers to communicating diagnostic news that related to the clinical impact of dementia. Therefore, a good delivery of a diagnosis of dementia requires the clinician to be able to manage these barriers or difficulties and to buffer any negative effect on attendees' experiences.

4.1.3. Primary objective: Identify key elements of practice to inform the design of a prototype tool with potential to support consultations in MAS clinics

The themes developed in phase one were structured around practice points for the delivery of a diagnosis of dementia. A review of these themes highlighted how all elements could be influenced by the clinician. However, as every diagnostic delivery occurs between at least a clinician and a patient, the elements that could be shaped by the patient, and companion where applicable, were also identified. This influenced the development of two tools; one for people delivering a diagnosis of dementia, and another for people receiving a diagnosis of dementia. Table 14 (see section 3.3 in extended results), provided an overview of where each theme was represented in both tools and Table 9 (see journal paper), briefly described how the most salient themes were incorporated into the tools.

The focus of the service deliverer's tool was to guide clinicians to view the diagnostic delivery as more than just the completion of a list of essential tasks. This was achieved by highlighting the need to build a supportive relationship with attendees and manage the dynamics of triadic encounters, as well as considering the clinician's own emotions and the effect of external pressures during a diagnostic delivery. The service deliverer's tool was also intended to be used to support

reflective practice or supervision, as well as supporting the professional development of inexperienced clinicians by highlighting key areas for preparation or practice.

The service recipient's tool focused on increasing the information available to people prior to attending MAS appointments and encouraging patients and companions to have a more collaborative relationship with the clinician. The tool attempted to promote a consideration of main concerns and questions before the appointment, and then prompted people to express these in their appointment. It also attempted to encourage patient choice and control by raising awareness in the information guide and providing prompting questions in the notes sheet relating to making decisions.

4.1.4. Primary objective: Obtain preliminary feedback on the acceptability of the prototype tool

The results from phase two provided positive feedback for both tools. Overall, both tools were assessed as potentially being able to support good practice in the delivery of a diagnosis of dementia. Negative feedback was also received as participants did raise concern about the acceptability of the inclusion of the prompt sheet within the service recipient's tool. The main concern related to the potential negative impact on time within an already constrained diagnostic appointment. These concerns were responded to by removing the prompt sheet and incorporating its aims of aiding memory recall by writing down information delivered in the appointment into the service deliverer's guide. There were also suggestions of alterations to wording, phrasing, and focus across both tools to improve acceptability. Both tools were modified based on the data from the focus groups, as outlined in Tables 15 and 16 in section 3.5.

It was deemed that by revisiting the design of both tools they would be able to meet a provisional level of acceptability. This suggests that the tools are an acceptable design to be considered to enter beta testing phase (Coulter et al., 2013). This phase of development includes field testing the tools with patients and clinicians to assess feasibility, followed by a final review of content to finalise the tools' design.

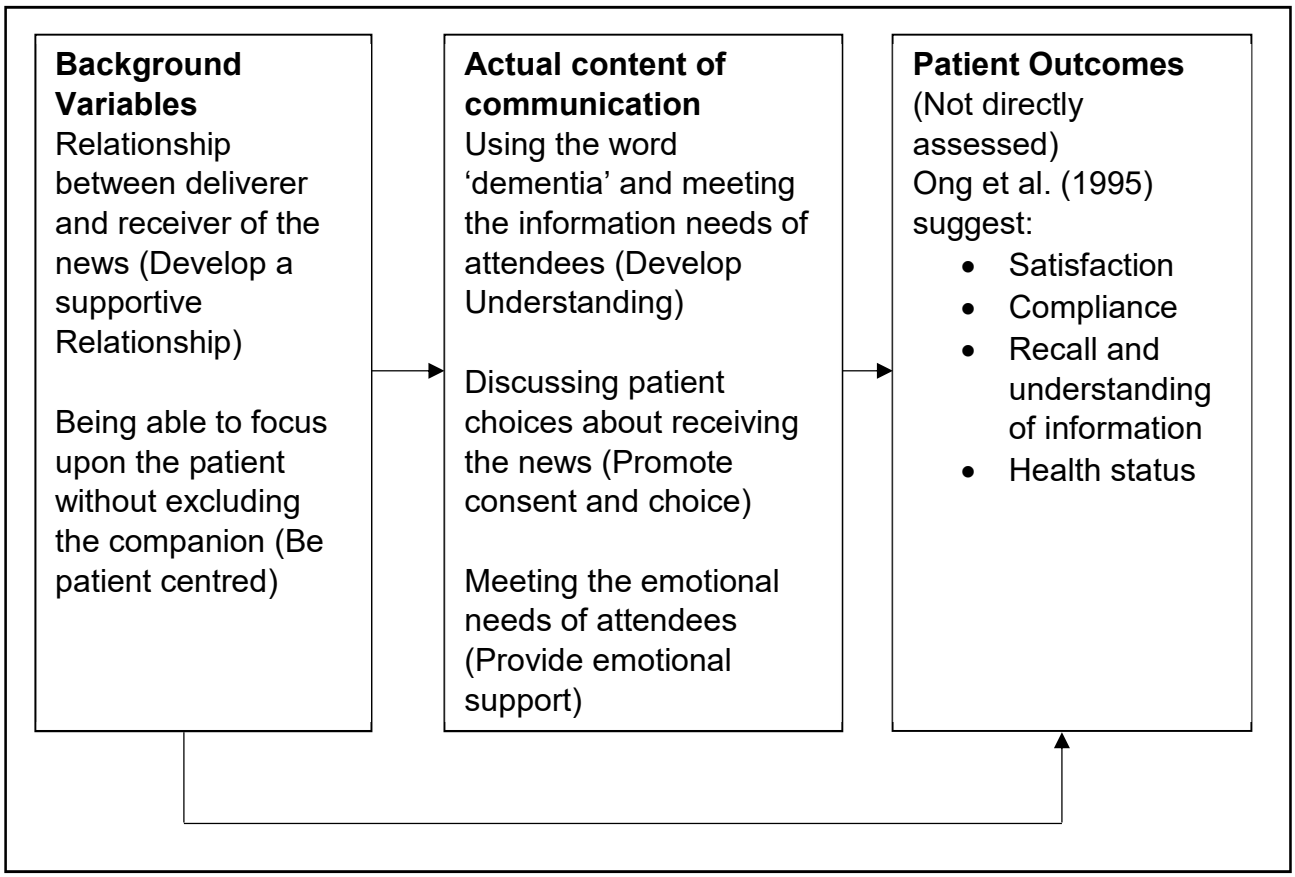
4.2. Theoretical understanding of results

This section will consider the themes developed in phase one with the theoretical understanding of breaking bad news discussed in the introduction (section 1.3). The theoretical understanding of any novel findings in this study will be discussed in section 4.4.

4.2.1. Communication and interpersonal relationships

Existing protocols for breaking bad news sometimes instruct the person delivering the news to engage in 'good' communication (e.g. ABCDE mnemonic (Rabow & McPhee, 1999)). In this study, the data enabled the development of themes that can begin to operationalise the constituents of 'good' communication. Within the overarching theme of *overt tasks* it could be argued that all five sub themes (provide emotional support, promote consent and choice, develop a supportive relationship, be patient centred, and develop understanding) could be associated with 'good' communication. These areas could be placed within Ong et al.'s (1995) model of doctor-patient communication, see Figure 6 below.

Figure 6: Model of communication in diagnostic delivery of dementia. Adapted from Ong et al. (1995)



Within the background variables of the model in Figure 6, the centrality of the relationship between clinician and attendees when discussing a diagnosis of dementia was highlighted by participants in phase one and is captured in the theme *develop a supportive relationship*. This echoes other commentators of the clinician-patient relationship who suggest that clinical medicine depends upon quality relationships between patients and their clinicians. This is based on a view that the relationship is the foundation from which quality communication is established (e.g.: Ong et al., 1995). Empirically, this has support, as improvement in communication is arguably linked to the quality of the interpersonal relationship, which is associated with enhanced patient satisfaction (Williams et al., 1998). Although a formal assessment of patient satisfaction was not included in this study, participants

explicitly referenced how a positive relationship helped them when receiving the diagnostic news.

The actual content of the communication was also identified by participants as important. It has been argued that clinicians should always switch from medical terminology to using everyday language to aid communication (Ong et al., 1995). However, clinicians, patients and companions noted the importance of using the term dementia. It was also reported to be helpful when both medical terminology and everyday language were used depending upon the preference and needs of the recipient. This finding may highlight particular times, such as when discussing a specific diagnosis, where medical terms aid communication.

As highlighted in this study, it is also important for deliverers of a diagnosis of dementia to attend to the emotional needs of the recipient. The importance of attending to emotional needs has previously been highlighted in theories of clinician–patient relationships such as Rogers' (1957) core conditions of empathy, warmth and genuineness of the clinician. Furthermore, it has been observed that patients who report dissatisfaction with communication in medical settings highlight a failure of the clinician to meet their emotional needs (Cavallaro, 2017).

4.2.2. Information matching

Matching and meeting the informational needs of the recipients was not an aim of the study. However, it is possible that the themes of *continual adaptation* and *develop understanding* link to information matching theory. Together they advocate for clinicians to continually assess and adapt how they deliver the diagnostic news to each recipient, and to use information to increase the recipient's understanding of their difficulties. This may go some way towards Kiesler and Auderbach's (2006) recommendation for clinicians to assess and adapt to patient preferences for information.

4.2.3. Learning

The zone of proximal development (ZPD) (Vygotsky, 1978) links to the theme of *develop understanding*. It was highlighted to be an important aim of the diagnostic delivery for the clinician to advance the recipient's understanding of their situation,

but also acknowledged that how this is completed will depend upon each individual attending. This relates to the principles of ZPD that suggest that the clinician needs to provide information that is just sufficiently beyond the recipient's current understanding, but is not beyond the potential of their understanding. In the findings of this study, where the person's ZPD is may relate to: their previous experiences of dementia; their own understanding of the difficulties or degree of insight; knowledge gained about the person from the assessment; and ongoing non-verbal cues about how the recipient is coping with the diagnostic news. By providing information that is within the recipient's ZPD the clinician is arguably more able to avoid under or overwhelming the recipient which may have a negative impact on their diagnostic experience.

4.2.4. Adjustment to illness

Adjustment to illness can be observed in the themes of *the journey of the delivery* and *attendee's emotions*. Within *the journey of the delivery* it is highlighted that the recipient's journey with dementia does not begin and end within the diagnostic appointment. This is evident with the psychosocial model of understanding diagnosis disclosure (Pratt & Wilkinson, 2003), which describes different processes within the individual's journey through a number of events such as noticing symptoms, the diagnostic process, the disclosure of diagnosis, the prognosis, maximizing coping strategies, denial and distress. This highlights how the event of diagnostic disclosure is one element of a wider journey and how emotions can change over time.

4.2.5. Emotions and processing the news

Within this study recipients of diagnoses of dementia did not specifically comment about how the news of their diagnosis altered their ability to retain or understand the news. However, clinicians referred to the need to attend to the recipients' emotions to attempt to prevent their emotional reactions impacting upon the comprehension of the diagnosis (see Susan's quote in the journal paper). Due to this observation within the results, it is not possible to understand if attentional control theory (Eysenck et al., 2007) discussed in section 1.3.5 is relevant to diagnostic delivery of dementia. However, goal-relevance theory (Levine & Edelstein, 2009) may link to the reflections provided by clinicians and

recommendations in the clinician's tool to provide emotional support. Goal relevance theory would explain this observation by suggesting that after a diagnostic delivery that attendees find distressing, the recipient's goal switches away from understanding the diagnostic information to managing the emotional response. Due to this switching in goal the attendees' attention is unable to focus on information provided by the clinician. Therefore, as in Susan's quote, if information was given at this point it may become overwhelming. Instead if clinicians can provide emotional support the attendee may be able to sufficiently manage or contain their emotional reaction. This could enable the attendee's information needs to regain priority and once again become the relevant goal.

4.3. Comparison of results with previous research

4.3.1. Breaking bad news

The revised prototype tool makes several recommendations that have been previously cited across a range of publications (see Table 17) .Common elements of general breaking bad news protocols that focus on the 'when', 'what', and 'how' (Ahmady et al., 2014; Ptacek & Eberhardt, 1996) (see section 1.8.1) are represented in the service deliverer's guide. This includes elements in the service deliverer's guide such as preparing the environment, locating existing knowledge prior to delivery, forming a supportive relationship, involving the patient in decision making, providing information or resources and providing emotional support[66].

4.3.2. Information matching

In partnership both tools incorporate recommendations from information matching literature. The service recipient tool prompts patients to consider their preferences for involvement and information prior to the appointment and share this with the clinician. The service deliverer's tool explicitly references assessing this and highlights the need for clinicians to adapt to any informational preferences. Both these elements were recommended by Kiesler and Auerbach (2006) and Street, Elwyn and Epstein (2012) when attempting to achieve optimal informational preference matching for diagnostic delivery.

[66] See journal paper for individualised approach and development of understanding over time

4.3.3. Triadic communication

Existing strategies for managing triadic encounters in medical interactions are also evident in the both tools. Laidsaar-Powell et al., (2013) made recommendations of welcoming companions into appointments with consent from patients, respecting patient choice for companion involvement, consideration of provision of space for 1:1 time, and reflection on clinician's behaviours towards companions are highlighted in the service deliverer's tool. The recommendation for clarifying the expected role of the companion is provided in the service receiver's guide, along with encouraging companions to attend with patient consent.

4.3.4. Current research for delivery of a diagnosis of dementia

Recommendations specific to dementia diagnostic settings are evident in the service deliverer's guide. Lecouturier et al. (2008) developed eight categories of essential components in the diagnostic disclosure of dementia (see Table 12 in extended background). Seven of these categories were represented in the themes developed in phase one and subsequently in the tools. However, the category of 'focusing on quality of life and wellbeing' was not evident in this study. (Section 4.5 discusses areas of the literature that are not represented in this study in more detail)

Other recommendations for the delivery of a diagnosis of dementia are represented in the tools. These include: for the delivery to be considered as a process that is individualised to the patient (Werner et al., 2013); for the clinician to assess patient preferences (Karnieli-Miller et al., 2007); ask if patients wish to know their diagnosis and who this can be shared with (Royal College of Psychiatrists, 2016); using the term dementia (Foy et al., 2007); including companions (Grossberg et al., 2010) but avoidance of speaking solely to the companion (Murphy & Gair, 2014); adapting written and verbal information to meet the needs of the recipient (Manthorpe et al., 2011); and to allow attendees to express their emotions (Murphy & Gair, 2014).

Despite the considerable overlap with existing research and recommendations, uniquely this tool combines these previously separated areas identified in existing research. Some of the elements of a good quality diagnostic delivery of dementia

developed in this study, and especially in phase one, have not previously been noted. These include: the importance of the clinician attempting to overcome barriers to good quality delivery; awareness and management of power; and the explicit consideration of both clinician and attendee's emotional experiences during delivery.

4.4. Elements of good diagnostic delivery of dementia unique to this study

4.4.1. Overcoming barriers

Many, if not all, other published protocols for breaking bad news or delivering a diagnosis of dementia have not explicitly included external barriers to good practice. Karnieli-Miller et al. (2007) acknowledged that clinicians required support to cope with difficulties in diagnostic practice, and other breaking bad news protocols have acknowledged the need to ensure that the environment is acceptable. For example, the 'S' (setting) in the SPIKES protocol (Baile et al., 2000) that encourages clinicians to ensure they have sufficient time and privacy for the interaction. However, the findings of this study suggest the wider context of the appointment and service setting could have a negative impact on diagnostic delivery. It indicates that clinicians are likely to aim for the best quality interaction they can facilitate. However, if they are experiencing pressure or frustration from service level or wider political issues this may lead to a restriction in the clinician's personal resources available during the encounter.

Theory of action may provide a way of understanding this finding. This suggests that people's actions that get repeated are subject to habituation where they become taken for granted (Berger & Luckmann, 1967). Habituation occurs in a series of stages: creative actions, repetitive acts, presumption, ritualism, and alienation (Berger & Luckmann, 1967). As we progress through each stage levels of conscious awareness, monitoring and retrospection of the action decreases (Jarvis, 1992). It is argued that in medical encounters actions that have entered the stages of presumption, ritualism, and alienation, risk dehumanising the patient and decreasing the patient experience (Jarvis, 1992). These later stages also risk preventing the clinician from adapting to each person and providing a personalised delivery of a diagnosis of dementia. Furthermore, it is possible that when clinicians are faced with long waiting lists, service and political level pressures, and the task

of delivering news of a stigmatised, non-curable disease, they are likely to detach themselves from the task increasing the risk of habituation.

