

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

Although, at first glance, more people receiving a diagnosis sooner appears to be a positive change, 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). In a recent systematic review of 35 qualitative papers, it was reported that many studies highlighted participants' dissatisfaction with the diagnosis of dementia and the information provided (Low, Swaffer, McGrath, & Brodaty, 2017). Furthermore, Low et al. (2017) suggest that, for many participants, poor diagnostic delivery also communicated implicit messages about an associated decline in social status and abilities. Low et al. (2017) argue that this can negatively impact a

person's ability to adjust to the diagnosis and may lead to feelings of disempowerment and stigmatisation. Alongside this, recent qualitative studies have described the negative impact on individuals. Samsi et al.'s (2014) exploration of the diagnostic process in UK NHS secondary-care settings highlighted that diagnostic disclosure was experienced as confusing and anxiety-provoking, with poor communication leading to general dissatisfaction. Furthermore, the process from first noticing difficulties to receiving a diagnosis of dementia has also been reported to be challenging, and to entail multiple levels of uncertainty (Campbell et al., 2016).

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). 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 delivery of bad news in other healthcare settings, which may have transferable concepts. Available clinician focused protocols (e.g., Baile et al., 2000; 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). 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 (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 lineal communication transaction between clinician and patient, which may not fully reflect the true complexities of actual clinician encounters (Villagran et al., 2010). Alongside these limitations, the Dementia Workstream of the British Psychological Society (BPS) Faculty of the Psychology of Older People (FPOP) are 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 (Robinson et al., 2011). 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.

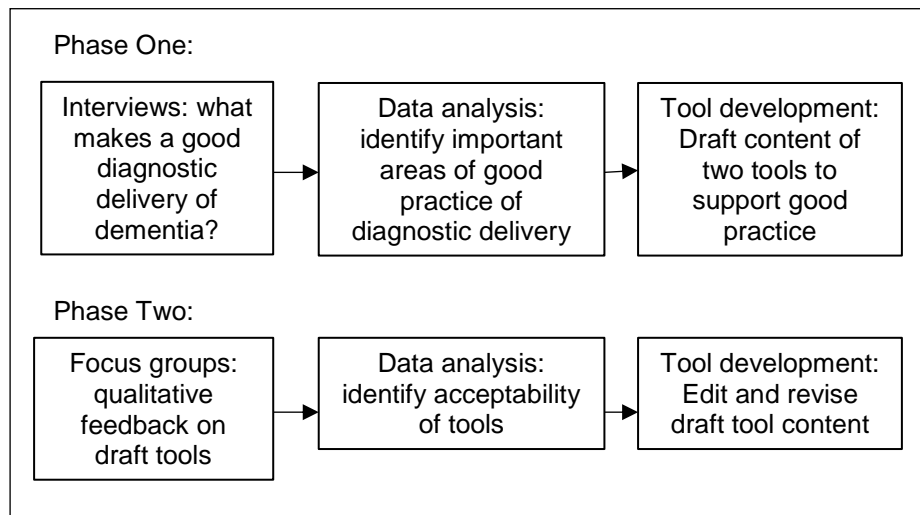
Due to the limited detail of the UK good practice guidelines and applicability of tools or interventions from other healthcare settings, it is critical that current research attempts to produce supportive tools for good practice. As such, the overarching aim of this study was to develop a prototype tool for dementia diagnostic delivery based on clinician, patient, and companion experiences of important features of dementia diagnostic disclosure in MAS settings.

## Methods

### Study Design

This study has taken a qualitative, sequential, two-phase design. Figure 1 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) that covered a large UK city and the surrounding county. Ethical approval for the study was obtained from East Midlands - Nottingham 1 Research Ethics Committee (reference number 16/EM/0097) and all participants gave written informed consent, which included the use of anonymised quotes.

Figure 1; Steps undertaken in each of the two study phases



## Phase One

### Sampling and Recruitment

Clinicians 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 informed, 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 informed, 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 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 and Analysis

Data were collected through ten audio-taped, face-to-face, semi-structured interviews 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 particular MAS, and changes in practice. Interviews were transcribed verbatim by a transcriptionist. 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 by the first author. Braun and Clarke's (2006) step-by-step guide and criteria for good quality thematic analysis was utilised. 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 excerpts 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 consultation with the second and third authors to identify the overarching themes and sub-themes. Finally, the first author defined and named the themes.

## 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

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 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 transcriptionist. 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 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

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. 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 as individuals. 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 1 outlines the theme structure.

Table 1, 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

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 lead to overfilling the appointment or rushing to deliver information. Quote 1 in Figure 2 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 Figure 2, 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.

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 Figure 2 when she delivers the news. These negative emotions are also experienced by the recipients, highlighted by Alan’s quote (Quote 5, Figure 2). Due to this, clinicians need to actively attempt to mitigate

Figure 2: 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.

any temptation to shy away from delivering the news, to ensure good quality diagnostic delivery.

#### Navigation of multiple journeys

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.

