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Barriers and facilitators in diagnosing dementia in migrant populations: a systematic review of European health professionals' perspectives

and;

Communicating a diagnosis of dementia in secondary care: a reflexive thematic analysis of multidisciplinary perspectives

Siobhan Rose Hurley
Doctorate in Clinical Psychology
The University of Edinburgh, May 2023
DClinPsychol Declaration of Own Work

Name: Siobhan Rose Hurley

Title of work: Barriers and facilitators in diagnosing dementia in migrant populations: a systematic review of European health professionals’ perspectives

and

Communicating a diagnosis of dementia in secondary care: a reflexive thematic analysis of multidisciplinary perspectives

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To my newest friends, who make Scotland feel like home, I am lucky to have found you all. Thank you to the ‘Crusts’ for your camaraderie and hilarity: I think we’ve forged something quite exceptional for a COVID cohort. Kate, I am so grateful for our weirdness and hysterical laughter, and Grace for your psychedelic mind. To Claire, Sam, Ellen, Dan, Sarah, Nate, Lilian, and Simon, thank you for all the comedy and depth you bring to my life.

Finally, to Aesop, Lola, and Želva, for your companionship and mischief along the way.
Dedication

This thesis is dedicated to the memory of Aesop, the gentlest and most marmalade of creatures. I hope my work embodies something of his curiosity, wisdom, and spirit.

[Image of a cat]

Aesop McCaig, October 2021 – April 2023
Thesis Portfolio Abstract

This thesis aimed to explore the experiences of clinicians delivering a diagnosis of dementia. The first chapter is a thematic synthesis of clinicians’ perceptions of the barriers and facilitators to communicating a diagnosis to those from migrant backgrounds. From the extant literature, several themes were constructed, including (1) service access (2) perceptions of migrant beliefs (3) relationships and (4) quality of diagnostic process. Barriers to the diagnosis of dementia were linked to migrants’ inability to access services as well as cultural beliefs impeding the acceptance of a diagnosis. Clinicians reported a need to enhance the provision and quality of interpreters to bolster the validity of the diagnostic process. Clinicians report a lack of cultural competence and require more training on cultural sensitivity. Further research examining facilitators to diagnosis of dementia is required, since the limited literature points mainly to barriers inherent in the process. Additionally, observational research is needed to corroborate self-reported practice.

The second chapter is an empirical study exploring how a diagnosis of dementia is shared and communicated by clinicians working in secondary care. The study aimed to explore clinicians’ perceptions of good diagnostic practice, as well as their experiences of communicating a diagnosis in the context of technological and linguistic barriers. Sixteen individual interviews were conducted with clinicians working in different areas of Scotland. Reflexive thematic analysis was used to construct themes and subthemes from the data. This resulted in four overarching themes: (1) Relationships involved in communicating a diagnosis; (2) Personal factors in communication; (3) Strategies and techniques in communication and (4) Equity and risk. The findings echo results from the extant literature on best practices in diagnostic communication, although the findings here offer points of subtle divergence. The study advances the current literature in its examination of diagnostic practice during COVID-19, as well as experiences of communicating a diagnosis to those from migrant backgrounds. To the researcher’s knowledge, this is the first study to explore these issues in a UK context. The study is limited by its small sample size, and by the self-reported nature of the data. Further observational research is needed to understand if clinicians implement their self-reported practice. Future research examining the value of self-reported practice is needed to synthesise comprehensive guidelines for communicating a diagnosis of dementia.

Total Thesis Word Count: 23,491
Lay Summary

This thesis contains two chapters. Both chapters explore the ways in which clinicians diagnose dementia in clinical settings. How a diagnosis is shared with patients and their caregivers is important given the emotional nature of receiving a progressive diagnosis. Several studies have indicated that the way a diagnosis is communicated could leave patients feeling disempowered and hopeless. Clinicians have also reported difficulties in imparting a dementia diagnosis and uncertainty around best practice. The COVID-19 pandemic changed the ways in which clinicians worked, with many diagnoses communicated virtually. In addition, clinicians are working in increasingly multi-cultural contexts and with patients who may possess a migrant background. Further knowledge is needed around best practices in the context of technological changes and linguistic differences.

The first chapter is a review of studies exploring clinical perspectives on diagnosing dementia in migrant populations. Studies that explored the beliefs and perceptions around the challenges of diagnosing dementia in this population were included. Three of the studies were observations of clinical practice, while eight of the studies were interview-focused and explored self-reported practices. Many of the studies revealed consistent challenges in diagnosing dementia in migrant populations, including difficulties in overcoming the language barrier even when an interpreter was used. Some clinicians felt that they needed further training and skills in working with this population. The review highlighted the need for more research to understand the challenges in diagnosing dementia for those with a migrant background. More studies that include observations of clinical practice would be useful to understand if clinicians implement the strategies they report.

The second chapter is a research study. This study interviewed clinicians who routinely deliver dementia diagnoses. Participants were asked about the experiences of diagnosing dementia and the strategies they use to communicate a diagnosis. Participants were also asked about how they diagnosed dementia during the COVID-19 pandemic, and how their communication was affected. Finally, participants were asked about their experiences of diagnosing dementia in migrants. The results showed that clinicians considered issues such as honesty and hope in their communication of the diagnosis. Several clinicians commented that virtual delivery was challenging for them, as was diagnosing dementia where there was a language barrier. Further research is needed to confirm the findings from this study, particularly in relation to the results relating to virtual communication.
Chapter 1. Systematic Review

Barriers and facilitators to diagnosing dementia in migrant populations: a systematic review of European health professionals’ perspectives

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Corresponding Author ( )

Prepared in accordance with guidelines for submission to the Journal of Dementia (Appendix A)

Word count: 10,466
Abstract

Background: Rates of dementia are increasing in migrant populations, and there is a need to understand the current barriers and facilitators in diagnosing this population according to clinicians’ perspectives. Although this has been explored from the view of migrants and caregivers, no review has synthesised the literature pertaining to clinicians’ viewpoints.

Methods: A systematic review of the literature was conducted. Databases included EMBASE, CINAHL, PsycINFO, MEDLINE and ProQuest. Qualitative studies from the perspective of European clinicians were included. The methodological quality of each study was assessed using the CASP tool. The analysis adopted a thematic synthesis approach as outlined by Thomas & Harden (2008).

Results: The review included 11 qualitative studies relating to the diagnosis of dementia in migrants. The quality of the studies was generally high, although few studies reported on the relationship between the researcher and the participants. The data related more to the barriers in diagnosing dementia, and few facilitators were found. Four themes were constructed: (1) service access (2) perceptions of migrant beliefs (3) relationships and (4) quality of diagnostic process.

Conclusions: The review is limited by the small number of studies available. The findings highlight significant clinical concerns in the diagnosis of migrants, in particular the underrepresentation of migrants within services and the barriers to access they may face. The quality of the diagnostic process was often thought to be undermined by a lack of culturally sensitive assessment tools. Further research on the use of an interpreter in diagnosing dementia is needed.