The service deliverer's tool suggests that reflective practice or supervision can help the clinician buffer against this effect of habituation by deliberately increasing conscious awareness, monitoring and retrospection of the action. This could support clinicians to become aware of any personal challenges and provide an avenue to air or address concerns and frustrations. If this can be successfully negotiated this may enable clinicians to temporarily place these difficulties aside, to then focus more personal resources on the clinical encounter.

It is argued that reflection and reflective practice are essential attributes of competent healthcare professionals (Johns, 2013; Mann, Gordon, & MacLeod, 2009; Schön, 1983). Schön (1983) defined reflective practice as a tool for revisiting an experience to learn from it and for reviewing complex problems in professional practice. Reflective practice is explicitly suggested in the clinician's tool, as both a tool to aid reflections and for achieving some key elements of good practice. Although reflective practice in medical settings is not a new concept, it is unusual for protocols or tools to make this recommendation for breaking bad news. It could be argued that other clinician focused interventions to improve quality in breaking bad news, such as training or reviewing protocols, may implicitly prompt reflections on practice. However, the service deliverer's tool attempts to actively encourage meaningful reflective practice. This mirrors movements within medical education programmes, where reflective practice has become increasingly important (Epstein & Hundert, 2002; Sandars, 2009). This suggests that the inclusion of prompts to engage in reflective practice is not only important to manage the delivery of a diagnosis of dementia, but also for ongoing professional development.

4.4.2. Power of the clinician

Within the experiences of patients, companions, and clinicians who participated in this study there were references to the power of the clinician delivering the diagnosis. Power is an aspect of all relationships, and within medical settings is often understood in terms of autonomy and dependency (Pappas, 1990). The concepts of power are not unique to dementia care settings, and within the medical

literature there are many references to the power held by doctors and healthcare professionals (e.g. Ainsworth-Vaughn, 1998; Furst, 1998). Furthermore, in encounters where diagnoses of dementia are discussed the clinician can hold certain types of power. Arguably the clinician holds expert power where the clinician's medical knowledge and skills gives them power to diagnose the patient's problems and this knowledge becomes powerful (French & Raven, 1960). Specific to the diagnostic appointment, the clinician holds a specific position of power as there is an imbalance of knowledge as the clinician knows the diagnosis yet the attendees are yet to be informed (Pope & Vasquez, 2007). Furthermore, by definition of their professional role a clinician may also hold professional-positional-role power (Zur, 2009). Here the clinician's power is based on the respect members of the public, patients and companions, have for medical professionals.

Over recent decades the expectations of the power dynamic between medical professionals and patients have changed from a paternalistic stance to a focus on collaborative relationships (this is highlighted by Edna's quote in section 3.1.1.1.). To support this change, research and clinical practice have focused on topics such as information matching (as described in section 1.8.2) and shared decision making (see (Kiesler & Auerbach, 2006)). Despite these attempts to balance power, power still tends to favour the medical professional (Gwyn & Elwyn, 1999) and it requires care and respect to prevent it becoming misused (Goodyear-Smith & Buetow, 2001). As such, elements of the tools explicitly aimed to promote as collaborative as possible relationship between the deliverer and recipient(s) of the diagnosis.

The theme relating to the awareness and management of power contributes to the documentation of the importance to manage power within medical encounters. It also appears to extend existing guidelines for the delivery of a diagnosis of dementia, where power does not appear to have been explicitly considered during the development phase. Furthermore, the tools appear to present a way of actively encouraging a more collaborative relationship within the delivery of a diagnosis of dementia, something that may be unique for dementia care settings.

4.4.3. Emotional journeys

As stated in the journal paper this study appears to present a unique focus on the emotional journey of the clinician[67]. Attending to emotions has been cited in previous protocols of breaking bad news, for example, the 'D' that stands for dealing with recipient reactions, and the 'E' that represents encourage and validate emotions, including attend to the clinician's own needs during and following the delivery of bad news in ABCDE protocol (Rabow & McPhee, 1999). Despite acknowledging that both recipients and clinicians may experience powerful feelings in the encounter, the ABCDE protocol does not provide insight into what these emotions may be or why they could be experienced. A theoretical account of experience of stress for both patients and clinicians in breaking of bad news has previously been proposed by Ptacek and Eberhardt (1996). They proposed that clinicians are likely to experience an increase in stress levels in the anticipation of the news, which peaks at the point of relaying the news, and then begins to fall to pre-encounter levels immediately after the news is broken. Ptacek and Eberhardt (1996) suggested that patients would also experience a similar rise and fall of stress. However, patient stress levels were theorised to remain low until the news was beginning to be discussed. At this point they would experience a sharp rise that was more intense than the clinician's stress with the communication of the news. Following this the patient was also likely to experience a heightened level of stress for a longer period than the clinician, with stress reducing much more slowly over time.

The descriptions provided by clinicians who participated in phase one do appear to mirror Ptacek and Eberhardt (1996) model's suggestion of an increase in anticipatory stress. However, it appears that clinicians may also experience a period of anxiety when waiting for a reaction to the news. This suggests that stress may stay at a higher level for a short period after the news is broken, rather than immediately falling. Also, contrary to the model, and perhaps due to the design of the MAS appointments leading to the diagnostic news, patients and companions did not appear to describe low levels of stress prior to the news. Instead participants described anxiety in the time before attending the diagnostic appointment that rose

[67] See discussion in the journal paper

to the point of the news, which appears to fit more with the model of clinicians' anticipatory stress.

In addition, the concepts of transference and countertransference are important to consider when understanding a clinician's emotions. Transference is a concept that was acknowledged by Freud in personal therapy where individuals displace emotional reactions and patterns of behaviour onto other persons, which in therapeutic encounters is the clinician. Countertransference is a process where the clinician's own biases and emotional needs are transferred to the patient, and can be in response to the patient's transference (Zinn, 1990). Although these concepts were developed to understand relationships in personal therapy they are arguably transferable to medical encounters. This includes breaking bad news encounters where the patient needs the clinician more, creating an asymmetric relationship (Zinn, 1990). Furthermore, as in personal therapy, the patients have increased emotional expression than the clinician, and the clinician is expected to prevent actions based upon their own emotional needs (Zinn, 1990). Due to these characteristics, transference and countertransference may arise in the breaking bad news encounter, which may trigger powerful but poorly understood emotions in the clinician (Vandekieft, 2001). Strategies to manage these emotional reactions include the clinician maintaining awareness of their own thoughts and emotions during the encounter (Hughes & Kerr, 2000). Having personal awareness was highlighted in the theme 'clinician's emotions' and reflected in Louise's quote "*you can't be frightened of the quiet [after diagnostic delivery] because I think that's about your own issues if you start filling it up, isn't it?"*. Maintaining this awareness could be supported by reflective practice, as the clinician's tool encourages.

In summary, the emotional experiences of the clinician in the diagnostic delivery highlighted by this study may be understood within frameworks such as anticipatory stress or transference and countertransference. Furthermore, the understanding and documentation of the emotional experience of clinicians clarifies the importance of clinicians remaining aware of, and managing, their own emotions during diagnostic delivery. Additionally, explicit consideration of the emotional overlap between both parties and importance of the clinician's emotions are rarely, if at all,

included in existing guidelines. Therefore, this could be considered a unique contribution of this study and prototype tool.

4.5. Areas from existing research not represented

As shown in Table 17 in section 3.5, there are some areas from existing literature about breaking bad news and diagnostic disclosure of dementia that are not explicitly referenced in the tools developed in this study. This includes: researching the diagnosis and preparing for questions (Narayanan et al., 2010); explicit consideration of when, who and where to deliver the news (Child Bereavement UK, 2011); focus on quality of life and wellbeing (Lecouturier et al., 2008); and exploring the meaning of the diagnosis with the patient (Foy et al., 2007). Alongside this there were differences between the tools in this study and the framework recommended for breaking bad news to people with intellectual disabilities (Tuffrey-Wijne, 2013), the main exclusions being the degree to how much the clinician should engage with people around the patient and strategies for helping the person understand the news.

Some of these areas appear to potentially lack transferability to dementia diagnosis disclosure, for example, recommendations when working with people with intellectual disabilities appear valid, but may risk patronising a person with dementia or underestimating people's informational needs. Alongside this, recommendations for breaking bad news to a bereaved child such as taking time to consider who is best placed to break the news, when and where is the most appropriate time to hold the conversation, also lack transferability to dementia diagnostic disclosure in MAS settings. This is due to the design of the service prescribing when, where and usually who will deliver a diagnosis. Despite this, these areas highlighted as important for breaking bad news to children may be important when considering the wider context of dementia diagnostic disclosure and whether MAS services are always the best placed service to deliver diagnostic information.

4.6. Strengths[68]

The main strength of this study was the development of a tool that could support clinical practice in the delivery of a diagnosis of dementia. Following a systematic review of the literature about disclosing a diagnosis of dementia, Werner, Karnieli-Miller and Eidelman (2013) recommended that future research adapt generic protocols for breaking bad news. This study goes beyond this recommendation by developing a prototype tool specific for the delivery of a diagnosis of dementia.

This study also adds to the knowledge base of the likely constituent parts in the diagnostic delivery of dementia, both in replicating other findings and highlighting previously unconsidered areas. Therefore, this study along with other studies previously discussed can begin to operationalise what the Department of Health may be referring to when they state clinicians should be 'breaking the diagnosis well to the person with dementia and their family' (Department of Health, 2009) (p37). It also adds to the evidence that the diagnostic delivery of dementia is a complex process that requires careful consideration and sensitive management.

4.7. Considerations

4.7.1. Researcher impact

In my reflective journal on several occasions I commented on the impact of my position of being employed by a NHS trust different to the hosting site. During data collection in phase one, I reflected how this 'outsider' position appeared to enable clinicians to openly discuss practice. On one occasion, a clinician asked if their employer had asked for the research to be conducted as part of a service evaluation. On this occasion, I felt the clinician was reassured that I was an 'outsider' and appeared to be easier about providing critical feedback relating to the pressures experienced as a MAS clinician. However, it is possible that for patients and companions the nuance of my employing organisation was less significant than my role as an NHS health professional. Therefore, it was conceivable that, for some participants, I was viewed as an 'expert' and a member of the service who provided their care. When participants perceived me in either of these roles, it is possible that they may have felt less able to provide critical accounts of their experiences of

[68] See journal paper for a strength relating to the process of the tool's development

diagnostic delivery. I attempted to overcome this potential bias during my introduction, however it remains a possibility that different data may have developed from interviews conducted by a non-NHS professional.

Contrary to my perceived role as an expert, as I have never worked in a MAS setting my self-perception was more closely related to a non-expert. I felt this position enabled me to enter phase one data collection with fewer preconceptions about the hosting MAS's approaches to diagnostic delivery. This helped me to generate detailed descriptions and explanations from participants as I was not automatically making as many assumptions during the interview.

Data collection in phase two was also influenced by how participants experienced my role as the researcher. In this phase, it is possible that my primary role was viewed as the 'owner' of the tools by participants. By holding this role alongside facilitating the focused group discussions it was possible that participants were restricted in how they spoke about the tool. They may have felt a requirement, because of social desirability, to provide me with positive feedback. I attempted to mitigate this effect by specially asking questions relating to negative aspects of the tools. Therefore, I felt that phase two results were likely to provide a sufficiently balanced account of the acceptability of the tools.

4.7.2. Hosting Service and Scope of this study

This study was located in a single hosting NHS Trust that managed a total of seven MAS clinic locations across a large city and surrounding county. It could be argued that this could impact on the ability to gain understanding about clinical practice of the diagnostic delivery of dementia that translates to other services. However, there were a number of areas of overlap in the findings between this study and existing protocols for breaking bad news encounters and guidelines specifically for delivering diagnoses of dementia (see sections 4.3 and 4.4). This suggests that observations and experiences of people within the sample of this study relate to similar experiences within other services and other diagnostic areas. Furthermore, drawing on theory to understand the findings (sections 4.2 and 4.5) provides important formulations of the processes within the wider breaking bad news context (representing an original contribution to broader knowledge in the field – as

expected of a doctoral research study) and moves this study away from an evaluation of the hosting service.

It could also be argued that, as this study did not seek to ascertain or quantify the quality of care and service provided by the single hosting NHS trust it is not clear if these results represent 'good' practice. However, the aims of this study were to obtain perceptions of what stands out as helpful and or challenging in people's experiences of dementia diagnostic delivery and translate these into key elements of practice. Furthermore, it is important to recognise that this study was not intending to intervene in the hosting NHS trust to improve practice. As such this study provides an important contribution to the components of this process in a format that can be taken forward into further research to establish if they represent good practice (see section 4.10). As stated in section 1.5 the output of this study is referred to as a tool, defined as any resource that helps a clinician improve their competence, knowledge or skills (Venes, 2017). Had this study intended to establish if the tool could be used as an intervention, defined as anything that has an intention to change the course of events for a person (Segen, 1992), it would have been critical to formally assess the hosting service's quality of care and practice to discover if the intervention was able to improve these factors.

4.8. Limitations[69]

4.8.1. Design

This study was a two-phase qualitative research project. The design was developed following recommendations for developing patient decision aids (Coulter et al., 2013) and with guidance from the Medical Research Council (Craig et al., 2008). Therefore, the scope of each phase was more limited than a design that contained each phase in a single project. A strength of this design was that two prototype tools have been developed that appear to be a suitable standard to take into beta testing (Coulter et al., 2013) and further development work. This begins to address a gap in the existing literature as tools specific to the diagnostic delivery of dementia are not readily available to clinicians. However, the two-phase design may have placed limits on the extent the experiences of diagnostic delivery and

[69] See journal paper for consideration of barriers to implementation

acceptability of the tools were fully explored. Nonetheless, the design does appear to have been able to meet the aims of this study. Also, other research has provided in depth and broader accounts of: the experiences of people's journey with dementia including diagnosis (Manthorpe et al., 2011); psychological reactions to a diagnosis of dementia (Robinson et al., 2005); and individual and family experiences of receiving a diagnosis (Robinson et al., 2011). This enables an increased confidence that the narrower focus and design of this study was appropriate.

4.8.2. Sampling[70]

4.8.2.1. Single hosting service

Recruitment was contained within a single hosting NHS Trust, which may limit the diversity of experiences in the sample. However, achieved sampling represented four MAS locations managed by the NHS trust, which included both rural and urban locations. This increases the possibility of diversity in participant's experiences and therefore improves the transferability of the findings than if the sampling had been contained with a single MAS in the hosting trust.

4.8.2.2. Opportunistic sampling via MAS clinicians

Using opportunistic sampling reduced the likelihood of obtaining a sample that represented the population of clinicians, patients and companions who are involved in the diagnostic delivery of dementia. This may decrease the confidence in the transferability of this study's findings. Despite this, the sampling strategy resulted in the recruitment of four triads in phase one (i.e. the clinician, patient and companion present in a single diagnostic delivery).

Examples of data triangulation include:

- Theme: Develop Understanding. Discussion of how previous knowledge or prior thoughts that someone may have dementia may affect the reaction to the news detailed in section 3.2.3.2 with quotes from Pat (Clinician who delivered Mary's diagnosis), and Mary (Patient) and John (Mary's

[70] See journal paper for discussion of recruitment of people who may have been ambivalent about their experience, and the failure to recruit any participants from BME communities

Companion). This triangulation provided observer data of this potential effect on the reaction of patients and companion, as well as self-report data from recipients of a diagnosis.

- Theme: Promote Consent and Choice. The importance of establishing consent and preference for the diagnostic information was highlighted as an important feature of Edna (Patient) and Alan's (Companion) appointment with Louise (Clinician) – see journal paper, Box 3, Quote 2. This also corresponded with Louise's description of how she checks and establishes consent and preference – see first quote in section 3.2.3.3.

- Theme: Remain aware of diagnosis's power. Consideration of how providing a diagnosis can be a positive experience as it provides understanding is highlighted in the quotes from Jane (Companion to Stephen whose diagnosis was delivered by Jennifer) and Jennifer (Clinician) – see section 3.2.4.1

Where triangulation occurred, data were examined to explore if specific elements of diagnostic delivery were highlighted by all parties (e.g. in the theme promote consent and choice), or if clinicians' observations of diagnostic delivery were also raised as important by patients and companions (e.g. in themes develop understanding and remain aware of diagnosis's power). Triangulation, such as the examples above, improves confidence in the quality of the data obtained in relation to the helpful or important aspects in the delivery of a diagnosis of dementia. This triangulation also supports increased confidence in the achievement of data that is sufficient to address the first primary aim of this study.