*Attendee's emotions.* During the diagnostic appointment people reported feeling anxious, sad, embarrassed, frightened of the unknown, and shocked during their appointment. There were also mixed emotions about receiving a diagnosis. A couple of the reactions of participants are highlighted by Quotes 1 and 2 in Figure 3.

*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

Figure 3: 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?

emotional journey. Jennifer and Louise discuss their emotional experiences in Quotes 3 and 4 in Figure 3.

#### Overt tasks

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



*Develop a supportive relationship.* To achieve best 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 Figure 4).

*Promote consent and choice.* Good diagnostic delivery works with attendees to enable patients and their companions to make choices. Quote 2 in Figure 4 is a discussion between Alan (companion) and Edna (patient) that evidences how people 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, Figure 4. However, introducing the word and concept of dementia requires careful management. The clinician needs to locate the attendees' current understanding of difficulties and develop this. Pat (clinician) describes how he locates attendees' understanding in Quote 4, Figure 4. 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, Figure 4).

*Be patient centred.* Best practice involves placing the patient as the central focus of the diagnostic delivery. However, this must not be at the exclusion of the companion. Edna (patient) describes how Louise (clinician) managed the interactions with herself and her husband (Alan) who accompanied her (Quote 6, Figure 4).

*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, Figure 4, highlights how emotional reactions need support and consideration to prevent difficulties in comprehension.

Figure 4: 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

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 should manage this power imbalance and work towards an equal partnership with attendees. When clinicians can collaborate with attendees this can provide a positive experience as described by Ann (companion) in Quote 1, Figure 5.

*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, Figure 5, Louise highlights how this adaptation requires effort and care. Supporting Louise's reflections, in Quote 3, Figure 5, 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, Figure 5. 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, Figure 5.

Figure 5: 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-verbals 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

Inspection of the themes appeared to indicate development of a single tool for the use of clinicians. However, it was 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 2 outlines which themes each tool targets and how the tool attempts to encourage each theme in clinical encounters.

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. It was advised 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. It was 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 were 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 and 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.

Table 2 outlines how aspects of the tool specifically derive from the thematic analysis of phase one data.

Table 2; 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  Remind clinicians to seek out patient's and companion's existing understanding and continually check out the development of understanding	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  Encourage patients and companions to consider the information they would like. Offer a space to record this.

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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 patients to  
consider bringing  
someone to support  
them in the appointment

Encourage clinician to ask people  
about their feelings and to remain  
aware of their own emotions

Table 2 continued

Phase One Results		Clinician's guide	Attendee's guide		
Theme			Information 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 actively and sensitively manage complex dynamics		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		



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	Highlight to clinicians the personal impact of diagnostic delivery and the importance of self-care
Overcoming barriers	Encourage use of reflective practice and supervision
	Acknowledge the complexity and difficulty of delivering a diagnosis of dementia

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## Phase Two

### Participants

To preserve anonymity, the participants are described in aggregate terms. All 13 participants were White British and three were male. Six service recipients contributed, two of which were people who had 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

#### Benefits

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

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

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 was 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?

### Alterations

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.

## 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. However, some participants also expressed that the tool may be less helpful for experienced clinicians than clinicians for whom delivering a diagnosis of dementia is a relatively new task. Despite this, 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.

A key strength 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 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 some way 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 barriers in 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 expressed 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.

A theme that is possibly unique to this study and tool is the detail of the emotional journey of the clinician during diagnostic delivery. In guidelines about breaking bad news, emotions of the clinician have been acknowledged, but the depth of detail and indication of how clinicians should manage their emotional experience has been limited. For example, '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 skillful 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 clinician's own emotional awareness and skills in negotiating their own and the attendee's emotions. It is suggested that by mastering these skills clinicians can lead to cohesion with, rather than distancing from, the attendee's emotions (Shapiro, 2013). This may well be especially important when negotiating the often highly emotive disclosure of a diagnosis of dementia.

The main limitation 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 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 understand if there are any unique differences in the acceptability of diagnostic delivery in these groups, thus representing a gap in this tool's development.

The sampling procedures may also limit the generalisability of the findings of this study. 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 participants' experiences and therefore improves the transferability of the findings (relative to sampling of a single MAS in the hosting trust). Alongside this, 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. Overall, the small sample size across both phases may also impact upon generalisability; however, inspection of the quality of the dialogue within phase one 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 to achieve data sufficiency and therefore increase the confidence in the quality of the data.

In the development of the tool it is possible that, due to the low number of each type of participant, the themes developed may not fully represent broader populations. Despite this, themes that were developed are to some extent represented in other research. For example, Lecouturier et al. (2008) previously advocated for an individualised approach to diagnostic delivery, and present study data were consistent with this. 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 were also highlighted in the current study's themes.

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. The next steps in this specific tool's development is to pilot implementation into practice. Further research 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 considered likely to encourage good practice. The tool was also adapted following concerns expressed about some aspects of the design and this is envisaged to improve the acceptability of 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. Copies of the developed tool can be obtained by contacting the primary corresponding author.

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## Notes

Copies of the developed tool or enquires relating to the research materials can be obtained by contacting the primary corresponding author.

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## Conflict of Interest

The Authors declares that there is no conflict of interest.

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