Keywords
Dementia;
Diagnosis;
Migrant;
Communication;
Background

Providing care for increasing rates of dementia is a major challenge for healthcare systems in Europe. By 2030, the number of people in Europe expected to receive a dementia diagnosis is 13.95 million, compared to 9.95 million in 2010 (WHO, 2012). Many European countries have identified the importance of a timely diagnosis to allow patients and families informed choices about the future, medical treatment, and legal affairs (Robinson et al., 2015). Further benefits of a diagnosis include the treatment of comorbidities such as depression, anxiety and poor sleep, as well as targeted disease-modifying therapies (Dubois et al., 2016). Delayed diagnoses are associated with poorer physical and mental health outcomes (Onyike, 2016) emphasising the value of receiving the diagnosis.

There is evidence to suggest that the European migrant populations are at increased risk of dementia due to social isolation (Berkman et al., 2000), lower education levels (Livingston et al., 2017) and dietary patterns (Moon et al., 2019). Although migrants may be more vulnerable to dementia, they are under-represented in older adult healthcare services (Parveen et al., 2017; Stevnsborg et al., 2016) and memory clinics (Goudsmit et al., 2011). A report from Alzheimer Europe recognised the urgent need to improve quality care for migrants due to their vulnerable socioeconomic status (Alzheimer Europe Ethics Report, 2018). Although data concerning the exact number of migrants with dementia in Europe is scarce (Monsees et al., 2022), there is evidence to suggest migrant populations may increase due to sociodemographic changes and migratory flows (Canevelli et al., 2021). The core structure of memory clinics throughout Europe is remarkably similar, with multidisciplinary teams including medical specialists, psychologists, other specialist therapists and MRI imaging (Frisoni et al., 2023; Winblad et al., 2008). The similarity of diagnostic procedure and memory clinic structure in Europe is a rationale for the focus of this systematic review on European settings.

A thematic synthesis of the barriers and facilitators to dementia care from a caregiver perspective was conducted by Chejor et al. (2022). In their synthesis, the authors identified the lack of culturally sensitive services and diagnostic tools as significant factors impeding the diagnosis of dementia in migrants. Further, cultural beliefs about dementia were reported to result in delays or avoidance of services. The review also identified that many services experience challenges in providing language-matched interpreters. Facilitators to care included the use of humour, conveying warmth with verbal and non-verbal language, and staying calm in instances of distress or agitation. However, the review focused predominantly on barriers and facilitators to accessing residential care settings. The challenges of accessing and using diagnostic services may be qualitatively, involving distinct communicative skills and assessment practices.
Arora et al. (2018) conducted a thematic synthesis related to barriers to healthcare from the perspective of older adult migrants. Their findings indicate that migrants may feel invisible in healthcare services due to time-constrained interactions and a perception that symptoms are dismissed by clinicians as normal ageing. For some, this led to avoidance or disengagement with services. However, a limitation of this review is its conflation of the migrant population with ethnic minorities. As such, there is a risk of oversimplifying the barriers to diagnosis based on cultural differences, when more specific factors related to migration and language may constitute barriers to care. Further, while the perspectives of migrants are vital to understanding obstacles to a diagnosis of dementia, an understanding of this topic is incomplete without the views of clinicians involved in the diagnostic process.

Although in its infancy, research has begun to turn its attention to clinicians’ perspectives. One cross-sectional survey conducted in Switzerland found that GPs felt less confident in the accuracy and management of dementia in migrants (Giezendanner et al., 2018). Another cross-sectional study conducted in Germany found that 71% of GP respondents reported a lack of confidence in assessing and communicating the diagnosis to migrants (Tillmann et al., 2019). This study also reported that GPs’ low confidence linked to a perception that migrants lack knowledge and acceptance regarding dementia symptoms. The findings highlight a potential barrier to dementia diagnoses in migrant populations, although the specific impact of low confidence upon the quality of diagnostic communication remains unclear. Additionally, correlational links between low confidence and migrants’ lack of acceptance may over-simplify a barrier to diagnostic care, locating the problem within the migrant population rather than clinical competence.

Lack of confidence in clinical aptitude is reported in qualitative literature. Using individual interviews and focus groups, one study found that clinicians lacked confidence in navigating diagnostic consultations that involved patients, family members and interpreters (Sagbakken et al., 2018). The language barrier was perceived as an additional complexity that generated hesitation and insecurity. The findings are concerning given that best practice in diagnostic communication encourages emotional congruence and therapeutic alliance (McKenzie & Brown, 2021). Although the impact of low confidence remains unexamined in Sagbakken et al.’s (2018) study, their findings raise questions regarding the ability to develop congruence and alliance within the context of a language barrier. Additionally, there is a need to understand reports of low confidence in greater detail. For example, low confidence may arise from a lack of cultural competence and training, as reported elsewhere.
(Monsees et al., 2022). Understanding the specific reasons underlying low confidence may promote a better understanding of the barriers to quality care.

A further barrier to quality care for migrants is the dearth of culturally sensitive assessment tools and testing norms available (Nielsen et al., 2011). Invalid assessment tools have reportedly led to both under and over-diagnosis of dementia in migrants (Canevelli et al., 2021). In semi-structured interviews conducted with Belgian clinicians, Berdai Chaouni and De Donder (2018) found that culturally sensitive assessment tools were often unavailable, meaning clinicians needed to ‘invent’ their own tests. These findings are particularly concerning given the threat they pose to the validity of assessments and diagnosis. Although these findings may not reflect the status of other European diagnostic settings, they point to the need to examine the factors underlying a lack of available testing tools. Greater exploration of the issues preventing ready access to appropriate tools, as well as clinicians’ practices in their absence, is needed.

Even when appropriate testing tools are available, additional challenges to the diagnostic process may include a lack of available interpreters, resulting in the use of family members or friends to translate (Nielsen et al., 2011). When family members are required to translate, this may occasionally distort or obscure the diagnosis, as families may want to minimise distress to their relative (Flores, 2005). When professional interpreters are available, there are concerns regarding the validity of assessments. In an observational study of a cognitive assessment conducted with a patient, interpreter and clinician, Plejert et al. (2015) found that their meaning of questions and responses could be changed. On occasion, this led to assumptions that the patient did not know the answer. Plejert et al.’s (2015) findings suggest that the accuracy and validity of cognitive assessments may be compromised, even when a professional interpreter is used. However, the interpreter was required to translate an assessment tool that had not been validated for the patient’s migration background, which may have increased miscommunication.

Synthesising clinicians’ perspectives of the barriers and facilitators to diagnosing dementia in migrants may improve outcomes for current and future service provision. Arguably, a thematic synthesis may produce more substantive findings than individual studies alone (Nicholson et al., 2016). To the researcher’s knowledge, no thematic synthesis of barriers and facilitators to diagnosing dementia in migrants has been conducted. Specifically, this review explores these issues from the perspective of clinicians. Individual studies in the area report a host of challenges, including lack of confidence, limitations in diagnostic tools and challenges in using an interpreter. Migrant populations across
Europe represent a high degree of cultural and linguistic diversity (Ahmad et al., 2020), pointing to the myriad service-adaptations potentially needed to competently diagnose this population. It is imperative to understand the current barriers and facilitators to diagnosing dementia in migrants to enhance current service provision.