4.8.2.3. Excluding people without a diagnosis

It is possible that the themes developed in phase one are applicable to delivering a diagnosis of 'non-dementia'. This could include a diagnosis of mild cognitive impairment or of no evidence of cognitive changes that fit a diagnosis of dementia or mild cognitive impairment. For some who may strongly believe they have dementia receiving news that this is not the case could be news that is negative in content. As such, it may be that as much care is required when communicating

diagnoses other than dementia. This could indicate that excluding people who had not received a diagnosis of dementia in this study could have limited understanding about the impact of these outcomes.

4.8.2.4. Achieved recruitment

A concern of the recruitment process was recruiting participants with a range of experiences of the diagnostic delivery. This was due to the ethical consideration of the appropriateness of discussing research after diagnosis delivery. To overcome this, clinicians used their judgement about who and when to introduce participation in the study. The clinician did not discuss the study when they assessed that people may feel increased distress or burden by the invitation to participate. This had the potential to reduce the likelihood that people who found the process of receiving a diagnosis distressing would be excluded from this study. Despite this concern, three of the five patients were recorded has having a high emotional reaction to the news, with two people seeming to accept the news, and one person denying the news. This suggests that people who may have experienced a degree of distress were recruited into the study.

The recruitment aims for both phases were not fully achieved. Recruitment was ceased in phase one after 14, rather than 16, people had participated to preserve the good will of the hosting MAS. Concepts of predicting potential informational power (Malterud et al., 2016) were drawn upon in establishing recruitment targets, see section 2.4.4.1. Information power was further considered when decisions were taken to cease recruitment in phase one. At this point, informational power was considered on the bases of the sample specificity and interview quality (Malterud et al., 2016). Inspection of the data collected in completed interviews in phase one suggested recruited participants could offer experiences and knowledge specific to the study aims. Alongside this there was diversity in experiences and ideas discussed relating to diagnostic delivery, evidenced by the variety of codes generated in initial stages of data analysis. This suggested that recruitment had provided a sample that was likely to provide data with both sufficient detail and variation to meet the study aims. Furthermore, inspection of the quality of the dialogue within the interviews suggested that participants had been able to articulate their experiences of either delivering or receiving diagnoses of dementia

to the interviewer. This improved the confidence that data collected in phase one could provide sufficiently extensive accounts from which a variety of codes and themes could be generated.

In phase two recruitment achieved 13 out of the intended 24 participants across the four focus groups. I felt that it was beneficial to run each group despite not achieving intended recruitment, as rearranging may not have been convenient for the people who had already indicated they would be attending and there was no guarantee that further participants would be identified. The lower recruitment rates may have limited the possibility of achieving data sufficiency.

See journal paper for discussion of recruitment from BME communities.

4.8.3. Method

4.8.3.1. Thematic analysis

Thematic analysis has provided an understanding of the self-reported experiences of the participants. Data generation methods did not enable observational data and understanding of the interactions in the diagnostic appointment that other methods such as conversational analysis may have provided. This limits the data and findings of this study to retrospective accounts reported in interviews. It also prevents any claims about the occurrence of the practice points contained with the tools within current clinical practice.

Analysing the data as a single sample, rather than as separate participant groups, may have limited the ability to explore any themes, or specific emphases within themes, that may be unique to a specific group. This may have also limited the ability to identify areas of convergence or divergence between participants within the analysis. Despite this, the analysis did identify areas where specific groups differed in perspective, such as in Phase Two theme ‘Barriers to uptake’ where clinicians held opposing views to those of patients and companions (section 3.4.3.2).

4.8.3.2. Retrospective interviews and focus groups

Throughout the study the methodology relied upon the retrospective accounts in phase one and retrospective application of knowledge in phase two. As discussed in section 1.7.2 people with dementia may struggle to retain information provided in the diagnostic encounter because of the disease. It is also possible that they may not have been able to have drawn fully upon their experience of the diagnostic encounter in phase one. This may have resulted in details of helpful or challenging experiences within this encounter being excluded from the data. To counter this, all but one patient engaged in the interview with the companion who had accompanied them to the appointment. In some interviews, the patient actively sought support from the companion to prompt memory or provide the linguistic description of their experiences. This dyadic interaction may protect the loss of important experiences of the patient.

It is also possible that participants without suspected or diagnosed dementia may also struggle to provide accurate reports of past events. To attempt to overcome any loss of saliency of the participant's experiences, patients and companions were interviewed as close to the diagnostic disclosure as ethically and practically possible. However, this was still at least one week after the encounter and the findings may not contain small nuances in participants' experiences. Other methodology such as serial interviews before, immediately after and after a week may provide an understanding if the important elements of diagnostic disclosure change over time. However, this methodology was not deemed to be able to address the aims of this study and therefore was beyond the scope of this study.

4.8.3.3. Tool development by first author

Within the study the tools were designed and modified by the first author with supervisory input from the secondary authors. This approach leaves open the possibility that biases held by the first author have influenced the tool's design and content. To protect against this limitation reflective logs, audit trails, mapping of the themes into the tools, and recording the changes made supported the researcher to maintain focus on the themes of the phases. Despite this, other methods such as consensus panels may have developed tools with different design or content. As such, it is important to note that it is hard to fully separate the tool's design from the

first researcher. This could be an area where future research provides further development to ensure the tools are not unduly influenced by individual developers.

4.8.4. Findings

Overall, due to the aims, design and achieved recruitment the findings of this study should be recognised as preliminary in nature and the recommendations in the tools are provisional pending further research. It is probable that the overlap with existing findings and underpinning by theory enables the findings and tools to be transferable to other settings where diagnoses of dementia are discussed, however future research is required to establish this.

4.8.4.1. Primary objective: To explore clinician, patient, and companion perceptions of what stands out as helpful and or challenging about their experiences of dementia diagnostic delivery within a local MAS.

The main limitations in relation to this primary objective include retrospective accounts, no observational data, and excluding people without a diagnosis of dementia. These limit the findings of phase one to the specific objective and may limit how generalisable the themes in phase one are to people receiving no diagnosis or one of mild cognitive impairment and to settings other than MAS clinics. It also cannot provide any understanding as to the actual occurrence of the themes in practice. Future research is required to understand if the themes from phase one apply in other services, such as primary care or MAS in other geographical areas. Further research could also attempt to gain prospective accounts of the relevance of the constituents of a delivery of a diagnosis of dementia prior to diagnosis and compare these to experiences post diagnosis.

4.8.4.2. Primary objective: To identify key elements of practice to inform the design of a prototype tool with potential to support consultations in MAS clinics.

This objective's main limitation was the development of themes in phase one and then the tools by the primary researcher. This introduces more opportunity for bias than methods such as consensus panels. Although steps were taken to mitigate this, it should be recognised as a potential limitation. Future research could now

take the prototype tools into further development to ensure any remaining researcher bias is overcome.

4.8.4.3. Primary objective: To obtain preliminary feedback on the acceptability of the prototype tool.

The main limitations in relation to the acceptability of the tool were the achieved recruitment, participants within both study phases, and scope of the study. The impact of these areas includes possible bias towards only partial positive feedback, limited understanding about whether the tools could be used in clinical practice, and no data about the uptake of the tools. These suggest the tools should be viewed as prototypes rather than fully developed and suitable for clinician practice. Future research is required to evaluate the tools, once development is fully completed, in beta testing (Coulter et al., 2013) and understand if they are adopted into practice.

4.9. Clinical Implications

The clinical implications of the development of the prototype tools are primarily related to the possible improvement of quality and consistency in the diagnostic delivery of dementia. The tools developed in this study have a primary function that could support clinicians in MAS settings to consider their practices when delivering a diagnosis of dementia, and may help patients and their companions during their involvement with MAS. The tools could have clinical implications, once the subsequent development work has been completed.

A secondary clinical implication of this study is the contribution to the knowledge of the constituent elements of a good diagnostic delivery of dementia. This study has replicated key findings of other research, but importantly has also highlighted the role of clinician's own emotions and the need to remain aware of barriers to intended good practice. It has emphasised the importance of reflective practice and supervision for all clinicians who undertake the complex task of delivering a diagnosis of dementia. This has potential clinical implications for producing recommendations for clinicians relating to the utility for developing and maintaining self-awareness through reflective practice when breaking bad news.

4.10. Future Research

4.10.1. Further development

Although the findings of this study map onto existing protocols for breaking bad news and recommendations of the elements of dementia diagnostic delivery (see sections 4.3 and 4.4) it is important that future research attempts to replicate the findings of this study in other clinical settings. This would contribute to understanding whether these themes and practice prompted by the tools are specific to MAS settings or whether, as anticipated, they transfer to broader settings wherein dementia is discussed and diagnosed. To establish this, future research could observe diagnostic practices in other NHS trusts that have a MAS function, with different service designs and/or clinical roles involved in delivering the diagnosis. The observations could then be mapped and a comparison draw to this study (as akin to comparisons completed between the tools developed in this study and existing literature in Table 17).

Further research could also consider completing further focus groups or consensus panels to establish the acceptability of the tools and contribute to further content and design decisions. These methods could also aid the establishment of how transferable the tool is to other service areas such as primary care where clinical appointments may differ in time and focus. It would also be important to understand if the themes and practice areas prompted by the tools are important to people as they progress through the process of receiving a diagnosis of dementia. This would clarify whether the retrospective accounts of this study's sample provide a robust assessment of the helpful or important elements of the delivery of a diagnosis of dementia.

4.10.2. Evaluation of the tool

An important future research agenda for this tool is to formally evaluate its quality and usability. This could be established in the beta testing phase of development (Coulter et al., 2013). This includes field testing the tools with patients and clinicians to assess feasibility, followed by a final review of content to finalise the tools' design. Furthermore, it is possible that the tools could be evaluated against guidance for NHS documents (e.g.: NHS toolkit for producing patient information (Department of Health, 2003)), or against checklists for clinical toolkits such as the United States' Agency for Healthcare Research and Quality Publishing and

Communication guidance for toolkits (Agency for Healthcare Research and Quality, 2016). These could establish if the design and formatting of the tools are appropriate and if future development work is required. The usability of the tool could also be established by future research once the tools have been sufficiently developed. This could include clinicians incorporating the tool into practice and providing qualitative reports about using the tool. Patients and companions could also provide similar subjective feedback. It would also be possible to obtain more objective data about usability by collecting data about the number of clinicians who draw on the tool, or number of recipients who use the tool in appointments. Low take up rates may indicate the tool is not seen as required or presented in unhelpful ways. High take up rates may indicate that the tool is useable and helpful.

4.10.3. Long term future research

It was beyond the scope of this project to begin the development of a feasibility study and piloting work. However, this study has produced a prototype tool that with further research could be deemed to be sufficiently acceptable to potential users to now be taken into the next phase of the Medical Research Council's framework for development of complex interventions (Craig et al., 2008).

Future research could develop understanding about the potential impact of both tools on clinicians', patients' and companions' experiences of diagnostic delivery. To achieve this, research will need to rigorously assess perceptions of the encounter where a diagnosis is shared, and investigate associated clinical outcomes. This will need to be established prior to the uptake of the tool as there is currently limited availability of published data which relates to the delivery of dementia diagnoses. It would be then necessary to develop a feasibility or pilot trial to establish an acceptable protocol for any future clinical trial. Any future trial would be required to implement the tool alongside control groups to begin to understand any effect the tools may have on diagnostic encounters. This would be the best practice, as outlined by the Medical Research Council, to be able to understand the potential impact of the tools on clinical practice.

Additionally, future research could also focus on observing and recording the behaviours in diagnostic deliveries after the tool had been introduced. This fidelity

checking could highlight specific areas of the tool that are more difficult to promote by a paper based tool, which could inform training packages or other interventions.

5.0 Critical Reflection

I used reflective practice and a reflective journal throughout the project, but here I have chosen to reflect in more depth on salient events that occurred during the completion of this project.

5.1. Study Development

During the preliminary development phase of this project the original design and focus was considerably altered. Initially I had intended to complete a feasibility trial to assess the outcomes of an intervention designed to improve information matching between clinicians and patients during the diagnostic delivery of dementia. Following feedback from research tutors this design was effectively abandoned due to the lack of an available and well-developed intervention to implement. Instead, and to address this research gap, the project presented in this document was developed.

The advice to change the focus of the project left me feeling frustrated and disappointed due to the time and emotional input I had invested in the original design. I also experienced a brief period where I felt uninspired and lacked motivation to apply myself to the revised study design. At this point I utilised supervision to explore my reactions and to develop ideas for the revised design. During supervision, I was also able to explore the rationale for the alteration to the design. This enabled me to contain my emotional reactions and connect with the advice at an intellectual level, allowing me to accept the need to change the design. Reviewing my experiences of this change after completing the alternative design, I now have positive emotional reactions. I experienced relief and gratitude as I was supported to identify and avoid what would have been a major problem.

This experience has enabled me to become aware of a tendency to allow my enthusiasm to obscure potential pitfalls in a research design. I need to remain aware of this for future research to allow me to plan and design robust projects. Alongside this, I have been able to broaden my research skills by experiencing the value in completing projects at a preparatory phase. I have also learnt how to incorporate critical feedback into my practice and the value of engaging in supervision when lacking motivation.

5.2. Methodology

During the revision of the project design, I identified a need to switch from using a mixed methods approach to a purely qualitative design. This was required to sufficiently explore people's perceptions of the diagnostic delivery of dementia, rather than attempt to quantify outcomes. I had initially been drawn to completing a mixed methods design as I felt more comfortable and competent with quantitative methodology following previous research experiences using mixed methodology. My prior experience of purely qualitative methods was limited to contributing as part of a team. Consequently, the task of a thematic analysis felt potentially overwhelming, leading me to feeling daunted by the revised project's methodology.

Utilising reflective practice, I identified that I had experienced similar reactions to other areas when completing my clinical training, such as using a different therapeutic approach. I discovered that I had previously been able to overcome this negative feeling by exploring the literature to deepen my understanding and engaging in regular supervision when putting the skills into practice. I combined this learning with an acknowledgement that my research supervisors believed that I was capable of successfully implementing a quality thematic analysis. I also developed a plan to ensure that I had access to pre-booked supervision during data analysis to maintain quality and progress.

Reflecting on this transition in methodology, I have noticed that I become anxious when pushed beyond my comfort zone. However, I have also observed that I can draw on my resources, both internally and externally, to help me overcome my anxiety to produce an acceptable standard of work. I have learnt the value of remaining open to alternative approaches, even when I perceive these to be unfamiliar, and how quality supervision can enable me to develop new skills and extend my practice.

Having now completed the project, I notice that I am drawn to considering the relative freedom that my chosen methodology granted. I feel it enabled me to connect in a meaningful way with the experiences of the participants, perhaps more so than if I had continued to implement a mixed methods design. This shift from

negative to more positive emotions mirrors the change I experienced during the study development. I have hypothesised that these changes reflect my development as a researcher, when I have learnt to tolerate and work with uncertainty in the research process. By finding a way to work through these difficulties I have also discovered that I have a degree of resilience and perseverance, both of which are helpful characteristics for future research and clinical practice.

5.3. Recruitment

The recruitment strategy for both phases involved handing some control to the MAS clinicians to recruit patients and companions. This design appeared to be the most practical and acceptable to the hosting service. However, it required me to share the responsibility for the progress of the project with people who may not have been as invested in the success of the project. Consequently, I had to manage my anxieties relating to failing to recruit sufficient participants and meeting deadlines in the projects time scale. I was also required to build positive relationships with the service managers and MAS clinicians. I felt that this engaged key staff members of the hosting service with the project, who then encouraged and facilitated other MAS clinicians to proactively recruit participants.

Once phase one recruitment was under way I was pleased with the initial positive responses of MAS clinicians and that some participants had given consent to be contacted. However, I then observed that the interest began to wane. I responded to this by re-engaging with the MAS clinicians via email, which lead to two more patient-companion dyads being recruited. After this spike, recruitment then appeared to cease. At this point I had recruited five patients and five companions out of the initial target of six in each participant category. I felt that any further prompts for participants may result in the MAS clinicians feeling too pressured and potentially unwilling to support recruitment in phase two. I also discussed these observations with the service managers who explained some of the other pressures MAS clinicians were under. Based on this information and with support from the project supervisors, I decided to end phase one recruitment.

I initially felt disappointed that I had not reached my target for phase one recruitment. However, I needed to remain aware of the impact of recruitment for the MAS clinicians. Reflective practice supported me to accept my feelings of lack of control and disappointment in phase one, and remain focused on the overall project. I was also able to value my development of positive relationships with the service managers and notice how instrumental this has been in progressing the whole project. Prior to engaging in reflective practice, I had not viewed the development of the relationships as a key element of the project's success.

These experiences in recruitment and sharing responsibility with others has broadened my awareness and appreciation of the value in taking time to foster positive relationships with stakeholders. This is particularly important for projects, such as this, that rely on people outside the research team to access participants. I need to explicitly embed this into my practice for any future projects or clinical work that requires collaboration with others.