Aim and Research Question
In synthesising the evidence base relating to clinicians’ perspectives on barriers and facilitators, this review aims to generate a deeper account of the current challenges and issues inherent to this process. The research question guiding this synthesis was ‘what are the barriers and facilitators to diagnosing dementia in migrant populations from the perspective of European clinicians?’. The question considered clinicians’ experiences of the assessment and diagnosis of dementia in migrants.

Methods
A thematic synthesis of clinical perspectives in assessing and diagnosing dementia in European countries was conducted, with a focus on facilitators and barriers to this process. Other methodologies were considered to synthesise the findings relating to phenomena of interest. For example, meta-ethnography was considered since it aims to synthesise data to enable new insights and theoretical contributions to healthcare practice (Noblit & Hare, 1998). However, meta-ethnography is recommended where studies have comparable methodologies, whereas the present review included wide-ranging qualitative methodologies. A “best fit” framework synthesis was considered (Ritchie & Spencer, 1994). Framework synthesis involves the preliminary identification of a priori themes, against which data is mapped. In essence, framework synthesis is a deductive approach. Although a framework synthesis may have been conducted within existing theoretical frameworks, there was a risk of data being forced into a framework that obscured the barriers and facilitators to migrant dementia diagnosis. The relative newness and scarcity of the research area persuaded the researcher to select an approach that was not theoretically bound.

The review adopted a thematic synthesis approach as outlined by Thomas and Harden (2008). Synthesising qualitative research has been previously contested since qualitative research is considered specific to a certain time, context, and group of participants (Thomas & Harden, 2008). However, others argue that qualitative synthesis has the potential to inform policy and practice, especially in healthcare settings (Campbell et al., 2003). Thomas and Harden’s approach aims to guide researchers conducting a systematic review of qualitative literature and to provide rigour akin to qualitative reviews. A rigorous search of the literature was therefore conducted to determine the
papers appropriate for analysis. A qualitative coding strategy was adopted, with codes then arranged into descriptive themes followed by overarching analytical themes (Schou-Juul et al., 2022). The review protocol is registered on PROSPERO (CRD42022373480).

Search Strategy
A search strategy was developed through reviewing the current literature, as well as discussion with an academic supervisor and librarian, to capture research relating to the review question. Various search terms were tried and tested across each database to ascertain the specificity and sensitivity of the search strategy. Trialling a range of search terms allowed the researcher to capture other frequently occurring phrases, concepts and relevant terminology used in the literature relating to the research question. This process also allowed the researcher to identify irrelevant search terms. For example, using specific dementia subtypes as search terms did not yield any additional literature. It was agreed with an academic supervisor that the final search strategy would include the term “ethnic minorit*” to capture any potential data relating to migrants, since these terms may be used interchangeably in the literature. A final search strategy was agreed upon between the researcher, librarian, and academic supervisor, and intended to capture a coherent set of relevant articles that related to the review question.

The search included the following words using AND/OR techniques: alzheimer* OR cognitive impairment OR dement* OR cogni* disor* OR cogni* func* AND identif* OR access* OR consult* OR disclos* OR communicat* OR difficult* OR facilitat* OR barrier* OR challenge* OR belief* OR understand* AND migrant* OR immigrant* or ethnic minorit* OR CALD OR “culturally and linguistically diverse” AND GP* OR general practitioner OR psychologist* or psychiatrist* OR neurologist* OR clinician* OR professional* OR primary care OR secondary care OR memory clinic OR memory centre OR memory center.

The SPIDER tool (Sample, Phenomenon of Interest, Design, Evaluation, Research type) (Cooke et al., 2012) was used to develop and guide the search strategy. In healthcare settings, qualitative research is increasingly deployed to understand the rich experiences of phenomena. The SPIDER tool has been used previously in qualitative systematic reviews as an alternative to the PICO tool (Population, Intervention, Comparison, Outcomes) commonly used to guide quantitative reviews (Methley et al., 2014). The qualitative nature of this review the SPIDER tool, with its addition of ‘design’ and ‘research type’, was considered most relevant to guide the research question. The sample was identified as clinicians working in diagnostic dementia settings, and the phenomenon of interest as diagnosing
dementia in migrant populations. The design was qualitative data collection and analysis, the evaluation experiences and perception, and the research type a qualitative method.

Inclusion and Exclusion Criteria
The SPIDER tool was used to guide the inclusion and exclusion criteria. The sample considered for this review were clinicians involved in the diagnosis of dementia in migrant populations. For the purposes of this review, migrants were defined as “people who move from their country of nationality to live in a foreign country that becomes their new place of residence” (International Organisation for Migration, 2022). However, it is acknowledged that the term migrant, particularly in research, is variable (Hannigan et al. 2016). In this review, the term migrant was viewed as distinct from “ethnic minority”, with ethnic minority encompassing wider criteria such as race, nationality, and ethnic origin (Liu et al., 2012). Migrant was also viewed as distinct from “refugee”, since migrants are generally considered to have choice regarding their global movement, whereas refugees are considered those who migrate specifically for international protection (Reeves et al., 2006).

The phenomenon of diagnosing dementia, most often taking place in memory clinics or specialised services, was considered distinct from general or medical dementia care. Studies focused solely on nursing or residential care were therefore excluded. Relevant clinicians involved in the diagnosis of dementia are wide-ranging in Europe; a variety of healthcare professionals were therefore considered in the inclusion criteria. A range of professional including GPs, psychologists, psychiatrists, neurologists, nurses, occupational therapists, and interpreters were considered. Studies were included if they encompassed mixed respondents (i.e. clinicians, patients and caregivers) and if the results from clinicians could be clearly separated. Studies focused solely on patient and/or caregiver experiences were excluded.

All subtypes of dementia were considered for the purpose of this review; however, the diagnosis of other neurological conditions such as stroke or brain injury were excluded. Studies were included if they explored the views, experiences, and perceptions of clinicians diagnosing dementia in migrant populations. The review was restricted to European settings due to the similarity in diagnostic services across countries, as well as the commonality of nationalised health services in many European countries. As the research question aimed to include the experiences of clinicians, the review was restricted to qualitative research. Qualitative research was defined according to the Cochrane qualitative methods group (Noyes, 2010). The Cochrane methods group defines qualitative research as studies using a qualitative data collection method and qualitative analysis. This review therefore
excluded quantitative studies. Qualitative research in this review considered phenomenological, ethnographic, grounded theory and case study design as relevant to the research question. A summary of the inclusion and exclusion criteria are collated in Table 1.

Five databases were searched including Embase, CINAHL, PsycINFO, MEDLINE and ProQuest. Including ProQuest in the search, and therefore grey literature, was intended to capture unpublished literature on the present topic, and to minimise publication bias. The search strategy included combined search terms related to (1) dementia and (2) the diagnostic process and (3) migrants and (4) clinicians. The search terms relating to the ‘migrants’ category included the term “ethnic minorit*”, since on occasion the international literature refers to ‘migrants’ and ‘ethnic minorities’ interchangeably (Monsees et al., 2022). Forward and backward citations were checked for additional relevant papers.

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
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<tbody>
<tr>
<td>Diagnosis of dementia</td>
<td>Other types of cognitive impairment such as brain injury and stroke</td>
</tr>
<tr>
<td>Studies conducted in EU/EFTA countries</td>
<td>Studies conducted outside of EU/EFTA countries</td>
</tr>
<tr>
<td>Qualitative research, including observational studies</td>
<td>Quantitative, surveys, questionnaires, systematic reviews, editorials, commentaries, conference abstracts</td>
</tr>
<tr>
<td>Focus on the facilitators and barriers in assessment and diagnosis</td>
<td>Focused on residential care, day-centre care, hospital care</td>
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<tr>
<td>Perspectives of clinicians (may be embedded within research containing patient/carer views)</td>
<td>Solely patient or carer-focused</td>
</tr>
<tr>
<td>Migrant populations</td>
<td>Studies concerned with “ethnic minorities”, refugees or indigenous populations</td>
</tr>
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</table>

Table 1. Inclusion and exclusion criteria.

Study screening and data extraction

Titles and abstracts of the identified studies were screened according to the inclusion and exclusion criteria, and a second reviewer (JW) conducted a 10% independent inter-rater reliability check. There were no discrepancies. Identified full texts were then assessed according to the inclusion criteria by two authors (SH and JW) to ensure a focus on clinician perspectives in the assessment and diagnosis of dementia in migrants. SH then extracted data from the final studies including: Author, Year, Country, Topic, Participants, Data collection method and Data analysis method.
Quality Appraisal

Qualitative research is increasingly recognised as offering valuable insight into evidence-based practice. Accordingly, there is increasing attention to critical appraisal tools evaluating qualitative research. The need for effective tools to evaluate qualitative research is particularly important when aiming to synthesise qualitative literature; however, critical appraisal tools in qualitative research is contested area (Dixon-Woods et al., 2007). How to best to critically appraise this type of research is murky, and there is little consensus as to what constitutes ‘quality’ within this type of research (Long & Brooks, 2020). The Critical Appraisal Skills Programme tool (CASP, 2018) is considered an appropriate tool for novice qualitative researchers to spark thought regarding the criterion for ‘quality’ in qualitative research (Long et al., 2020), encouraging researchers to appraise major domains such as validity, results and local utility. The Critical Appraisal Skills Programme tool (CASP, 2018) has been used in qualitative systematic reviews and is thought to successfully review the quality of qualitative research, owing to its ten-question checklist covering aspects of quality and rigour.

To enhance the rigour of this review and reduce error, the methodological quality of papers was assessed by two authors (SH, JW) independently, and discrepancies were resolved through discussion. The quality rating did not affect whether the paper was included in the thematic synthesis, given the limited literature available on the topic and the desire to capture multiple perspectives across Europe. The final ratings are demonstrated in Table. 2.

Quality Appraisal Findings

The ratings according to the CASP tool indicated that all studies included a clear statement of research aims, selecting a research methodology and design appropriate to the intended research question(s). Further, almost all studies reported on their recruitment strategy, and all studies collected data in a manner appropriate to the research question. These findings are promising and indicate that almost all studies met validity criterion to a high standard. However, very few studies included a reflexive statement outlining their positionality, or the relationship between the researcher and the participants included within the studies. Without a clear statement on the researcher’s position in relation to the research topic and research process, biases that may have influenced the research remain unknown.

All but one study reported on the process of obtaining ethical consent, as well as the ethical considerations inherent to their study. The analyses were presented coherently and clearly in each of
the studies, and findings were discussed in relation to the research question. These quality appraisal findings suggest that the results may be reliably interpreted and possess local utility and relevance. Taken as a whole, each of the studies were found to meet most, if not all, of the CASP criterion for quality appraisal. However, it is important to consider that many papers did not elucidate their reflexive position, and biases may have influenced any stage of the research process. Without further information on the relationship between the researcher and the participants, it is unknown how this relationship may have influenced the findings within each study. In addition, the CASP tool was not modified for the evaluation of the studies included in this review. Other considerations may be important to the evaluation of qualitative research, for example the consideration of the researcher’s ontological position. The CASP tool may require modification to consider the researcher’s ontological position, whether there are problematic assumptions in the chosen method of data analysis, and whether, for example, an inductive approach is consistently applied across the analysis and interpretation (Long et al. 2020). Additionally, further modifications of the CASP tool may be needed to evaluate observational studies using ethnographic approaches.
<table>
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<tr>
<th>Study</th>
<th>Aim</th>
<th>Method</th>
<th>Design</th>
<th>Recruitment</th>
<th>Data collection</th>
<th>Relationship</th>
<th>Ethical issues</th>
<th>Analysis</th>
<th>Finding</th>
<th>Value</th>
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<tr>
<td>Question considered within each domain</td>
<td>Clear statement of the research aims?</td>
<td>Is qualitative methodology appropriate?</td>
<td>Research design appropriate to aims?</td>
<td>Recruitment strategy appropriate to aims?</td>
<td>Data collection addresses research issue?</td>
<td>Relationship between researchers and participants considered?</td>
<td>Adequate consideration of issues?</td>
<td>Sufficiently rigorous?</td>
<td>Clear statement of findings?</td>
<td>How valuable is the research?</td>
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<tr>
<td>Torkpoor et al. (2022), Sweden</td>
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</table>

Note. ✓ = criteria met, - = cannot tell or criteria partly met, X = criteria not met.

Table 2. Quality appraisal using Critical Appraisal Skills Programme (2018) qualitative checklist
Researcher reflexivity

The idea for this review was generated between a researcher and academic supervisor with an interest in cross-cultural neuropsychology, and a desire to learn more about the current challenges clinician experience in diagnosing dementia in migrant populations. All members of the research team possessed clinical experience in the assessment and diagnosis of neurological conditions. Collectively, there was less experience with migrant populations specifically, although each member possessed their own experiences and hypotheses regarding the barriers and facilitators to dementia diagnosis in more general populations. The team shared the sense that migrant dementia care is a social justice issue requiring further empirical investigation. The shared passion for improving healthcare conditions for migrants was highlighted as a potential source of bias and acknowledged throughout the research process. The researcher engaged in reflexive practice with an academic supervisor in the generation of the research question and the coding of the data. The development of descriptive and analytical themes were constructed in discussion with another researcher, paying attention to the review question and to any conscious bias regarding the subject matter. Reflexive journaling was undertaken to elucidate bias in the coding and thematic development phases (Appendix. I). The goal was not to eliminate bias, rather to document the ways in which it may have influenced the overall synthesis.
Findings

Search results

A total of 995 records were identified from the database searches. The breakdown of papers found within each database are as follows: APA Psycinfo (262), Embase (157), Medline (108), CINAHL (400) and ProQuest (68). After de-duplication, abstract and title screening, 57 texts were assessed for inclusion and exclusion criteria. A total of 11 papers met the criteria.

Figure 3. PRISMA flow diagram (Moher et al., 2009) of search and screening process
Characteristics of studies included

Of 11 studies, two studies collected data through individual interviews only and two collected data solely through focus groups. Three studies used observational data. The remaining studies (5) blended data collection methods including individual interviews, dyadic interviews, and focus groups. The most used data analysis was thematic analysis, followed by analysis methods drawn from phenomenology. Within 11 studies, there were a total of 166 clinicians. The clinicians interviewed included GPs, psychiatrists, neurologists, clinical psychologists, nurses, occupational therapists, and dementia coordinators. Table 4 includes a full list of the characteristics of the studies.