5.4. Data analysis

Data analysis in phase one was a specific time that triggered a mixture of feeling daunted, overwhelmed, and excited. I experienced initiating the beginning of data analysis as a difficult task. I felt this was due to being unsure if I was going to be able to manage to find the right balance of description and interpretation during coding. Once I had started I utilised supervision to provide feedback on my coding and found I felt less daunted. However, I then experienced feeling overwhelmed by the volume of codes even within a single transcript.

Prior to the start of data analysis, I had contemplated using NVivo software to support my analysis, however I initially chose to complete coding 'by hand' with codes annotated in the margins of the transcripts. When I noted that I had begun to feel overwhelmed by the volume of codes I revisited NVivo to explore how it may be able to help me manage the data set. I decided that it would be worth investing time into learning how to use NVivo, even just as a way of managing the codes generated. Once I had transferred my hand-written codes into NVivo, I quickly began to appreciate the organisational power it provided. I observed that finding a way to organise the codes meant I felt much less overwhelmed and began to feel

excited about the data I had collected. Reflecting on why NVivo initiated this change I noted that I often feel better able to cope when I have been able to organise elements of a task. Therefore, even though I was effectively no further forward using NVivo than I was 'by hand', the sense of organisation allowed me to move towards generating themes.

I also felt challenged when developing the theme structure in phase one. At one point, I noted that I had fallen into developing themes that simply re-described the codes, rather than relating themes to the practice of delivering a diagnosis of dementia. When I noticed this, I altered my approach ensuring that I had the research question visible and for each theme I could provide a summary as to how it answered the question. Again, I found the flexibility that NVivo provided crucial in overcoming feelings of stagnating and not progressing the analysis at this point. This was because NVivo displayed the code with the coded data; allowed codes to be easily grouped and re-grouped as frequently as required; and to efficiently link back to the original data when I required more context to the coded data. This enabled me to make changes to the theme structure without significant effort and allowed me to feel able to continue to develop the theme structure. I hypothesised that I may have felt more reluctant to continue to alter and adapt the theme structure had I completed this without a software package. For the second phase of this project, I used NVivo from the outset of analysis and felt much more confident in the analysis. In any future qualitative research projects, I would opt for using a software package from the outset.

5.5. Tool development

A particularly salient phase of this project was developing the first draft of the tool. Prior to beginning the data analysis in phase one, I raised in supervision a concern about who I would give priority to in understanding a good delivery of a diagnosis of dementia to develop the tool. I noted that this was based on my assumption that participants may have focused on a small number of practice points, but failed to agree on how they should be delivered. By discussing this assumption in supervision, I believed that I could remain aware of it and mitigate any effect it may have had on the data analysis. I felt I had been able to overcome my assumption as when I reviewed the codes and themes I noticed that rather than being in

opposition, participants had provided many complementary and often nuanced points. This observation also effectively disproved my original assumption and highlighted how important it is to remain open to the data, rather than being guided by prior assumptions. For future projects, I would explicitly engage in supervision or reflective practice to identify my assumptions of the data prior to analysis as I feel this supported me to remain more open to the data.

Alongside this, I also noted that I felt enthusiastic to move into the second phase of the project. I reflected that this was due to wanting to gain feedback about the draft tool and to continue to progress the project. I also hypothesised that I am drawn to rushing or allowing my enthusiasm to rule when I feel inspired, such as in my original study design. On noticing this, I utilised supervision to slow my pace and develop a detailed draft tool, rather than failing to observe any potential pitfalls in the design of the tools. I incorporated the completion of an audit trail, in a series of tables, of how the tool related to the themes. This forced me to focus and to map the themes generated from the data into practice points and then into the tools. It also provided the foundations for Tables 9 and 14 when writing up the project.

Both the changes in the study design and the tool development phase of this project, have highlighted my tendency to allow my enthusiasm to encourage me to rush rather than attend to details. As stated in section 5.1, I need to remain aware of this for future research and clinical work.

Overall, this project has been interesting and challenging, on both personal and academic levels. I have extended previous skills, as well as developing new techniques. It has also highlighted personal tendencies that I need to be aware of in any future projects.

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Appendices

Appendix A: Critical appraisal pro forma (Systematic Review)

Question		Rating Anchors (score)
1	Did they provide a clear statement of the aims of the study?	Good (4) – Clear statement with objectives and research questions Very poor (1) – No aims or objectives stated
2	Was the study design appropriate and clearly explained?	Good (4) – Clear description, linked to aim. Very poor (1) – study design not detailed, or method inappropriate to address aim
3	Was the sampling strategy appropriate?	Good (4) – details to include: size, recruitment rate, recruitment procedure, location/context, size is justified Very poor (1) – no details
4	Was the data collection appropriate for the aims of the study?	Good (4) – Clear link to aims, process of data collection explicitly stated, measures and interview schedules stated or explained where appropriate Very poor (1) – data collection not detailed or inappropriate for aims
5	Is the description of the data analysis sufficiently detailed?	Good (4) – Data analysis is clearly explained, data reported where discussed, themes explained (if appropriate), appropriate tests used, significance referred to, sufficient data reported to support conclusions Very poor (1) – no discussion about how data were analysed
6	Have ethical and bias issues been considered?	Good (4) – ethical approval reported, details about patient consent, sensitivity, confidentiality (where necessary), researcher bias considered (where necessary) Very poor (1) – no mention of issues
7	Is there a clear statement of the findings?	Good (4) – Clear statement of findings, tables references, discussion of to the findings in relation research aims Very poor (1) – findings don't relate to the research aims
8	Are the findings transferable or generalizable?	Good (4) – sampling and description of study is sufficient to allow comparison to other studies/settings, Very poor (1) – context of the study is not explained
9	How valuable is this study?	Good (4) – contributes new knowledge, makes suggestions for future research or practice/policy implications Very poor (1) – None of the above (in good rating)

To gain an overall rating scores on each question will be summed. (good (4), fair (3), poor (2), very poor (1)) *Rating classification cut off is the mid-point, e.g.: poor = 13.5 – 22.5, fair 22.5 – 31.5*

Appendix B: Results of data evaluation (Systematic Review)

Study	Reviewer	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Overall	Comment
Brotherton & Abbott 2009 [37]	CB	F	G	G	G	F	F	F	F	G	Fair (31)	Ethical approval described, researcher bias and epistemology not detailed. More quotes would have been helpful justify patient themes.
Brotherton & Abbott 2009 [37]	DDB	G	F	F	F	F	G	F	F	G	Fair (30)	Aims clear; study design appropriate but not described in detail; sampling appropriate; interviews described & questions given but some not relevant and follow-up questions unknown; analysis processes named but not explained; findings need more quotes to illustrate; findings given in context; of reasonable value, contributes new knowledge, acknowledges limitations.
Brown et al., 1997 [40]	CB	G	G	G	G	G	G	G	G	F	Good (35)	Design strength – questionnaires administered directly before and after consultation.
Brown et al., 2009 [41]	CB	F	G	G	G	P	VP	F	G	F	Fair (28)	No information about ethical approval. Data displayed in 3D graph which is hard to read figures from. Unstandardized beta reported, no data to support conversion or to calculate effect sizes.
Cvengros et al., 2009 [42]	CB	G	G	G	G	G	P	F	F	F	Fair (31)	Ethical approval described but no reference to discussing consent at interview, or consideration of bias. Results are presented mainly in text and hard to link to graphs used to display data.
Farin et al., 2011 [44]	CB	G	G	F	F	G	F	G	P	G	Fair (31)	Sample/study location not included. No information about how informed consent was achieved. Generalisability limited due to lack of information about sample location.
Farin et al., 2012 [43]	CB	F	F	G	F	F	F	G	F	G	Fair (27)	Coding for questionnaire is presented but explanation requires 2012 paper to understand fully. Paper is generally hard to follow but information required is evidenced for results reported.
Fujimori et al., 2014 [46]	CB	F	G	G	G	G	F	G	F	F	Good (32)	Outcome measures (satisfaction and trust) were assessed on one single Likert scale. Intervention (oncologist communication training) was based on preferences of cancer patients in three other studies but no information about how transferable these preferences are to this sample – concerns about ability of training to be meeting the current sample's preferences.
Mackenzie et al., 2013 [39]	CB	G	G	G	G	G	G	G	G	G	Good (36)	Very clearly presented and detailed. Results presented around study aims. Good implications for future research and practice made.
Mulder et al., 2014 [38]	CB	G	G	G	G	G	F	G	F	G	Good (34)	Ethical approval, confidentially and consideration for participant's distress considered and reported, no consideration for any bias or epistemology stated. Themes explained with helpful use of quotes.

Appendix B: Continued

Study	Reviewer	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Overall	Comment
Murtagh & Thorns 2006 [47]	CB	G	F	G	G	G	G	G	F	G	Good (34)	Intervention is addition of questionnaire to elicit patient preferences but no details of what happened to this information. Left to assume this was given to the physician. Good description of how study was conducted in a sensitive way with patients who were at the end of their life.
Murtagh & Thorns 2006 [47]	DDB	G	F	G	G	G	G	G	G	G	Good (35)	Aims clear; design seems appropriate but not clearly described; sampling fine; data collection appropriate to aims and in their form; data analysis simple but clearly purposed; good consideration of ethical issues; findings clear and given in context; contributes new knowledge, acknowledges limitations.
van den Brink-Muinen et al., 2007 [45]	CB	F	G	G	G	F	P	G	G	F	Fair (31)	Data presented in lengthy tables which prevented easy extraction of occurrence of preference match. Ethical approval not stated but confidentiality and informed consent detailed. Could make recommendations for future research.
van den Brink-Muinen et al., 2007 [45]	DDB	G	F	F	G	G	P	G	F	F	Fair (29)	Two-fold aims are clearly articulated; design seems appropriate but not clearly explained; sampling appropriate but not described in detail; appropriate data collected and described in context; no consideration of ethical concerns noted; reasonable contextualising and value.

Note: CB = Author Claire Bennett, DDB = Author Danielle DeB

Appendix C: Hosting service permission letter

[redacted] NHS Trust

Positive about integrated healthcare

Mental Health Services for Older People

MHSOP Management Office

[redacted]

E-mail: [redacted]

Date 8th January 2016
Our ref: OJ/KSM
Your ref:

Private & Confidential

Claire Bennett
Trainee Clinical Psychologist
[redacted]

Dear Claire

RE: Development of an intervention to improve the delivery of a diagnosis of dementia

I am writing to confirm that Mental Health Services for Older People (MHSOP), [redacted], is prepared to support this project.

I note that access is required to permit recruitment from within the memory assessment service (MAS)

The project is planned for two phases with an overall aim to start recruitment in April 2016 and to be completed by February 2017. The project will be primarily conducted by you in your capacity as a, Trainee Clinical Psychologist, Trent DClinPsy Training Course, University of Nottingham under supervision of the Chief Investigator Dr Danielle De Boos, Research Clinical Psychologist, Trent DClinPsy Training Course, University of Nottingham.

Phase One: Original data will be collected from a local MAS clinic about clinician, patient and patient's companion's experiences of diagnostic delivery. [redacted] will be utilised to recruit participants. The recruitment aim is to interview six patient-companion dyads and four clinicians. It is planned that phase one recruitment will start in April 2016 and data collection (interviews to be conducted) in May and June 2016

Phase Two: Two focus groups are planned to review a possible clinical tool. One focus group will be for service providers with a recruitment aim of 12 clinicians or stakeholders. Clinicians with wide range of roles, experience and perspectives will be asked to participate. As such both MAS clinicians and stakeholders that are outside the current MAS service but within MHSOP will be identified. MHSOP will also be utilised to recruit to a second focus group for service recipients with a recruitment aim of 12 people with dementia, patients and companions. Phase Two recruitment is planned to start in July 2016 with data collection (focus groups to be planned) for the end Sept 2016.

I can confirm that I support this project within MHSOP, subject to the project receiving ethical approval.

Yours sincerely

[redacted]

Consultant in Old Age Psychiatry/Clinical Director

Appendix D: REC provisional opinion letter

NHS
Health Research Authority
East Midlands - Nottingham 1 Research Ethics Committee
Royal Standard Place
Nottingham
NG1 6FS

17 March 2016

Dr Danielle De Boos
Trent DClinPsy Programme Division of Psychiatry & Applied Psychology University of Nottingham
YANG Fujia Building, B Floor Jubilee Campus Wollaton Road
Nottingham
NG8 1BB

Dear Dr De Boos,

Study Title:	**Developing an intervention to improve diagnostic delivery of dementia**
REC reference:	**16/EM/0097**
Protocol number:	**16008**
IRAS project ID:	**192681**

The Research Ethics Committee reviewed the above application at the meeting held on 08 March 2016. Thank you for organising for Claire Bennett to attend to discuss the application on your behalf.

Provisional opinion

The Committee is unable to give an ethical opinion on the basis of the information and documentation received so far. Before confirming its opinion, the Committee requests that you provide the further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.

Further information or clarification required

- The applicant must wait at least one week after the patient's initial diagnosis of dementia before making contact regarding the study.
- A topic guide for the focus groups must be submitted as a substantial amendment.
- Clarification must be provided regarding the age-range of the participants.
- Participants must not be given a £5 high street voucher, and must instead be provided with travel expenses.
- The following changes must be made to the participant-facing documents:
    - The information sheets must be read through for errors
    - The poster must be read through for errors
    - The information sheet for those with dementia must be shorter and clearer

- It must be clear that a break will be provided during the focus groups
- Information must be added regarding the reimbursement of travel expenses, the opportunity to receive a copy of the final report, the confidentiality of focus groups and the process in case of disclosures
- The other researchers must be listed on the Consent Form

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact the REC Manager, Rachel Nelson.

When submitting a response to the Committee, the requested information should be electronically submitted from IRAS. A step-by-step guide on submitting your response to the REC provisional opinion is available on the HRA website using the following link: http://www.hra.nhs.uk/nhs-research-ethics-committee-rec-submitting-response-provisional-opinion/

Please submit revised documentation where appropriate underlining 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 REC application form unless you have been specifically requested to do so by the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 16 April 2016.

Summary of the discussion at the meeting

- **Social or scientific value; scientific design and conduct of the study**

  The Committee asked the applicant to explain where the need for the intervention had come from. *The applicant explained that the idea had arisen from the political agenda encouraging the diagnosis of dementia earlier. The applicant noted that this could lead to a case of quantity of diagnoses rising but not the quality. The applicant felt it was important to understand the best way to give a diagnosis of dementia as there was disparity amongst the current standard. It was noted that there had been a similar development in oncology to improve the way patients received their prognosis.*

  The Committee queried the use of the term 'a diagnosis of non-dementia' in the protocol and asked why this would occur. *The applicant explained that the route to the memory clinic could also be for a secondary assessment of on-going memory issues, so the diagnosis may not be dementia.* The Committee asked the applicant to clarify which of the participants would have a diagnosis of dementia. *The applicant clarified that in phase I of the study the participants would all either have a diagnosis of dementia or support someone with this diagnosis. In phase II however, the applicant planned to use those with experiences that could help develop the tool, including people who have concerns about their memory.*

The Committee asked if the tool was going to be used as a 'one size fits all' process. *The applicant explained that it would be a paper-based tool to help clinicians work out the best way to speak to a patient about their diagnosis. The applicant noted that in some cases, the patient may not want a lot of information about their diagnosis, but their companion may want more.*

It was noted that the applicant planned to include a varied group of people with dementia by creating categories based on how they responded to their diagnosis in clinic. The Committee commented that the patients may respond very differently outside of the clinic. The Committee asked the applicant how these categories would be created. *The applicant explained she would have a three category approach, and would work alongside clinicians to learn more about the range of emotions involved. The applicant commented that she had not done this yet as she did not want to involve any clinicians too early.* The Committee queried what kind of categories the applicant thought she might use. *The applicant clarified that she would categorise the emotions on a scale from relief and confirmation at one end, and disbelief, shock and rejection of the diagnosis at the other end.*

- **Recruitment arrangements and access to health information, and fair participant selection**

The Committee noted that the recruitment process assumed the involvement of all four clinicians from the memory clinic. The Committee asked whether this assumption was too hopeful, and queried what would happen if not all of the clinicians wanted to be involved. *The applicant agreed that it was hopeful and explained that she would like to have as many different viewpoints as possible, but assured the Committee that as long as she had a nurse and support worker involved, the study would still be successful.* The Committee asked what would happen if the clinicians did not agree to be interviewed. *The applicant assured the Committee that she had other services to use as a backup plan.*

The Committee queried how long the time interval would be between the initial diagnosis and the recruitment to the applicant's study. *The applicant replied that she did not want to wait a long time after the diagnosis as their experience would change over time, but she also did not want to immediately try to recruit the participants.* The Committee agreed the applicant should wait at least one week after the initial diagnosis to attempt to recruit the participant.

The Committee commented on the inclusion criteria, noting that people ages 18 years and above were included. The Committee asked why this age group had been chosen, as a case of dementia in an 18 year old would be very different to dementia in an older person.

- **Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity**

The focus groups were discussed and the Committee noted that one – two hours was a long time for the participants. It was agreed that it must be made clear in

the Participant Information Sheets that a break would be provided during that time.

The Committee queried what the process would be for ensuring confidentiality in the focus groups. *The applicant clarified that she would be making a statement about confidentiality at the beginning of each group, explaining that the participants must respect each other's experiences and must keep anything they hear confidential.* The Committee noted that would need to be explained in the Participant Information Sheets, as well as including some information about the process in place if anything is disclosed during the group.

The payment of a £5 high street voucher was discussed, and the Committee agreed it would be more useful to provide travel expenses, as paying for car parking could be very expensive. *The applicant agreed to amend this.*

- **Informed consent process and the adequacy and completeness of participant information**

  The Committee noted that it was not clear from the Participant Information Sheet for Clinicians that the staff would be taking part in the study during their own time, rather than during work. It was also commented that there were a number of errors in the Participant Information Sheets, such as the use of the phrase 'your medical care will not be affected' on the Companion Information Sheet, and the use of the Patient Advice Liaison Service (PALS) contact details on the Clinician Information Sheet. *The applicant queried what the alternative for providing PALS contact details would be.* The Committee suggested using the contact details of the research supervisor.

  It was agreed that the Participant Information Sheet for those with dementia could be clearer and more concise.

  It was stated that there was no information about whether the participants could receive a copy of the results after the study ended.

  The Committee commented that the Poster was contradictory, referring to the tool as both 'being made' and 'made'.

  The Consent Form was discussed and the Committee agreed the names of the other researchers should also be listed.

- **Suitability of supporting information**

  The Committee commented that a topic guide for the focus groups had not been included and would need to be reviewed.

Documents reviewed

The documents reviewed at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [ADVERT for focus groups]	1.0	17 February 2016
Copies of advertisement materials for research participants [ADVERT for interviews]	1.0	17 February 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance]	1.0	18 February 2016
Interview schedules or topic guides for participants [INTERVIEW TOPIC GUIDE clinicians]	1.0	17 February 2016
Interview schedules or topic guides for participants [INTERVIEW TOPIC GUIDE service recipients]	1.0	17 February 2016
IRAS Checklist XML [Checklist_18022016]		18 February 2016
Letter from sponsor [Sponsor Letter]	1.0	18 February 2016
Participant consent form [CONSENT FORM focus groups Service Deliverers]	1.0	17 February 2016
Participant consent form [CONSENT FORM focus groups Service Recipients]	1.0	17 February 2016
Participant consent form [CONSENT FORM interviews Clinicians]	1.0	17 February 2016
Participant consent form [CONSENT FORM interviews companions]	1.0	17 February 2016
Participant consent form [CONSENT FORM interviews Patients]	1.0	17 February 2016
Participant information sheet (PIS) [PARTICIPANT INFO SHEET Focus Groups with Service Recipients]	1.0	17 February 2016
Participant information sheet (PIS) [PARTICIPANT INFO SHEET Focus Groups with Service Stakeholders]	1.0	17 February 2016
Participant information sheet (PIS) [PARTICIPANT INFO SHEET interviews with clinicians]	1.0	17 February 2016
Participant information sheet (PIS) [PARTICIPANT INFO SHEET interviews with companions]	1.0	17 February 2016
Participant information sheet (PIS) [PARTICIPANT INFO SHEET interviews with patients]	1.0	17 February 2016
REC Application Form [REC_Form_18022016]		18 February 2016
Referee's report or other scientific critique report [ACADEMIC REVIEW]	1.0	19 December 2015
Research protocol or project proposal [Protocol]	1.0	17 February 2016
Summary CV for Chief Investigator (CI) [CV DDeBoos]	1.0	11 December 2015
Summary CV for student [CV CBennett]	1.0	11 December 2015
Summary CV for supervisor (student research) [CV Nima Golijani Moghaddam]	1.1	19 December 2015

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet

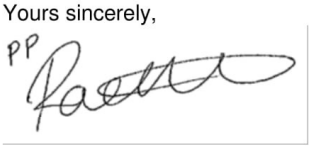
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research

Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

16/EM/0097	**Please quote this number on all correspondence**

Yours sincerely,



Revd Keith Lackenby
Chair

Email: NRESCommittee.EastMidlands-Nottingham1@nhs.net

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments.*

Copy to: [redacted]

East Midlands - Nottingham 1 Research Ethics Committee

Attendance at Committee meeting on 08 March 2016

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Glenys Caswell	Research Fellow	Yes	
Professor Cris Constantinescu	Professor of Clinical Neurology	Yes	
Dr Carl Edwards	Investment Advisor	No	
Dr Sarah Forster	Respiratory Registrar	Yes	
Dr Ursula Holdsworth	Retired Staff Grade Community Paediatrician	Yes	
Reverend Keith Lackenby	Lay member	Yes	(Chair)
Mrs Sarah Lennon	Ex-Surgical Registrar (GMC registration maintained)	Yes	
Ms Ellen Milazzo	Development and Change Management Consultant	No	
Mrs Rita Patel	Contracts and Innovation Manager	Yes	
Dr James Rathbone	Clinical Psychologist	Yes	
Mr Ian Thompson	Retired Deputy Head Teacher	Yes	
Mrs Norma Thompson	Clinical Research Nurse	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Ms Rachel Nelson	REC Manager
Ms Stephanie Sampson	Observing

Appendix E: Additional information supplied to REC

Claire Bennett
Trainee Clinical Psychologist – Trent DClinPsy
Division of Psychiatry & Applied Psychology
University of Nottingham
YANG Fujia Building, B Floor
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB

5th April 2016

Dear Revd Keith Lackenby,

RE: 16/EM/0097

Please find below an overview of the changes made to the documents for the project titled: Developing an intervention to improve diagnostic delivery of dementia. These have been made following the REC review on 8th March 2016 and subsequent letter dated 17th March 2016.

Protocol

Changes have been highlighted within the document to aid review.

- A seven-day period between receiving a diagnosis to the interviewer contacting the participant, outside of the Memory Assessment Clinic (MAS) has been included.
- Information about the age range of participants who could be recruited via MAS and Working Age Dementia Services has been added into the inclusion criteria.
- More clarity has been included into the remainder of the inclusion/exclusion criteria across all phases and participant types
- A description of how participant reactions will be captured has been included for Phase One
- Detail about how the researcher will manage any participants who come forward to participate directly from the poster/advert has been included
- Information regarding travel expenses in Phase Two have been included
- A description about how confidentiality and disclosure will be managed during the focus groups has been included
- A break has been included in the design of the focus group

PIS

These have been updated to include accurate information regarding PALs or research supervisors, where appropriate. Updates have also included addition of how to access a final report, and inclusion of details about travel expenses for the focus groups. A break has been specified in the focus group PIS, alongside information about confidentiality. The PIS for patients has been reviewed for conciseness and edited where possible, without excluding required information.

Consent Forms

All researchers are now named in the consent form. For the consent forms to be used for the focus groups, a statement has been included regarding the confidentiality of the group discussion.

Poster/Advert
These have been reviewed for errors and corrected.

Topic Guide
A topic guide for phase two has been included in the submission. Should any changes be required following phase one a revised guide will be re-submitted to REC.

Other
A copy of the travel claim form required by the University of Nottingham has been included in the documents submitted.

I hope that this outline clarifies the revisions completed. Should there be any questions please do not hesitate to contact me.

Yours Sincerely,

C Bennett

Claire Bennett
msxceb@nottingham.ac.uk

Appendix F: Confirmation of REC approval

NHS
Health Research Authority
East Midlands - Nottingham 1 Research Ethics Committee
Royal Standard Place
Nottingham
NG1 6FS

12 April 2016

Dr Danielle De Boos
Trent DClinPsy Programme Division of Psychiatry & Applied Psychology University of Nottingham
YANG Fujia Building, B Floor Jubilee Campus Wollaton Road
Nottingham
NG8 1BB

Dear Dr De Boos,

Study title:	**Developing an intervention to improve diagnostic delivery of dementia**
REC reference:	**16/EM/0097**
Protocol number:	**16008**
IRAS project ID:	**192681**

Thank you for your letter of 7th April 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Ms Rachel Nelson, NRESCommittee.EastMidlands-Nottingham1@nhs.net.

Confirmation of ethical opinion

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

Conditions of the favourable opinion

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

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

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

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

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

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

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

Registration of Clinical Trials

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

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

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

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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

Ethical review of research sites

NHS sites

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

Non-NHS sites

Approved documents

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

Document	*Version*	*Date*
Copies of advertisement materials for research participants [ADVERT for interviews]	1.0	17 February 2016
Copies of advertisement materials for research participants [ADVERT for focus groups]	2.0	28 March 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance]	1.0	18 February 2016
Interview schedules or topic guides for participants [INTERVIEW TOPIC GUIDE clinicians]	1.0	17 February 2016
Interview schedules or topic guides for participants [INTERVIEW TOPIC GUIDE service recipients]	1.0	17 February 2016
Interview schedules or topic guides for participants [FOCUS GROUP TOPIC GUIDE service Recipients]	1.0	01 April 2016
Interview schedules or topic guides for participants [FOCUS GROUP TOPIC GUIDE service deliverers]	1.0	01 April 2016
Letter from sponsor [Sponsor Letter]	1.0	18 February 2016
Other [Travel claim form University of Nottingham]	1.0	01 April 2016
Other [Covering letter outlining revisions]	1.0	05 April 2016
Participant consent form [CONSENT FORM focus groups Service Deliverers]	2.0	28 March 2016
Participant consent form [CONSENT FORM focus groups Service Recipients]	2.0	28 March 2016
Participant consent form [CONSENT FORM interviews Clinicians]	2.0	28 March 2016
Participant consent form [CONSENT FORM interviews companions]	2.0	28 March 2016
Participant consent form [CONSENT FORM interviews Patients]	2.0	28 March 2016
Participant information sheet (PIS) [PARTICIPANT INFO SHEET Focus Groups with Service Recipients]	2.0	28 March 2016
Participant information sheet (PIS) [PARTICIPANT INFO SHEET Focus Groups with Service Stakeholders]	2.0	28 March 2016
Participant information sheet (PIS) [PARTICIPANT INFO SHEET interviews with clinicians]	2.0	28 March 2016
Participant information sheet (PIS) [PARTICIPANT INFO SHEET interviews with companions]	2.0	28 March 2016
Participant information sheet (PIS) [PARTICIPANT INFO SHEET interviews with patients]	2.0	28 March 2016
REC Application Form [REC_Form_18022016]		18 February 2016
Referee's report or other scientific critique report [ACADEMIC REVIEW]	1.0	19 December 2015
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Summary CV for student [CV CBennett]	1.0	11 December 2015
Summary CV for supervisor (student research) [CV Nima Golijani Moghaddam]	1.1	19 December 2015

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

User Feedback

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

HRA Training

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

16/EM/0097	**Please quote this number on all correspondence**

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

Yours sincerely,

Reverend Keith Lackenby
Chair

Email:	NRESCommittee.EastMidlands-Nottingham1@nhs.net
Enclosures:	"After ethical review – guidance for researchers"
Copy to:	[redacted]
	[redacted]

Appendix G: R&D Permission

[redacted]

[redacted] NHS
NHS Foundation Trust
Research and Development
[redacted]

E-mail [redacted]

Date of NHS Permission: 18 April 2016

Dr D De Boos
Trent DClinPsy Programme
University of Nottingham
Yang Fujia Building
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB

Dear Dr De Boos

Study title: Developing an intervention to improve diagnostic delivery of dementia
Sponsor: University of Nottingham
IRAS/REC ID: 192681/16/EM/0097
Principal Investigator: Claire Bennett

Thank you for submitting your project to the [redacted] R&D Department. The project has now been given NHS permission by:

Dr [redacted] R & D Director, on behalf of [redacted]

NHS permission for the above research has been granted on the basis described in the application form, study protocol and supporting documentation. The following documents were reviewed:

Document	Version	Date
Copies of advertisement materials for research participants [ADVERT for focus groups]	1.0	28 March 2016
Copies of advertisement materials for research participants [ADVERT for interviews]	1.0	17 February 2016
Interview schedules or topic guides for participants [INTERVIEW TOPIC GUIDE clinicians]	1.0	17 February 2016
Interview schedules or topic guides for participants [INTERVIEW TOPIC GUIDE service recipients]	1.0	17 February 2016
Focus Group topic guide – service recipients	1.0	01 April 2016
Focus Group topic guide – service deliverers	1.0	01 April 2016
Participant consent form [CONSENT FORM focus groups Service Deliverers]	2.0	28 March 2016
Participant consent form [CONSENT FORM focus groups	2.0	28 March 2016

[redacted] Stonewall DIVERSITY CHAMPION POSITIVE ABOUT DISABLED PEOPLE INVESTORS IN PEOPLE | Silver

Service Recipients]		
Participant consent form [CONSENT FORM interviews Clinicians]	2.0	28 March 2016
Participant consent form [CONSENT FORM interviews companions]	2.0	28 March 2016
Participant consent form [CONSENT FORM interviews Patients]	2.0	28 March 2016
Participant information sheet (PIS) [PARTICIPANT INFO SHEET Focus Groups with Service Recipients]	2.0	28 March 2016
Participant information sheet (PIS) [PARTICIPANT INFO SHEET Focus Groups with Service Stakeholders]	2.0	28 March 2016
Participant information sheet (PIS) [PARTICIPANT INFO SHEET interviews with clinicians]	1.0	17 February 2016
Participant information sheet (PIS) [PARTICIPANT INFO SHEET interviews with companions]	1.0	17 February 2016
Participant information sheet (PIS) [PARTICIPANT INFO SHEET interviews with patients]	1.0	17 February 2016
Research protocol or project proposal [Protocol]	1.0	17 February 2016

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, ICH GCP [ONLY if applicable], and NHS Trust policies and procedures available http://www.nottinghamshirehealthcare.nhs.uk/contact-us/freedom-of-information/policies-and-procedures/

The research sponsor or the Chief Investigator, or the local Principal Investigator at a research site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The R&D office should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The R&D Office should be notified within the same time frame of notifying the REC and any other regulatory bodies. All amendments (including changes to the local research team) need to be submitted in accordance with guidance in IRAS.

Please note that the NHS organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This is achieved by random audit of research.

Yours Sincerely

[redacted]

Head of Research and Innovation

cc.

Sponsor

Appendix H: R&D Letter of access

[redacted]

[redacted]
NHS Foundation Trust

Research and Development

[redacted]

Claire Bennett
Trainee Clinical Psychologist
Trent DClinPsy Programme
University of Nottingham
Yang Fujia Building
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB

Dear Claire

NHS Letter of access for research

Project Title: Developing an intervention to improve diagnostic delivery of dementia
Reference: IRAS: 192681

Letter of access for research at [redacted]

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is responsible for ensuring such checks as are necessary have been carried out. This letter confirms your right of access to conduct research through [redacted] **Foundation Trust** for the purpose and on the terms and conditions set out below. This right of access commences on **18/04/2016** and ends on **20/09/2017** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to [redacted] **Foundation Trust**. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through [redacted] **Foundation Trust,** you will remain accountable to your employer [redacted] **Foundation Trust** but you are

[redacted]

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required to follow the reasonable instructions of your nominated manager in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with [redacted] **Foundation Trust,** policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with [redacted] **Foundation Trust,** in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on [redacted] **Foundation Trust** premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

[redacted] **Foundation Trust** will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

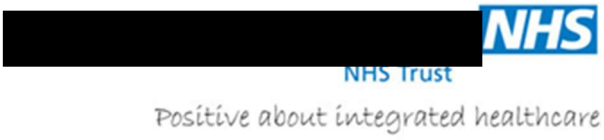
Yours sincerely

[redacted]

Head of Research and Innovation

Cc: Employers HR

Appendix I: Participant information sheets for all phases of the project



Participant Information Sheet for Interviews with MAS Clinicians
(Final version 2.0 28.03.16)

Title of Study: Development of an intervention to improve the delivery of a diagnosis of dementia

Name of Researcher(s): Dr Nima Moghaddam, Dr Danielle DeBoos and Claire Bennett

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?
This study is part of a larger project that is planning to develop a tool to help clinicians, patients and their companions deliver and receive a diagnosis of dementia. The first part of the project is to find out clinician's experiences of delivering a diagnosis of dementia and opinions about what makes a good diagnostic delivery. This project also serves as partial completion of the researcher's thesis submission as part of the Doctorate in Clinical Psychology.