<table>
<thead>
<tr>
<th>Author and country</th>
<th>Topic</th>
<th>Participants</th>
<th>Data collection</th>
<th>Analysis</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plejert et al. (2015), Sweden</td>
<td>Interpreter-mediated cognitive assessment</td>
<td>1 patient, 1 clinician, 1 interpreter</td>
<td>Observational study</td>
<td>Conversation Analysis</td>
<td>The cognitive assessment was considered culturally invalid, as well as inappropriate for the participant’s educational background. Participants were observed to engage in a process of ‘repair’ i.e. a joint problem-solving effort to resolve communication difficulties.</td>
</tr>
<tr>
<td>Sagbakken et al. (2018), Norway</td>
<td>Challenges in diagnosing dementia</td>
<td>27 clinicians</td>
<td>Individual interviews, dyadic interviews, and focus group discussions</td>
<td>Phenomenological analysis</td>
<td>Clinicians perceived migrants to attribute symptoms of dementia to normal ageing processes, and to hold culturally-specific beliefs about dementia as a shameful condition. Language barriers and the involvement of an interpreter complicated and undermined the diagnostic process. Clinicians lacked knowledge regarding culturally valid assessment tools.</td>
</tr>
<tr>
<td>Atcha (2018), United Kingdom</td>
<td>Barriers to service engagement and dementia diagnosis</td>
<td>34 participants, including 9 clinicians and 24 patients</td>
<td>3 focus groups</td>
<td>Thematic analysis</td>
<td>South Asian migrants are under-represented in dementia diagnostic services. Health professionals consider migrants to reach diagnostic services in the later stages of dementia, relating to perceptions of cultural beliefs and stigma.</td>
</tr>
<tr>
<td>Vissenburg et al. (2018), Netherlands</td>
<td>Barriers to providing primary dementia care</td>
<td>17 clinicians</td>
<td>3 focus groups</td>
<td>Thematic analysis</td>
<td>GPs reported barriers to diagnosing dementia in migrants as a lack of culturally competent services and lack of culturally valid screening tools. The language barrier was seen to impact the ability to understand care needs.</td>
</tr>
<tr>
<td>Berdai Chaouni &amp; Donder (2018), Belgium</td>
<td>Providing of dementia services for Moroccan migrants in Belgium</td>
<td>31 participants, including 12 informal</td>
<td>One focus group and 25 one-to-one interviews</td>
<td>Grounded theory</td>
<td>Dementia care services were perceived as inaccessible due to their limited cultural sensitivity. The paper reported that clinicians could overlook the lack of</td>
</tr>
<tr>
<td>Study</td>
<td>Study Design</td>
<td>Participants/Methods</td>
<td>Analysis</td>
<td>Findings/Implications</td>
<td></td>
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<td>--------------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Plejert &amp; Majlesi</td>
<td>Interpreter-mediated cognitive assessment</td>
<td>3 clinicians including 1 occupational therapist, 1 patient and 1 professional interpreter</td>
<td>Observational study of one cognitive assessment</td>
<td>Interpreter-mediated cognitive assessment results were considered the product of three individuals working collaboratively. Concerns regarding the reliability of testing were raised, relating to interpreter alterations in meaning and clinician understanding.</td>
<td></td>
</tr>
<tr>
<td>(2018), Sweden</td>
<td></td>
<td></td>
<td>Conversation Analysis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sagbakken et al.</td>
<td>Perceptions of dementia and access to care</td>
<td>81 participants including 51 migrants, 12 family members and 18 clinicians</td>
<td>Focus groups, individual interviews, dyadic interviews</td>
<td>Clinicians perceived migrants to hold culturally-specific and/or spiritual beliefs about dementia. Some clinicians believed migrants saw dementia because of ‘karma’. Clinicians believed socioeconomic factors could explain the underrepresentation of migrants within services.</td>
<td></td>
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<tr>
<td>(2019), Norway</td>
<td></td>
<td></td>
<td>Phenomenological analysis</td>
<td></td>
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</tr>
<tr>
<td>Czapka &amp; Sagbakken</td>
<td>Barriers and facilitators in accessing dementia care</td>
<td>8 families with migrant backgrounds, 6 migrant community representatives, 5 clinicians</td>
<td>19 individual semi-structured interviews</td>
<td>Clinicians perceived migrants to lack knowledge and understanding of dementia, serving as a barrier to the diagnosis. Service barriers were identified including linguistically competent services, as well as a lack of medically-trained interpreters.</td>
<td></td>
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<tr>
<td>(2020), Norway</td>
<td></td>
<td></td>
<td>Thematic analysis</td>
<td></td>
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</tr>
<tr>
<td>Nielsen et al.</td>
<td>Barriers in access to dementia care</td>
<td>35 participants including 23 clinicians and 12 caregivers</td>
<td>19 individual interviews and 6 focus groups</td>
<td>Clinicians perceived migrants as possessing a lack of knowledge about dementia and inaccurate beliefs relating to the condition. The paper called for greater outreach and awareness raising within migrant communities.</td>
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<tr>
<td>(2021), Denmark</td>
<td></td>
<td></td>
<td>Phenomenological analysis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wirz (2022), Switzerland</td>
<td>Obstacles to dementia care</td>
<td>16 clinicians</td>
<td>16 individual interviews</td>
<td>Four themes relating to obstacles to a dementia diagnosis were found: (1) delayed diagnosis and lack of diagnostic tools (2) obstacles to seeking help (3) lack of migration sensitivity in services and (4) administrative and financial obstacles. Clinicians reported an under-representation of migrants within services and the need to educate clinicians further on cultural competence.</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Thematic analysis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Challenges in interpreter-mediated dementia assessment</td>
<td>Participants</td>
<td>Audio and video recordings</td>
<td>Method</td>
<td>Interpretation</td>
</tr>
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<td>-------------------------------------------</td>
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<tr>
<td>Torkpoor et al. (2022), Sweden</td>
<td>Challenges in interpreter-mediated dementia assessment</td>
<td>57 participants, including 19 patients, 19 clinicians and 19 interpreters</td>
<td>Audio and video recordings of 19 dementia assessments</td>
<td>Constant comparative method</td>
<td>Interpreters may change the meaning and content of cognitive assessments. Alterations of meaning could impact judgment of patients’ cognitive abilities, resulting in changes to treatment and support.</td>
</tr>
</tbody>
</table>

*Table. 4. Characteristics of included studies*
Thematic Synthesis

Data Extraction

In their outline of the method for conducting a thematic synthesis, Thomas and Harden (2008) acknowledge that data extraction from qualitative studies may be a challenging process. Defining ‘what counts as data’ is complex due to variations in reporting style as well as misrepresentation of data as findings (Sandelowski & Barroso, 2002). Within this review, ‘data’ was often readily identifiable in the form of quotations from participants. More nebulous and scattered, however, were the authors’ summaries of findings and identification of key concepts. Consistent with Thomas and Harden’s approach, this review took study findings to lie within the ‘results’ or ‘findings’ sections of papers. Occasionally, additional findings were listed in the ‘discussion’ sections of papers. Often, data relating to clinicians’ perspectives was included in papers exploring patient and carer perspectives. This data was extracted, although data relating to patient and carer perspectives was not subjected to line-by-line coding. The results and discussion sections of each identified paper were entered verbatim into Nvivo 20’s software for qualitative data analysis.

Coding

A total of 11 qualitative studies examined the views of clinicians involved in the diagnosis of dementia in migrant populations. The findings from studies were entered verbatim into Nvivo and coded in alphabetical order. One researcher coded the findings from each study line-by-line. Coding the data line-by-line is thought to mitigate unconscious selectivity that may arise from initial interactions with the data (Skjott Linneberg & Korsgaard, 2019). Codes were created inductively by the researcher to condense meaning and were not organised within a hierarchical structure. Thomas et al. (2017) emphasise coding as a fundamental task in thematic syntheses that permits key concepts to be translated across studies. A ‘bank’ of codes was developed within Nvivo after the coding of each paper, and new codes were generated where data did not fit with the pre-existing ‘bank’. On many occasions, lines of text were labelled with multiple codes. The generation of codes, and the decision of whether to generate another - or to label a line with multiple codes - constitutes the process of translation that Thomas and Harden emphasise as essential.

The researcher was careful not to merge codes in the initial stages, consistent with other reflexive practice (McMahon et al., 2022). The initial generation of codes resulted in the creation of similar sounding labels, for example interpreter not translating everything and interpreter not translating word for word. At first glance, these codes indicated high similarity, yet subtle differences lay in their
context. For instance, the former code related to untranslated exchanges between interpreters and patients, while the latter related to accurate conveyance of a diagnosis. The nuanced approach to the data resulted in 153 codes, which were clarified and revised in discussion with an academic supervisor. The evolution and refinement of codes were logged separately to the coded data within Nvivo 20. An example of an initial coding approach is documented in Appendix G.

Development of Descriptive Themes
The second stage of thematic synthesis requires the researcher to organise codes into descriptive themes. While Nvivo 20 was used to code the data, the researcher wrote each code onto a card to begin developing descriptive themes. Written cards allowed the researcher to organise codes into initial conceptual groups and to serve as the first point of brainstorming. The ability to move codes by hand permitted further immersion in the data and creative exploration of the relationships between codes. Figures 1. and 2. depict this initial stage.

Figure 1. Handwritten codes

Figure 2. Codes arranged into initial conceptual groups
Codes were organised and refined to generate descriptive themes. This process was protracted, requiring the researcher to consider both the independence and correlation between codes, the prominence of codes, and where codes were relevant to multiple categories. In reflexive dialogue with another doctoral researcher, codes were reordered until final descriptive themes were reached.

**Development of Analytical Themes**

Until this point, the synthesis reflected a more literal depiction of the findings from the data. The task of the researcher during the analytical stage of a thematic synthesis is to ‘go beyond’ the descriptive findings to answer the research question. This required insight and judgment, using inference to answer the original question regarding barriers and facilitators to diagnosing dementia. In discussion with another researcher, views expressed in the data were then considered in relation to ‘barriers’ and ‘facilitators’, where more abstract and analytical themes were constructed. For example, ‘clinician confidence’ was a descriptive theme identified in the earlier stage of analysis. While clinicians did not explicitly refer to their confidence as a barrier to diagnosis, the researchers inferred confidence as a barrier, since low confidence could result in hesitancy or aversion to the diagnostic process. The analytical stage of the synthesis resulted in 4 superordinate and 12 subordinate themes, reflected in Table 3. The table also designates the contributions from each article.
<table>
<thead>
<tr>
<th>Study</th>
<th>Socio-economic factors</th>
<th>Family arrangements</th>
<th>Service factors</th>
<th>Improving Access</th>
<th>Views on nature of dementia</th>
<th>Beliefs delaying diagnosis</th>
<th>Beliefs about consequences</th>
<th>Beliefs about role of family</th>
<th>Clinician relationships</th>
<th>Interpreter relationships</th>
<th>Assessment accuracy</th>
<th>Translation quality</th>
<th>Clinician confidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plejert et al. (2015)</td>
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<td>Bordai Chaouni &amp; Donder (2018)</td>
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<tr>
<td>Plejert &amp; Majlesi (2018)</td>
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<td>Sagbakken et al. (2019)</td>
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<tr>
<td>Czapka &amp; Sagbakken (2020)</td>
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<tr>
<td>Torkpoor et al. (2022)</td>
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</tbody>
</table>

*Table 3. Analytical themes and corresponding subthemes, with study contributions*
Results of the Synthesis

The included studies reported on a range of barriers and facilitators in the assessment and diagnosis of dementia in migrants. This section presents the themes that were constructed from the primary data and the authors’ interpretations of the primary data. Four themes were constructed: (1) service access (2) perceptions of migrant beliefs (3) relationships and (4) quality of diagnostic process. Table 4 documents the analytic themes and corresponding subthemes.

<table>
<thead>
<tr>
<th>Analytic Theme</th>
<th>Subtheme</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service access</td>
<td>Socioeconomic factors</td>
<td>Occupational, educational, and financial factors explain barriers to service access</td>
</tr>
<tr>
<td></td>
<td>Family arrangements</td>
<td>Patterns of caregiving result in migrants not accessing services, or advanced presentations when they do</td>
</tr>
<tr>
<td></td>
<td>Service factors</td>
<td>Culturally insensitive services, including lack of tailored resources, prevent engagement</td>
</tr>
<tr>
<td></td>
<td>Improving access</td>
<td>Outreach efforts may reduce barriers to access and increase diagnosis</td>
</tr>
<tr>
<td>Perceptions of migrant beliefs</td>
<td>Views on nature of dementia</td>
<td>Clinicians perceive migrants to hold inaccurate beliefs about dementia regarding aetiology and curability</td>
</tr>
<tr>
<td></td>
<td>Beliefs delaying diagnosis</td>
<td>Dementia regarded as a shameful condition or denoting madness, resulting in concealment of symptoms</td>
</tr>
<tr>
<td></td>
<td>Beliefs about the consequences of diagnosis</td>
<td>Clinicians perceive migrants to hold beliefs that a diagnosis may result in being removed from their family, or that a diagnosis may damage a family’s reputation</td>
</tr>
<tr>
<td></td>
<td>Beliefs about the role of family</td>
<td>Clinicians believe families to assume responsibility for declining cognitive ability, and to take on higher degrees of caring</td>
</tr>
<tr>
<td>Relationships</td>
<td>Clinician relationships</td>
<td>Clinicians viewed trust-building with patients and caregivers as important, and to maintain awareness of caregiver burden</td>
</tr>
<tr>
<td></td>
<td>Interpreter relationships</td>
<td>Interpreters may have pre-existing links to migrant communities and compromise privacy. Interpreter competence may negatively impact the patient experience.</td>
</tr>
<tr>
<td>Quality of diagnostic process</td>
<td>Assessment accuracy</td>
<td>Culturally invalid tests and lack of appropriate testing norms may result in misdiagnosis</td>
</tr>
<tr>
<td></td>
<td>Translation quality</td>
<td>The availability of interpreters is not always guaranteed, and interpreters may change the content and meaning of assessments</td>
</tr>
<tr>
<td></td>
<td>Clinician confidence</td>
<td>Clinicians reported low confidence in their diagnostic abilities, resulting in aversion to assessment or hesitation in communication</td>
</tr>
</tbody>
</table>

Table 4. Summary of analytic themes and subthemes
Service access

In asking about the challenges of assessing and diagnosing dementia, it was apparent across many papers that it was not possible to discuss assessment and diagnosis without addressing the relative absence of migrants in services. Clinicians attributed a lack of migrant-presence in services to a range of factors relating to socioeconomic position, family arrangements, service issues and the need for greater outreach.