Why have I been invited?
You have been invited because you work in [redacted] Trust's Mental Health Services for Older People and are currently involved in delivering diagnoses of dementia. We are asking up to four clinicians to take part in phase of 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 keep this information sheet 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?
You will be asked to take part in a face to face interview with a member of the research team. This will involve asking you about your thoughts and opinions about delivering a diagnosis of dementia. The interview is expected to last around 30 minutes and will take part at the MAS clinic at a time that will be

arranged with you. The interview will be audio recorded and transcribed by either the researcher who interviewed you or professional transcription services. Quotes from the interview may be used when the study is written up but to protect your identity you will be given a pseudonym when the interview is transcribed.

Expenses and payments
Participants will not be paid to participate in the study. As the interviews will take place at your place of work or own home it is not anticipated that there will be any travel costs associated with participating in the study. Therefore, travel expenses will not be able to be re-claimed from the research team.

What are the possible disadvantages and risks of taking part?
The possible disadvantage of taking part in this study is that you may have to spend a small amount of time taking part in an interview. The researchers are experienced in supporting people to make the interview as positive as possible, but some people can find talking about their experiences upsetting. If this happens, you will be able to stop the interview at any time and/or ask not to discuss a particular question. It is also possible to discuss any concerns raised by participating in the project during your usual clinical supervision or with the staff counselling service. Participation is excepted to occur within your own time.

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 improve the ways that diagnoses of dementia are delivered in future.

What if there is a problem?
If you have a concern about any part 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.

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, the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people 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.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you will have your name

and address removed (anonymised) and a unique code will be used so that you cannot be recognised from 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 will have access to your personal data.

Although what you say in the interview 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 then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?
The findings of the study will be reported back to [redacted] Foundation NHS Trust and MAS clinics. The Faculty for Psychology of Older People and Dementia will also be contacted for potential dissemination of the findings. The study will also be prepared for publication in an appropriate peer-reviewed journal and presented at relevant conferences. Participants will not be identified in any publications. This project also serves as partial completion of the researcher's thesis submission as part of the Doctorate in Clinical Psychology.

Who is organising and funding the research?
This study is organised and funded by Health Education East Midlands as part of the Doctoral Training of Claire Bennett, Co-investigator.

Who has reviewed the study?
All research in the NHS 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 East Midlands – Nottingham 1 Research Ethics Committee.

Further information and contact details
For any questions or to obtain a copy of the final report, please contact:

Claire Bennett
Trainee Clinical Psychologist
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
Email: dementia.diagnosis@gmail.com
Tel: 07557 866929

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

The University of Nottingham
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[redacted] NHS Trust
Positive about integrated healthcare

Participant Information Sheet - Interviews with companions
(Final version 2.0 28.03.16)

Title of Study: Development of an intervention to improve the delivery of a diagnosis of dementia

Name of Researcher(s): Dr Nima Moghaddam, Dr Danielle DeBoos and Claire Bennett

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?
This study is part of a larger project that is planning to develop a tool to help clinicians, patients and their companions deliver and receive a diagnosis of dementia. The first part of the project is to find out people's experiences of receiving a diagnosis of dementia and opinions about what makes a good diagnostic delivery. This project also serves as partial completion of the researcher's thesis submission as part of the Doctorate in Clinical Psychology.

Why have I been invited?
You have been invited because you supported someone who was given a diagnosis of dementia at the Memory Assessment Clinic (MAS). We are asking up to six patients, who have received a diagnosis of dementia, and up to six people that support someone who has recently received a diagnosis to take part in this 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 keep this information sheet 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?
You will be asked to take part in a face to face interview with one of the researchers if you receive a diagnosis of dementia. This interview can be on your own or with the person that you attended the memory clinic appointment with, it is your decision. It will involve asking you about your thoughts and

opinions about receiving a diagnosis of dementia. The interview is expected to last around 30 minutes and will take part either at the Memory Clinic or at your home.

You received this information at the end of the appointment at the memory clinic.

if you agreed to be contacted by the researcher, Claire Bennett, you were also asked to complete a contact form. The researchers will be selecting up to six patients and six companions to take part. If there are more than 12 people who volunteer you might not be selected. If you are selected to be interviewed, Claire Bennett will contact you by telephone to arrange a time and place with you.

The interview will be audio recorded and transcribed either by the researcher who interviewed you or a transcription service. Quotes from the interview may be used when the study is written up but to protect your identity you will be given a pseudonym when the interview is transcribed.

There is a second phase to this study planned. You maybe be asked if you would like to be contacted about in the future. You do not have to consent to this if you take part in this second phase.

Expenses and payments
Participants will not be paid to participate in the study. As the interviews will be able to done in a place that suits you, it is not expected that you will have any extra travel to take part. Therefore, there won't be any options for travel expenses to be reclaimed.

What are the possible disadvantages and risks of taking part?
The possible disadvantage of taking part in this study is that you may have to spend a small amount of time taking part in an interview. The researchers are experienced in supporting people to make the interview as positive as possible, but some people can find talking about their experiences upsetting. If this happens, you will be able to stop the interview at any time and/or ask not to discuss a particular question. If you would like further support after the interview with any difficulties relating to supporting someone with dementia, there are organisations such as Alzheimer's Society Tel: [redacted] and the Carers Federation Tel: [redacted], who may be able to provide support.

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 improve the ways that diagnoses of dementia are delivered in future.

What if there is a problem?
If you have a concern about any part 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 should then contact [redacted]

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, the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people 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.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from 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 will have access to your personal data.

Although what you say in the interview 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 at the memory clinic will not be altered in any way. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?
The findings of the study will be reported back to [redacted] Foundation NHS Trust and MAS clinics. The Faculty for Psychology of Older People and Dementia will also be contacted for potential dissemination of the findings. The study will also be prepared for publication in an appropriate peer-

reviewed journal and presented at relevant conferences. Participants will not be identified in any publications. This project also serves as partial completion of the researcher's thesis submission as part of the Doctorate in Clinical Psychology.

Who is organising and funding the research?
This study is organised and funded by Health Education East Midlands as part of the Doctoral Training of Claire Bennett, Co-investigator.

Who has reviewed the study?
All research in the NHS 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 East Midlands – Nottingham 1 Research Ethics Committee.

Further information and contact details
For any questions or to obtain a copy of the final report, please contact:

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Participant Information Sheet - Interviews with Patients
(Version: final 2.0 28.03.16)

Title of Study: Development of an intervention to improve the delivery of a diagnosis of dementia

Name of Researcher(s): Dr Nima Moghaddam, Dr Danielle DeBoos and Claire Bennett

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?
This study is part of a larger project that is developing a tool to help clinicians when delivering a diagnosis of dementia. The first part of the project is to find out people's experiences of receiving a diagnosis of dementia and opinions about what makes a good diagnostic delivery.

Why have I been invited?
You have been invited because you have been given a diagnosis of dementia at the Memory Assessment Clinic (MAS). We are asking patients who have received a diagnosis of dementia to take part in this 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 keep this information sheet 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. Taking part will not affect the care that you receive from any health care services.

What will happen to me if I take part?
You will be asked to take part in a face-to-face interview with one of the researchers: Claire Bennett. This interview can be on your own or with the person that you attended the memory clinic appointment with, it is your decision. The interview will ask you for your thoughts and opinions about receiving a diagnosis of dementia. The interview is expected to last around 30 minutes and will take part either at the Memory Clinic or at your home,

according to your preference. Claire Bennett will contact you by telephone to arrange a time and place with you.

The interview will be audio recorded and transcribed either by Claire Bennett or a transcription service.

Expenses and payments
Participants will not be paid to participate in the study. As the interviews will be able to done in a place that suits you, it is not expected that you will have any extra travel to take part. Therefore, there won't be any options for travel expenses to be reclaimed.

What are the possible disadvantages and risks of taking part?
The main disadvantage to you is the time required to take part in the interview. Some people can find talking about their experiences upsetting. If this happens, you will be able to stop the interview at any time and/or ask not to discuss a particular question. If you would like further support after the interview with any difficulties relating to living with dementia, organisations such as Alzheimer's Society ([redacted]) may be able to provide support.

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 improve the ways that diagnoses of dementia are delivered in future.

What if there is a problem?
If you have a concern about any part 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 should then contact

[redacted]DR

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, the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people 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.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from 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 will have access to your personal data.

Although what you say in the interview 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 at the memory clinic will not be altered in any way. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?
The findings of the study will be reported back to local clinical services and relevant conferences, written up as part of Claire Bennett's Doctoral thesis, and prepared for publication in an appropriate peer-reviewed journal. You will not be identified in any report or publication and any quotes will be anonymous.

Who is organising and funding the research?
This study is organised and funded by Health Education East Midlands as part of the Doctoral Training of Claire Bennett, Co-investigator.

Who has reviewed the study?
All research in the NHS 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 East Midlands – Nottingham 1 Research Ethics Committee.

Further information and contact details
For any questions or to receive a copy of the final study report please contact:

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Participant Information Sheet – Focus Groups with Service Recipients
(Final version 2.0 28.03.16)

Title of Study: Development of an intervention to improve the delivery of a diagnosis of dementia

Name of Researcher(s): Dr Nima Moghaddam, Dr Danielle DeBoos and Claire Bennett

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?
This study is planning to develop a tool to help clinicians, patients and their companions deliver and receive a diagnosis of dementia. The first part of the project has investigated what makes a good delivery of a diagnosis of dementia. This part of the project is planning to design the tool based on the findings of the first part of the project. This project also serves as partial completion of the researcher's thesis submission as part of the Doctorate in Clinical Psychology.

Why have I been invited?
You have been invited because you have recently attended the Memory Clinic or because you are in contact with the [redacted] of the Alzheimer's Society. We are asking up to 12 people who either have a diagnosis of dementia or support someone who has a diagnosis of dementia to take part in a focus group. This will be to guide the design of a tool which may help how a dementia diagnosis is given to people.

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 keep this information sheet 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. Taking part will not affect the care that you receive from any health care services.

What will happen to me if I take part?
You will be asked to take part in a focus group with up to 12 participants and one of the researchers. This will involve asking you about your thoughts and

opinions about the design of a tool that may be used in memory clinics in the future. The focus group is expected to last around one to two hours. A break will be given after one hour[redacted]. Travel costs can be reclaimed. Directions can be provided.

If you would like to attend please confirm your place by contacting **Claire Bennett via email: dementia.diagnosis@gmail.com or Tel: 07557 866929**.

Although the researchers will take every precaution to maintain confidentiality of the data, the nature of focus groups prevents the researchers from guaranteeing confidentiality. Please respect the privacy of your fellow participants and do not repeat what is said in the focus group to others.

The discussion will be audio recorded and transcribed by a professional transcription company. Quotes from the interview may be used when the study is written up but to protect your identity you will be given a pseudonym when the interview is transcribed.

Expenses and payments
If you take part in this focus group, you will be able to reclaim travel expenses incurred. If you wish to claim your expenses, a receipt (e.g. parking or bus ticket) should be provided. Please bring details of the bank account you would like the repayment to be made into. This includes the account number and sort code. This information will only be used to process your claim and will not be retained by the researchers.

What are the possible disadvantages and risks of taking part?
The possible disadvantage of taking part in this study is that you may have to spend a small amount of time taking part in the focus group. The researchers are experienced in supporting people to make the experience as positive as possible, but some people find talking about their experiences upsetting. Should this happen, you will be able to leave the focus group, and therefore stop your involvement in that particular question, if you wish. If you would like further support after the group with any difficulties relating to living with or supporting someone with dementia, there are organisations such as the Carers Federation Tel: 0[redacted]r Alzheimer's Society Tel[redacted]0, who may be able to provide support.

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 improve the ways that diagnoses of dementia are delivered in future.

What if there is a problem?

If you have a concern about any part 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 should then contact [redacted]

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, the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people 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.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from 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 will have access to your personal data.

Although what you say in the interview 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 at the memory clinic will not be altered in any way. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?
The findings of the study will be reported back to [redacted] Foundation NHS Trust and MAS clinics. The Faculty for Psychology of Older People and Dementia will also be contacted for potential dissemination of the findings. The study will also be prepared for publication in an appropriate peer-reviewed journal and presented at relevant conferences. Participants will not be

identified in any publications. This project also serves as partial completion of the researcher's thesis submission as part of the Doctorate in Clinical Psychology.

Who is organising and funding the research?
This study is organised and funded by Health Education East Midlands as part of the Doctoral Training of Claire Bennett, Co-investigator.

Who has reviewed the study?
All research in the NHS 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 East Midlands – Nottingham 1 Research Ethics Committee.

Further information and contact details
For any questions or to obtain a copy of the final report, please contact:

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Participant Information Sheet – Focus Groups with Service Stakeholders
(Final version 2.0 28.03.16)

Title of Study: Development of an intervention to improve the delivery of a diagnosis of dementia

Name of Researcher(s): Dr Nima Moghaddam, Dr Danielle DeBoos and Claire Bennett

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?
This study is planning to develop a tool to help clinicians, patients and their companions deliver and receive a diagnosis of dementia. The first part of the project has investigated what makes a good delivery of a diagnosis of dementia. This part of the project is planning to design the tool based on the findings of the first part of the project. This project also serves as partial completion of the researcher's thesis submission as part of the Doctorate in Clinical Psychology.

Why have I been invited?
You have been invited because you work; in [redacted] Trust's Mental Health Services for Older People and are currently involved in delivering diagnoses of dementia, or working with people who have dementia. We are asking up to 12 professionals to take part in a focus group to guide the design of the tool.

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 keep this information sheet 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?
You will be asked to take part in a focus group with up to 12 participants and one of the researchers. This will involve asking you about your thoughts and opinions about the design of a tool that may be used in memory clinics in the future. The focus group is expected to last around one to two hours and will

[redacted]

If you would like to attend please confirm your availability by contacting **Claire Bennett via email: dementia.diagnosis@gmail.com or Tel: 07557 866929**.

If you agreed to take part, you will be contacted to indicate your availability for two potential dates for this focus group. The most popular date will be the date for the focus group. The researcher will contact you at least one week before the dates to indicate which day most people are able to attend.

Although the researchers will take every precaution to maintain confidentiality of the data, the nature of focus groups prevents the researchers from guaranteeing confidentiality. Please respect the privacy of your fellow participants and do not repeat what is said in the focus group to others.

The discussion will be audio recorded and transcribed by a professional transcription company. Quotes from the interview may be used when the study is written up but to protect your identity you will be given a pseudonym when the interview is transcribed.

Expenses and payments
If you take part in this focus group, you will be able to reclaim travel expenses incurred. If you wish to claim your expenses, a receipt (e.g. parking or bus ticket) should be provided. Please bring details of the bank account you would like the repayment to be made into. This includes the account number and sort code. This information will only be used to process your claim and will not be retained by the researchers.

What are the possible disadvantages and risks of taking part?
The possible disadvantage of taking part in this study is that you may have to spend a time taking part in the focus group. The researchers are experienced in supporting people to make the experience as positive as possible, but some people find talking about their experiences upsetting. Should this happen, you will be able to leave the focus group, and therefore stop your involvement in that particular question, if you wish. You will also be able to discuss any concerns raised from participation in this study in your usual clinical supervision or with your staff counselling services.

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 improve the ways that diagnoses of dementia are delivered in future.

What if there is a problem?
If you have a concern about any part 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.

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, the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people 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.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from 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 will have access to your personal data.

Although what you say in the interview 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 then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?
The findings of the study will be reported back to [redacted] Foundation NHS Trust and MAS clinics. The Faculty for Psychology of Older People and Dementia will also be contacted for potential dissemination of the findings. The study will also be prepared for publication in an appropriate peer-reviewed journal and presented at relevant conferences. Participants will not be identified in any publications. This project also serves as partial completion of the researcher's thesis submission as part of the Doctorate in Clinical Psychology.

Who is organising and funding the research?
This study is organised and funded by Health Education East Midlands as part of the Doctoral Training of Claire Bennett, Co-investigator.