Socioeconomic factors. Clinicians in many papers reported that they had limited contact with migrants, including clinicians working in migrant-dense parts of Europe. Clinicians could attribute the underrepresentation of migrants to a range of socioeconomic factors, including occupation, education, and financial status. In several papers, clinicians reported that socioeconomic status explained underrepresentation more than migrant status, culture, or language:

“The participant believed that socio-economic status, defined by the combination of education, income and occupation, is a more important factor revealing inequities in access to dementia care than minority ethnic background” (Sagbakken et al., 2018, p. 5).

“I wouldn’t overemphasize the cultural differences. I think historical differences play a bigger role, in the sense that often affected people, if they are also socioeconomically disadvantaged, it makes the whole situation even more difficult.” (Wirz, 2022, p. 10).

Family arrangements. There appeared to be mixed perceptions regarding migrants’ social support and how this could impact access. Some clinicians reported that migrants may be more dependent on family members to support them access and attend appointments. Conversely, other findings were that migrants were aware of not wanting to “burden” (Wirz, 2022, p. 13) their family and therefore did not expect accompaniment to appointments, contradicting the notion that families could serve as an access barrier. Several participants in studies saw an access barrier as social isolation, with many older migrants removed from their typical family care patterns in their native countries.

There was speculation that families may want to avoid accessing dementia services and therefore discussing “intimate and exposing” issues with their family member (Nielsen, 2021, 1428). One clinician believed that cultural norms relating to caring responsibilities for older family members was a “problem” (Czapka & Sagbakken, 2020, p. 6) in that it interfered with service access, rather than any barriers inherent to the Norwegian healthcare system. In several papers, the view that families could
act as gatekeepers to dementia services was echoed. There was a sense that due to hierarchical and gendered roles, specific family members may need to approve a decision to seek a dementia assessment:

“In this family, all arrangements must be cleared with the son. In this way it’s the son who makes the decisions [...] even though it’s the daughters who... one of them is employed there [as a paid family carer], so it’s her who knows everything (Nielsen, 2021, p. 1428, dementia coordinator)”

Service factors. Many clinicians acknowledged the lack of culturally sensitive services as a significant barrier to access. An absence of sensitivity was defined by a lack of “linguistically competent services” (Czapka & Sagbakken, 2020, p. 7), including professional interpreters and information resources in a range of languages. The availability of information resources for migrants was sometimes viewed as a potential facilitator to service access, although there was disagreement elsewhere in the literature. One clinician felt that facilitating access was “not about a brochure I put in their hands” (Wirz, 2022, p. 12) but rather the establishment of trust and connection with the patient, community representatives and other professionals.

Improving access. There was a view in several papers that access issues for migrants may be improved by greater outreach efforts. A clinician in one paper considered that offering migrants examples of “people from the same ethnic group using dementia care services... could facilitate the process of understanding dementia” (Czapka & Sagbakken, 2020, p. 10). Three papers acknowledged that it was incumbent upon services to actively engage and reach out to migrant communities to facilitate the awareness and existence of services. Suggestions included approaching multicultural link workers to act as a link between services and migrant populations, to disseminate information about services and to encourage the normalisation of dementia.

Perceptions of Migrant Beliefs
Across studies, many clinicians speculated that migrant beliefs about dementia, its symptoms, and the role of family could serve predominantly as barriers to the diagnosis of dementia. Clinicians saw migrants as holding inaccurate beliefs about dementia as a curable condition or a form of insanity. Clinicians regarded migrant families as believing dementia to be a shameful condition that could impact their prospects. While clinicians believed migrant families took on more responsibility for older
family members than majority ethnic counterparts, there was a sense that this served as a barrier to a timely diagnosis.

**Views on nature of dementia.** Many clinicians reported that migrants’ beliefs about the cause, prognosis and treatment of dementia often affected the acceptance of a diagnosis, thus presenting a barrier to diagnostic communication. Clinicians believed that migrants viewed dementia as a medical, “Western construct” (Sagbakken, 2018, p. 10) and that the diagnosis was therefore not meaningful to them. Several papers reported that migrants could view dementia as a form of madness or insanity, resulting in a reluctance to accept the diagnosis. Beliefs that dementia may be “transient” (Sagbakken, 2020, p. 2201) or curable were reportedly held by several patients with a migrant background. Similarly, beliefs about the curability of dementia could result in families requesting additional testing and treatment, where clinicians would normal cease investigation: “In other such severe cases you would normally renounce investigation and treatment, but among some of the immigrants... for them that is totally incomprehensible” (Sagbakken, 2020, p. 2205). There was variability in perceptions of migrants’ beliefs regarding the cause of dementia. Most papers reported a sense that migrants viewed symptoms of dementia as normal ageing:

“I think other barriers are that they don’t... people are not aware of what dementia actually is. They perceive some of the symptoms as part of getting old and don’t perceive it as an illness necessarily” (Atcha, 2018, p. 161)

“Many of his patients with a background from countries in Asia tended to consider memory loss to be within the frame of a ‘normal’ reduction of memory getting older, even those with rather pronounced memory loss” (Sagbakken, 2020, p. 2200).

Conversely, however, a few clinicians in one study reported the view that migrants’ knowledge about the symptoms of dementia was akin to ordinary lay knowledge. There was the perception that migrants know “dementia can happen to anyone at any age, making it distinct from normal ageing” (Atcha, 2018, p. 162), and that health literacy was not a factor impacting the diagnostic process.

**Beliefs delaying diagnosis.** Migrants’ beliefs about dementia were commonly seen as a barrier to timely diagnosis. Stigmatising beliefs about dementia were often linked to delayed diagnosis:
“The high level of stigma associated with dementia leads to a reluctance to acknowledge the symptoms, which in turn delays formal help-seeking and diagnosis” (Czapka & Sagbakken, 2020, p. 6)

“Stigmatizing beliefs about dementia, particularly that dementia is a form of insanity, was another issue that prevented or delayed dementia care seeking” (Nielsen et al., 2021, p. 1428)

Several papers reported the view that due to cultural norms around caring responsibilities, many migrant families believed in managing symptoms of dementia within the home without professional aid. A frequently held belief was that due to these cultural norms, migrants with dementia were cared for in the home until families reached a “crisis-point” (Atcha, 2018, p. 174). Some clinicians believed that families would deliberately deny symptoms of dementia and attempt to “maintain the façade that the patient is functioning normally in daily life” (Vissenberg et al. 2018, p. 6). Attempts to conceal symptoms of dementia were reported, with families “keeping people with dementia in their homes and hiding them away when cognitive or behavioural symptoms became apparent” (Nielsen et al., 2021, p. 1428). Clinicians reported scepticism regarding the accuracy of reported daily functioning and this was viewed as another impediment to timely diagnosis. Further, the concealment of dementia was connected to more advanced presentations by the time migrants were able to access services. Communicating the diagnosis to a person with a more advanced presentation was considered challenging, although an advanced presentation served often as a facilitator, in that clinicians could be more certain of a diagnosis due to overt symptoms.