Who has reviewed the study?
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Further information and contact details
For any questions or to obtain a copy of the final report, please contact:

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Appendix J: Contact sheets for all phases of the project

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Contact Sheet for Interviews

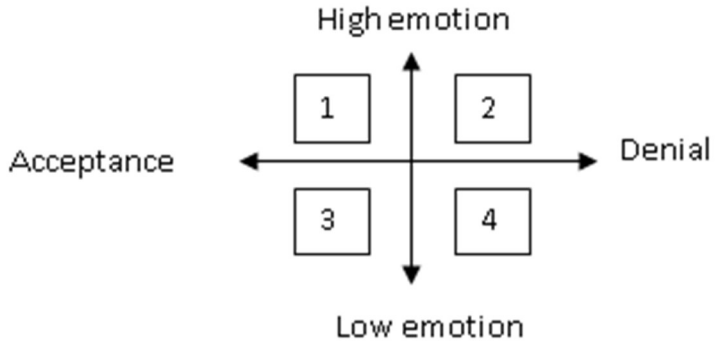
Title of Study: Development of an intervention to improve the delivery of a diagnosis of dementia

Name of Researcher(s): Dr Nima Moghaddam, Dr Danielle DeBoos and Claire Bennett

Name of clinician:
Date of appointment:
Clinic Location:

Name of Patient (circle preferred contact person)	
Name of Companion (circle preferred contact person)	
Diagnosis of Dementia Confirmed	**Yes / No**
Consent to be contacted to participate in interview?	**Yes / No**
Contact Telephone Number	
Alternative Telephone Number	
Email address	

Category:



Guidance:
Axis 1: high emotion - low emotion

- 'high': any clear expression of a feeling (positive or negative) about what they have been told. This may be feelings of anger, sadness, fear etc.
- 'low': A person that seems numb or indifferent to what's being said. It may leave you feeling unsure about how they feel.

Axis 2: acceptance - denial.

- 'acceptance': The person may verbally agree with what you've said 'Oh I knew it was something bad' and the conversation gives you the impression they agree with what you've told them, even if they are upset by it.
- 'denial': the person may verbally disagree with the diagnosis or may continue to question it 'are you sure?' or ask for further tests or time to make sure. They may offer examples of the person getting better e.g. 'but he remembered his tablets last week and he never used to'.

For researcher use

Date invited to participate	
Outcome	
Follow up call?	
Interview date and time	
Interview venue	

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Contact Sheet for Focus Groups

Title of Study: Development of an intervention to improve the delivery of a diagnosis of dementia

Name of Researcher(s): Dr Nima Moghaddam, Dr Danielle DeBoos and Claire Bennett

Name of Participant (circle preferred contact person)	
Consent to be contacted to participate in focus group?	**Yes / No**
Contact Telephone Number	
Alternative Telephone Number	
Email address	

For researcher use

Date invited to participate	
Outcome	
Follow up call?	
Interview date and time	
Interview venue	

Appendix K: Consent forms for all phases of the project

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INTERVIEW CONSENT FORM
Companions
(Final version 2.0 28.03.16)

Title of Study: Development of an intervention to improve the delivery of a diagnosis of dementia

REC ref: ***16/EM/0097***

Name of Researchers: Claire Bennett, Danielle DeBoos, Nima Moghaddam

Name of Participant:	**Please initial box**
1. I confirm that I have read and understand the information sheet version number 2.0 dated 28.03.16 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 give permission to be contacted and participate in an interview. I understand that the interview will be recorded, transcribed by a professional transcription company that is external to the research team and that anonymous direct quotes from the interview may be used in the study reports.	☐
5. I understand that confidentiality may be broken if there are any safeguarding concerns raised during my participation in the study	☐
6. 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

INTERVIEW CONSENT FORM
Patients
(Final version 2.0 28.03.16)

Title of Study: Development of an intervention to improve the delivery of a diagnosis of dementia

REC ref: ***16/EM/0097***

Name of Researcher: Claire Bennett, Danielle DeBoos, Nima Moghaddam

Name of Participant:	**Please initial box**
1. I confirm that I have read and understand the information sheet version number 2.0 dated 28.03.16 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.	☐
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5. I understand that confidentiality may be broken if there are any safeguarding concerns raised during my participation in the study	☐
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 and 1 for the medical notes

INTERVIEW CONSENT FORM
Clinicians
(Final version 2.0 28.03.16)

Title of Study: Development of an intervention to improve the delivery of a diagnosis of dementia

REC ref: ***16/EM/0097***

Name of Researchers: Claire Bennett, Danielle DeBoos, Nima Moghaddam

Name of Participant:	**Please initial box**
1. I confirm that I have read and understand the information sheet version number 2.0 dated 28.03.16 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 employment and 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.	☐
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4. I give permission to be contacted and participate in an interview. I understand that the interview will be recorded, transcribed by a professional transcription company that is external to the research team and that anonymous direct quotes from the interview may be used in the study reports.	☐
5. I understand that confidentiality may be broken if there are any safeguarding concerns raised during my participation in the study	☐
6. 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

FOCUS GROUP CONSENT FORM
Service Deliverers
(Final version 2.0 28.03.16)

Title of Study: Development of an intervention to improve the delivery of a diagnosis of dementia

REC ref: ***16/EM/0097***

Name of Researchers: Claire Bennett, Danielle DeBoos, Nima Moghaddam

Name of Participant:		**Please initial box**
1.	I confirm that I have read and understand the information sheet version number 2.0 dated 28.03.16 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 employment 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 focus group discussion will be recorded and transcribed by a professional transcription company that is external to the research team. I understand that anonymous direct quotes from the interview may be used in the study reports	☐
5.	I understand that confidentiality cannot be guaranteed for information which I might disclose in the focus group	☐
6.	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

FOCUS GROUP CONSENT FORM
Service Recipients
(Final version 2.0 28.03.16)

Title of Study: Development of an intervention to improve the delivery of a diagnosis of dementia

REC ref: ***16/EM/0097***

Name of Researchers: Claire Bennett, Danielle DeBoos, Nima Moghaddam

Name of Participant:		**Please initial box**
1.	I confirm that I have read and understand the information sheet version number 2.0 dated 28.03.16 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.	☐
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4.	I understand that the focus group discussion will be recorded and transcribed by a professional transcription company that is external to the research team. I understand that anonymous direct quotes from the interview may be used in the study reports	☐
5.	I understand that confidentiality cannot be guaranteed for information which I might disclose in the focus group	☐
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 and 1 for the medical records

Appendix L: Topic guides for all phases of the project

Interview Topic Guide – Clinicians

Development of an intervention to improve the delivery of a diagnosis of dementia

Each interview will begin and end with prepared statements

Opening statement:

Thank you for agreeing to be interviewed. I would just like to check again – are you happy for us to audio-record this interview?

Closing statement:

Thank you again for your time. Is there anything else you feel we haven't covered in the interview or anything you would like to clarify? Is there anything else you would like to ask about this study?

Sections below outline topics areas to be covered in the interview and provide some example questions.

Dementia Diagnosis Process

To gain a factual description of their experience to allow comparisons between participants.

What is their role when delivering a diagnosis or potential diagnosis?

Dementia Diagnosis Experience

To gain an understanding about how delivering a diagnosis is experienced by clinicians.

What is it like to deliver diagnoses of dementia? How to you manage the consultation where this is delivered to the patient and supporter? How do they adapt when people have different expectations of the consultation and different perspectives about diagnosis? What do they do to adapt practice to each patient's needs? What do they find easiest and hardest about the delivery?

Patient Experience

To gain information about the views of clinicians about how patients experience diagnostic delivery.

How do they think patients and their supporters experience the service and diagnostic delivery which they work in? Do they think patients and supporters would want anything changing? Do they think that the service is able to deliver diagnostic information in patient centred ways? If so (or not) how and why?

Improving Practice

To gain understanding about how things could be better or different.

Is there anything that is particularly good or bad about the services and way diagnosis is delivered? Was there anything they think particularly helps or doesn't help? Is there anything that they would like to include or do differently that isn't available currently?

Interview Topic Guide – Patients and Supporters

Development of an intervention to improve the delivery of a diagnosis of dementia

Each interview will begin and end with prepared statements

Opening statement:

Thank you for agreeing to be interviewed. I would just like to check again – are you happy for us to audio-record this interview?

Closing statement:

Thank you again for your time. Is there anything else you feel we haven't covered in the interview or anything you would like to clarify? Is there anything else you would like to ask about this study?

Sections below outline topics areas to be covered in the interview and provide some example questions.

Dementia Diagnosis Process

To gain a factual description of their experience to allow comparisons between participants.

Has a diagnosis been confirmed? Gain a description of how the diagnosis was delivered.

Dementia Diagnosis Experience

To gain an understanding about how receiving the diagnosis was for the service recipients.

How did you feel before you were told of the diagnosis? What was it like to receive the diagnosis? What was their position regarding the diagnosis prior to receipt – e.g. was it confirming what they already knew/suspected, was the diagnosis expected, was it a shock? Did anything help you before, during, after receiving the diagnosis? Did they do or think about anything between assessment and receiving the diagnosis – e.g. research, support groups?

Memory Assessment Service Experience

To gain information about the specific experience at the MAS Clinic.

When did they attend the MAS clinic? How many times have they been? Was there anything helpful for them at the MAS clinic? Was anything unhelpful? How was the process explained? How were they involved/did they discuss how they would like information to be delivered? Was the diagnosis – both the amount of information and type of information – inline with their preferences?

Improving Practice

To gain understanding about how things could be better or different.

Was there anything that stood out for them that was particularly good or bad about their whole experience? Was there anything that helped or didn't help? With the benefit of hindsight would they have found anything helpful that wasn't suggested/available/they didn't know about? If they could receive the diagnosis/go through the process again what would it be like in an ideal situation/what would you change?

Focus Group Topic Guide – Service Deliverers

Development of an intervention to improve the delivery of a diagnosis of dementia

The Focus Group will begin and end with prepared statements

Opening statement:

- Thank you for agreeing to take park.
- Confidentiality statement: “Although the researchers will take every precaution to maintain confidentiality of the data, the nature of focus groups prevents the researchers from guaranteeing confidentiality. Please respect the privacy of your fellow participants and do not repeat what is said in the focus group to others.”
- Aim to take an hour, should it go on for any longer a short break will be provided after one hour. Should you need to take a break before or after this please feel free to leave the group.
- Participants will be asked, in turn, to clearly state their name at the start of the audio recording of the focus group to aid transcription.

Closing statement:

- Thank you again for your time. Is there anything you would like to clarify? Is there anything else you would like to ask about this study?
- Reminder about confidentiality
- Explain travel expenses – provide travel claim form and support.

Sections below outline topics areas to be covered in the group and provide some example questions.

Aim of the tool

To gain an idea if the design selected is meeting the tool’s aim to help diagnosis delivery become more easily in line with patient preferences

Outline the aim, do you think that this tool could achieve this? Are there any ways that it could do this better or differently?

User acceptability

To gain an understanding if people involved in providing services to people who have concerns about memory think that the tool might help them in their role.

Would this tool be helpful to you in your job role? Are there any ways in which this tool could be useful? How is this tool not helpful?

Up take of tool

To gain information about the likelihood that the tool would be used in clinical practice.

Do you think that you would ever find it helpful to use a tool like this? Do you think that people using the MAS services might find the tool helpful? What are the barriers to using it?

Focus Group Topic Guide – Service Recipients

Development of an intervention to improve the delivery of a diagnosis of dementia

The Focus Group will begin and end with prepared statements

Opening statement:

- Thank you for agreeing to take park.
- Confidentiality statement: "Although the researchers will take every precaution to maintain confidentiality of the data, the nature of focus groups prevents the researchers from guaranteeing confidentiality. Please respect the privacy of your fellow participants and do not repeat what is said in the focus group to others."
- Aim to take an hour, should it go on for any longer a short break will be provided after one hour. Should you need to take a break before or after this please feel free to leave the group.
- Participants will be asked, in turn, to clearly state their name at the start of the audio recording of the focus group to aid transcription.

Closing statement:

- Thank you again for your time. Is there anything you would like to clarify? Is there anything else you would like to ask about this study?
- Reminder about confidentiality
- Explain travel expenses – provide travel claim form and support.

Sections below outline topics areas to be covered in the group and provide some example questions.

Aim of the tool

To gain an idea if the design selected is meeting the tool's aim to help diagnosis delivery become more easily in line with patient preferences

Outline the aim, do you think that this tool would help to do this? Are there any ways that it could do this better or differently?

User acceptability

To gain an understanding if people who have concerns about memory and those that support them think that the tool might be helpful before and during receiving a diagnosis of dementia.

Would this tool be helpful to you if you were attending the memory clinic? Are there any ways in which this tool could be more useful? How is this tool not helpful? Would you want to use it, and why? How would you change it?

Appendix M: Case report form

CASE RERORT FORM

Title of Study: Development of an intervention to improve the delivery of a diagnosis of dementia

Subject ID	Subject Initials	Form Completed	Initials of researcher

Primary details

Email:			
Telephone contact number:			
Address:			
Age		Gender	

Participation information

	Date scheduled	Completed?
Phase one interview		
Phase two focus group		

Participant Type	MAS Clinician / ASW / MAS Patient / Companion
Focus Group	Deliverer / Recipient

Demographics

Clinicians – length of experience	

Patient – date of diagnosis	
Patient – length of time accessing MAS service	
Patient – who usually attend MAS with?	

Companion – relationship to patient	
Companion - length of time accessing MAS service	

Administration

Date consent form signed			
Transcription sent		Transcription completed	
Consent for future participation			
Requested final report			

Appendix N: Extract of transcript with coding

Data from Jennifer (Clinician) (interviewer is emboldened)	**Code**
Could you tell me what it's like for you to deliver a diagnosis?	
Because it's such a huge diagnosis to give to anybody and it can be quite nerve wracking. I've been doing it for quite some time and you still get a butterfly type feeling the minute you are about to deliver it because you are aware of the impact it's going to have on that family, that person, and the responses that you get, you think, a lot of people are expecting it, so it reassures you if anything and some days, in my own words, you feel like the Grim Reaper, so it's such a variable experience and it's on a day to day.	Transfer of ownership Delivery is a big responsibility Anticipation just prior to delivery Gravity of diagnostic delivery Diagnosis can confirm own ideas Emotional impact of delivering a diagnosis Diagnosis is negative Can't anticipate how it will feel to deliver
What keeps you doing this job?	
It's the challenge and it's knowing that I'm helping somebody. At the end of the day we often get, or I've often had from a patient, you've given me a name to it now, there is something definitely wrong. So a lot of older people think they're losing it, they're getting older but you've actually given them a name now and they feel quite comforted by that, even though it is dementia but they've got a name and they've got something to work with. I feel quite rewarded by doing that and knowing that the prognosis is poor but you know there is a lot of support out there and that they are still a person.	Delivery as effortful and draining Diagnosis as helpful Diagnosis is powerful Diagnosis alleviates fears Diagnosis as a transition point from what is wrong to the future implications Delivery as bitter sweet Dementia has power to remove people's independence
So some people find it a positive thing. Are there times when that doesn't feel that, where it can feel quite hard?	With support it is possible to alter a person's perspective about the diagnosis
Yes, probably I can recall two or three patients if anything that have cried and said, "That's the end of it, there's no hope for me" and it's meant a lot of work with that person helping them to understand that they are still that person at the end of the day and it can be still quite a shock to receive that reaction.	Diagnosis of dementia can feel hopeless Dementia does not have to mean a loss of identity Emotional impact of delivering a diagnosis

Appendix O: Phase one initial theme development

i) **List of all initial themes generated in first sort of codes**

Theme	Sub-theme(s)
Power	Diagnosis's power; Dementia's power; Clinician's power
Impact of diagnosis	
Relationships	
Service level challenges	
Clinician's approach	
Choice and control	
Dynamics	
Journey of diagnostic appointment	
Emotions	
Understanding diagnosis	Language use
Information management 'The What'	
Experience of diagnosis 'The How	
Miscellaneous	

Theme in italics is displayed in more detail below

ii) **All codes within theme *'Emotions'* from initial theme development**

Acceptance is varied

Anticipation of patient's response post delivery

Appointments are anxiety provoking

Assessment as embarrassing

Can only accept the diagnosis

Clinician is emotionally affected by patient

Clinician maintaining self-awareness

Clinician managing own anxiety post delivery

Clinician providing emotional support as well as information

Clinician remaining self-aware during and after diagnosis

Clinician required to manage a variety of reactions within the same appointment

Confrontation better than avoidance of dementia

Delivery as bitter sweet

Delivery as effortful and draining for clinician

Dementia as distressing

Dementia diagnosis is scary for family and friends

Dementia emotionally affects those around the PWD more than the PWD

Dementia is frightening to experience

Diagnosis as sad and a loss

Diagnosis of dementia can feel hopeless

Diagnosis of dementia is hopeless

Diagnostic delivery can feel negative but try to hold onto the small areas you can help

Diagnostic journey removes shock

Diagnostic process is complex and stressful for service recipients

Disclosure of diagnosis to family members can be painful

Emotional build up prior to diagnostic appointment

End of MAS input as a loss

Expectation of diagnosis process as a negative experience explicitly consider companion's emotional needs

Fear about consequences of asking for help

Fear factor as dementia is a mental illness

Fear of disclosing diagnosis to others

Fear of the unknown

Feel safe with expert feeling abandoned after diagnosis

Heightened emotions can prevent information from being absorbed

Importance of using own emotions and emotional expression during appointment

Living with worries about coping in the future

Maintain an awareness of person's emotions

MAS process as anxiety provoking

Patient aware of clinician's emotions

Patient masking emotions during appointment

People can come to appointment with worries about non-dementia diagnoses

Privilege to deliver a diagnosis

Prompt service is helpful for reducing anxiety

Receiving a diagnosis as emotional

Supporting someone with dementia is upsetting

The moment of delivery can trigger a release of emotion

Using humour as a coping strategy

Waiting for results is anxiety provoking

iii) **Code contained within the theme '*Emotions'* with corresponding data**

Code: Delivery as effortful and draining

Data Source	Data extract
Alan (Companion)	I wouldn't have liked to be in his position.
Jennifer (Clinician)	It's the challenge
	It's very wearing
Louise (Clinician)	just know about how I work but I know that I do put a lot of myself and put a lot of energy into that
Susan (Clinician)	can be quite tiring and draining

Appendix P: Extracts from reflective diary

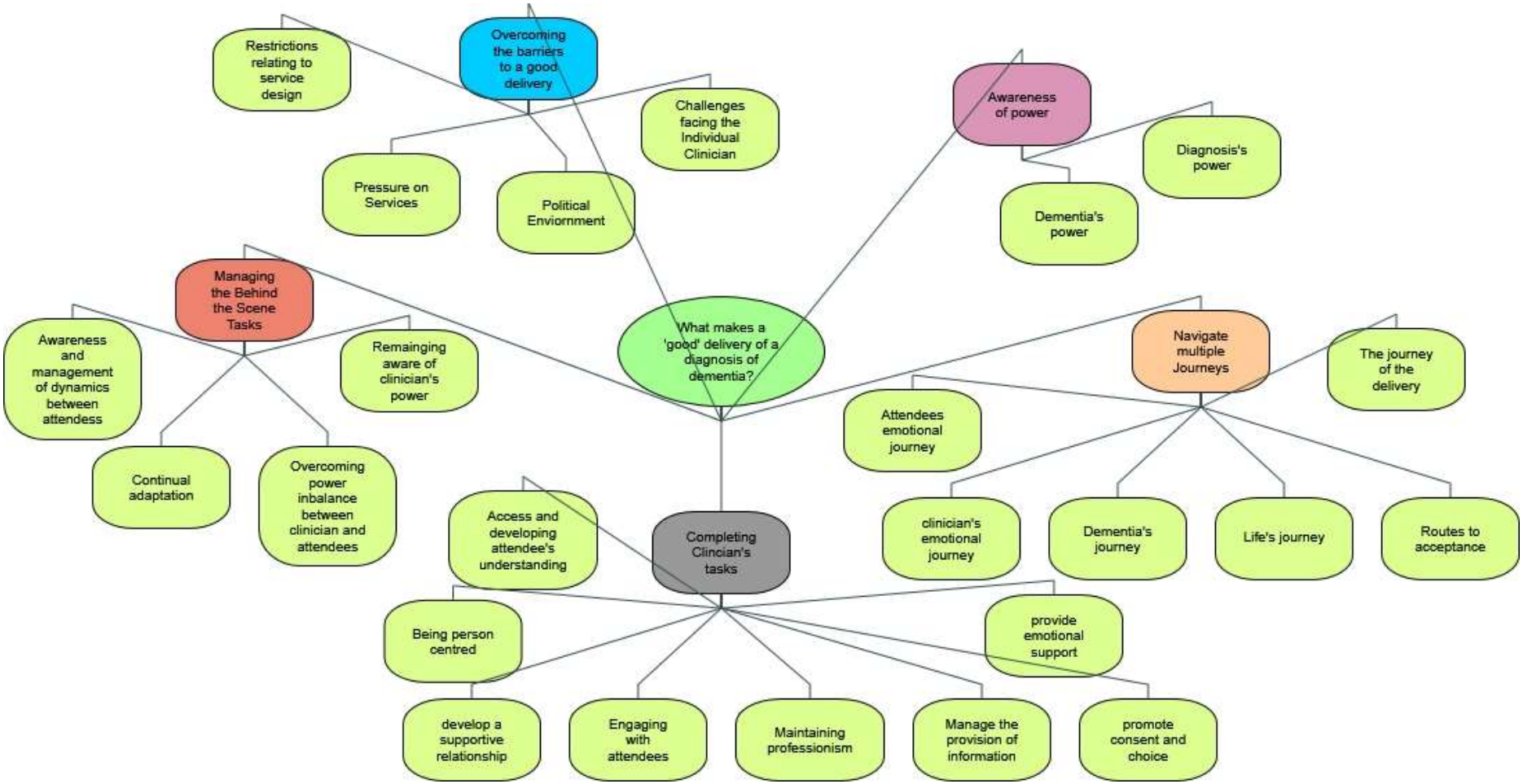
“Reviewing the themes, I have created many but they appear to lack the ability to tell me about practice. But I am feeling overwhelmed by the volume of themes and unsure of how to manage the process of refinement. Perhaps learning how to manage themes in NVivo may be helpful at this stage. This helped me manage the codes in the previous stage of analysis.”

“I have noticed how my confidence in managing the process of theme development has grown. Explaining the meaning of the themes in supervision has contributed to this process, helping me to be clear about the central concept of each theme. Mostly I feel that my confidence has been supported by NVivo as moving codes and reorganising themes seems easy and less permanent than in a word programme. I have noticed that this has helped me contain my worries about making a change I then regret. I have also noted that I have become more confident to make changes after using this reflective diary to record my thoughts and observations. For example, after recording the entry below I then felt confident that my own observations were appropriate and should be reflected in my theme structure.

The emotions connected to receiving a diagnosis seems logical from my observer perspective. What has surprised me is the way clinicians describe their own emotional connection both with the recipients and with the news that they are bringing. If I am surprised by this, would other people be? Does the emotional change and experience of clinicians when delivering a diagnosis need to be specifically highlighted as a separate entity?”

Appendix Q: Phase one themes: version three

i) Theme Map



ii) **All codes within theme '*Clinician's emotional journey'*** (located in overarching theme Navigate multiple journeys).

Anticipation of patient's response post delivery
Clinician is emotionally affected by patient
Clinician maintaining self-awareness
Clinician managing own anxiety post delivery
Clinician remaining self-aware during and after diagnosis
Clinician's expectations of reaction can be wrong
Delivery as bitter sweet
Delivery as effortful and draining for clinician
Emotional impact of delivering a diagnosis
Importance of using own emotions and emotional expression during appointment
Patient aware of clinician's emotions
Privilege to deliver a diagnosis

In the final theme structure this theme was further refined and was located within the overarching theme Navigation of multiple journeys, and sub-theme Emotional Journey. This sub-theme was then further divided resulting in this theme pathway:

Navigation of multiple journeys > Emotional Journey > Clinician's emotions

By the final revision, an additional code had been included. This was the code *'Anticipation of patient's response post-delivery'*. The data within this code was:

Jennifer (Clinician): it's waiting for that response when you've just told them the diagnosis. You just never know,

Appendix R: Extract from reflective diary

“Now that I am feeling confident about the process of generating and modifying the themes, I am now struggling with producing theme titles that clearly link to the content and meaning of the theme. For example, the theme managing behind the scenes tasks is clunky and long winded. If I were ‘new’ to this data I am unsure if I would understand what this was referring to. I want to do justice to my data and I think this is holding me back. Maybe I need to go back to basics. Perhaps explicit and implicit tasks could be a step forward?”

Appendix S: Initial draft of service deliverer's tool

Dementia Diagnostic Delivery – A guide for Deliverers

Prototype – Content Review

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 back to every so often. It may also be helpful if you have had a negative delivery to see what may have been able to have been done differently or to use in supervision or reflective practice.

It can be used alongside a guide, notes sheet and prompt 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.
- Record what they have been told in their appointment, including their diagnosis where appropriate
- Collate information about next steps, services, and who to contact with questions.

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.

Terminology
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. This means that it can be a difficult to manage the dynamics and focus of the appointment.

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:

- actively ask questions, rather than waiting for the person to offer information.
- ask easy questions such as how their week has been to break the ice at the beginning of the appointment and slowly build up to more in depth questions.
- maintain an open body posture, for example facing the person, and not folding arms.
- giving people space and time to answer any questions or express themselves. Try not to talk over people.
- 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.

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.

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. Many people who attend will require some emotional support or at least some 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 and always support their 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 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!

Appendix T: Initial draft of service recipient's tool

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Memory Assessment Services – A Guide
Prototype – Content Review

Introduction
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 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.

Information about Memory Assessment Service
You have received this guide because you have an appointment at the Memory Assessment Service. This is because there are some worries about your memory at the moment.

The Memory Assessment Service is where specialist doctors and nurses assess people's memory. People may have difficulties with a range of different things and it is their job to try and understand what is causing these difficulties.

To start with, you will be asked to attend the Memory Assessment Service for an Assessment Appointment. Many people will have a range of tests or assessments completed with them in this appointment. You may need to have brain scan but this will be at a different time. In this appointment you will also be asked about how things are going at the moment and what things you are finding difficult.

Once all the tests have been done the nurse will ask you to come back into the clinic to explain 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 are a range of different types of dementia including Alzheimer's Disease and Vascular Dementia. The nurse will explain to you about your diagnosis and what this could mean.

Depending upon what the results of your tests showed, you may need to go back for another appointment. This is to check any medication that you have been given.

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 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 Clinic to send them copies of letters, then you can tell the nurse this 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
- 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?

If you think of these things before your appointment, why not write them down?

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Memory Assessment Services – Notes Sheet
Prototype – Content Review

Use this sheet to make any notes about your choices, concerns and questions. Bring this to your appointment. The nurse may like to read this sheet.

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.

Name: **Date:**

Main Concerns and Questions
Have you noticed any differences in your memory?

What are your main concerns at the moment?

What questions would you like to find out about at your appointment?

Any other worries that you want to discuss?

Making Choices
Use this section to record your wishes and choices

Who do you wish to come into your appointment with you?

What do you want know about your diagnosis?
(for example: Tell me everything, give me a brief an overview, just tell me the name, nothing)

Would you like the nurse to go through your results with you?

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 that you would like to tell the nurse about?

Other important information to ask or remember in the appointment
Use this space to make any other notes for using in your appointment.

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Memory Assessment Services – Notes Sheet
Prototype – Content Review

Use this sheet to make any notes about your choices, concerns and questions. Bring this to your appointment. The nurse may like to read this sheet.

This is a second copy – you may want to give this to the person who is coming with you to your appointment to fill in.

Name: **Date:**

Main Concerns and Questions
Have you noticed any differences in your memory?

What are your main concerns at the moment?

What questions would you like to find out about at your appointment?

Any other worries that you want to discuss?

Making Choices
Use this section to record your wishes and choices

Who do you wish to come into your appointment with you?

What do you want know about your diagnosis?
(for example: Tell me everything, give me a brief an overview, just tell me the name, nothing)

Would you like the nurse to go through your results with you?

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 that you would like to tell the nurse about?

Other important information to ask or remember in the appointment
Use this space to make any other notes for using in your appointment.

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Memory Assessment Services – Prompt Sheet
Prototype – Content Review

Use this sheet in your appointments to help you remember everything that you wanted to find out about. You could ask the nurse to help you fill it in.

Main Concerns and Questions
Have you gone through all your concerns and questions on your Notes Sheet?

Have you asked any other questions that you have thought of during your appointment? If not ask now.

Choices
Have you told the nurse about your choices? If not tell them now.

Do you need to make any choices after this appointment? Use this space to write them down.

Results
Do you understand what has been said about your results? If not tell the nurse

Write down here what you have been told so that you can refer back to it later.

Information
Have you got as much information as you would like, or that the nurse could give you? If not ask now

Write down here any contact information of local services or support that might be helpful.

Next Steps
Do you know what is happening to you next?

Write it down here.

Contact information
Who can you contact if you have questions after this appointment? Write it here.

Any other important information?
Use this space to write down anything else important or interesting.

Appendix U: Final version of service deliverer's tool

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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 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 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.

Appendix V: Final version of service recipient's tool

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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?
Assessment Appointment
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
- 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 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?

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

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?
(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

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

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?
(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.

Poster

Understanding diagnostic delivery of dementia

The University of Nottingham
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Claire Bennett[1], Danielle De Boos[1], Nima G Moghaddam[2]

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Introduction

Current political drivers are set to increase the volume of people receiving a dementia diagnosis (1,2). However, there are problems with how diagnoses are being delivered (3), with people reporting it to be confusing, anxiety provoking, and being generally dissatisfied (4).

Limited guidance exists that could help improve the delivery. Research has begun to explore the components of a good delivery of a diagnosis of dementia (5), however interventions to support clinicians to deliver diagnoses are limited.

Aim: develop a prototype tool that could be used by clinicians, patients and companions who are involved in the delivery of diagnoses of dementia.

Methods

Two phase sequential design

Phase One:

10 Interviews: what makes a good diagnostic delivery of dementia? → **Data analysis:** Use thematic analysis to identify areas of good practice → **Tool development**: Devise two tools to support good practice in delivering diagnoses

Phase Two:

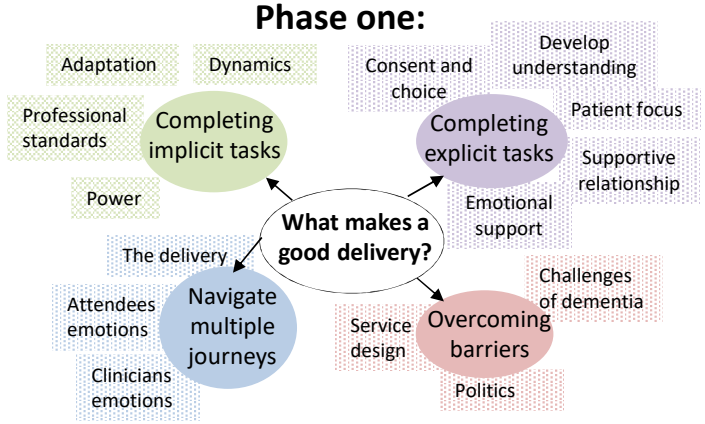
4 Focus groups: qualitative feedback on draft tools → **Data analysis:** Use thematic analysis to judge tools acceptability of → **Tool development:** Edit and revise the tools in line with feedback

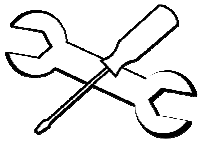
Participants

From one local Memory Assessment Service (MAS)
Phase One: 4 clinicians, 5 patients, 5 companions
Phase Two: 7 service deliverers, 6 service recipients

Results

Phase one:





Tool Design: Two paper based tools

Service Deliverer's Guide

Guide to support reflective practice and skill development.

Service Recipient's Guide

Three elements:

- information guide – overview of MAS appointments and outcomes, introduction to choices, bringing a relative or friend
- notes sheet – supported consideration of main concerns and choices, provision of space to record answers
- prompt sheet – to use during appointments to prompt question asking, and recording information discussed

Phase two:

Overall feedback was positive and both tools were deemed to be acceptable.

The tools were modified to remove the prompt sheet and incorporate the principles into the service deliverer's guide.

Some minor adaptations to improve acceptability of phrasing.

Discussion

Developed novel tool for supporting good practice in the delivery of dementia diagnoses/is. This study also contributes towards the knowledge of dementia diagnosis and provides an alternative narrative of quality diagnostic delivery, rather than diagnostic volume.

A key strength was the development process. Other breaking bad news protocols, e.g. SPIKES (6), were not reported to have included the patient's perspective during development (7). The development of this tool goes someway to combat this common occurrence of professionals speaking on behalf of people with dementia (8).

The tool uniquely articulates clinicians' experiences of diverse and changing emotional responses to the process of diagnosis delivery and of their management of this to prevent impact on the recipient. It is suggested that by mastering these skills clinicians can facilitate cohesion with, rather than distancing from, the attendee's emotions (9). This is argued to be important in view of the recognition that a diagnosis of dementia is highly emotive.

Sampling strategy may have resulted in people who were ambivalent about their experience of diagnostic delivery being unlikely to participate. As such, it is possible that only a selection of important elements of good practice have been explored. Therefore, the content of the tools should not be viewed as exhaustive.

Future directions

The next steps are to continue to develop and evaluate the tool.

Further research is required to understand the acceptability and feasibility of both tools, and if they can promote improved diagnostic delivery of dementia. Future development work should continue within the Medical Research Council guidelines for development of complex interventions (10).

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