Beliefs about the consequences of diagnosis. Several papers reported the perception that migrants may fear the consequences of a dementia diagnosis. These feared consequences were presented as barriers to effectively communicating the diagnosis. This included a fear that a person may be “taken away” because of the diagnosis. A frequently reported consequence of a dementia diagnosis was the “damage” (Wirz, 2022, p. 12) it could cause to a family’s reputation. Clinicians reported that migrants may believe that dementia is hereditary and therefore that “insanity is running in the family” (Nielsen et al. 2021, p. 1428), affecting potential marriage prospects for children and grandchildren. Social shame was also presented a potential consequence of a dementia diagnosis:

“So the perception is that, oh, if we go into a mental health setting or if we go to the GPs or if we drop into a dementia awareness facility or an access point where there’s
information on dementia and we’re seen to be doing that, then people will automatically assume that they... there’s an issue of dementia in the family. So that then will spread within the community and that will be a dishonour to our family” (Atcha, 2018, p.71)

Beliefs about the role of family. A barrier to dementia diagnosis was believed to stem from the notion that declining memory may be perceived as a shared, familial responsibility in migrant communities. This could be perceived as a facilitator to communicating the diagnosis, in that it meant families believed they could compensate for memory loss and saw this as their responsibility. There was a general perception that a barrier to diagnosing dementia was the strongly rooted sense of obligation and duty families felt to care for relatives themselves:

“Our findings confirm that caring for the elderly constitutes a strong moral obligation in many cultures. Moral norms were often found to be deeply internalised, and any violation could invoke internal and external sanctions.” (Czapka & Sagbakken, 2020, p. 6)

Although clinicians often commented on families’ sense of obligation to care for their family member, there was a sense that clinicians saw this as a problem and barrier, even if family members did not. One study reported on the “increasing amounts of care-giving work without articulating the caring as a problem or contacting healthcare services” (Sagbakken et al. 2020, p. 2206).

Relationships

Relationships between the clinician, patient and family members were regarded as essential in the process of assessment and diagnosis. Establishing trust, familiarity and rapport were considered key. In relationships between interpreters, patients and caregivers, clinicians reported concerns regarding the practice of interpreters during sessions and how this could negatively impact a patient’s mood. Privacy concerns were reported to threaten the integrity of the diagnostic process, for example where an interpreter may have pre-existing links to a migrant community.

Clinician Relationships. Building relationships with patients, caregivers and professionals was often viewed as the foundation of good diagnostic practice, although could be perceived as both a barrier and facilitator dependent on the quality of relationships. In some of the studies, the language barrier was represented as an obstacle to developing positive relationships with patients and families, although a sensitivity to a migrant’s “needs and habits” (Wirz, 2022, p. 14) could facilitate an alliance. Non-verbal facilitators to the clinician-patient relationship could be the use of gaze. One observational
study documented a clinician using gaze and head movement to involve the patient, even when the interpreter was still speaking: “she keeps her gaze toward the patient and does not turn it to the interpreter” (Majlesi & Plejert, 2018, p. 146). On occasion, non-verbal cues from the patient that were not detected by the clinician create discomfort or exclusion. However, in observational studies, clinicians were frequently found to attempt to problem-solve and troubleshoot communication difficulties. This was through clarification and repetition of questions, corrections and altering their language to make meaning more accessible.

Collaboration with families was seen to facilitate the diagnostic communication. Collaboration could be defined as “building trust” (Czapka & Sagbakken, 2020, p. 10), actively instigating family meetings, and including multiple family members in the consultation. In one study, clinicians viewed it as their responsibility to include the family (Vissenberg, 2018), although this could lead to a communicative dilemma where a range of family expectations could not be met:

“The various family members involved all wanted information, wished to participate in caring for the older person and had different opinions and expectations.” (Berdai Chaouni & Donder, p. 6, 2021).

Clinicians appeared to use intuition to build relationships with caregivers. Several studies reported the need to pay careful attention to a potential mismatch between caregiver reports and the observed reality:

“Even when they are completely overloaded, they show up with a smile. If you ask how they are doing they respond: "We don’t need any help from strangers, we do everything ourselves for Mama” (Vissenberg et al., 2018, p. 9)

Maintaining an awareness of caregiver stress in the diagnostic process was often viewed a facilitator to communication, where clinicians adapted or modified their practice to acknowledge the burden caregivers may face.

Professional relationships beyond the consultation room were viewed as important to facilitating diagnostic communication, although these claims often read as nebulous. Some papers presented the view that relationships with third sectors, welfare facilities and public campaigns needed to be stronger. There was a belief that greater liaison with outside services could bolster awareness of
dementia in migrant communities. This was hypothesised to facilitate the diagnostic process, in that migrants may come with more awareness, knowledge and insight surrounding dementia and its symptoms, making the diagnosis easier to impart.

Interpreter relationships. Across many papers, there were various concerns about how the interpreter-patient relationship could affect communication. An interpreter’s personal links to patients’ communities could raise concerns about the privacy of the consultation and how information could be shared beyond the room. One study reported that a pre-existing relationship between the interpreter and patient had not been declared (Torkpoor et al., p.57, 2022) resulting in questions regarding the validity of the assessment and resulting diagnosis. Conversely, the unfamiliarity of the interpreter could create an atmosphere of uncertainty:

“Some emphasized the vulnerability associated with a situation with an unfamiliar interpreter present or a situation that could be unfamiliar, scary, and humiliating” (Sagbakken et al., 2018, p. 9)

Imparting a diagnosis in the context of increased unfamiliarity was viewed as a concerning barrier to good diagnostic practice. Troublingly, one study observed the detrimental effect of an interpreter’s view on a dementia diagnosis:

“The interpreter, who knew the patient privately, thought he should not complain over his situation. “What are we to do now. We can so much... Listen, we’ve become old, now illnesses come, we shouldn’t complain, we’re well, it’s good…” (Example 6, observation 7). After this conversation, between him and the interpreter, the patient was silenced and did not tell much more about himself.” (Torkpoor et al., 2022, p. 57)

Although clinicians more commonly reported concerns regarding the interpreter-patient relationship, some facilitators to relationship were also observed, including the use of non-verbal gestures to build alliance. In one study, the interpreter is seen to mirror the gestures of the clinician and use pointing to reinforce the understanding of the task:

“He also recycles the occupational therapist’s body movement showing two loci on the paper although with a difference in the manner of display: he does it by pointing fingers and not by a pen” (Majlesi & Plejert, 2018, p. 146)
Non-verbal gestures, particularly those that mirrored clinicians, were viewed in several papers as attempts to put the patient at ease and facilitate the smooth assessment of dementia, as well as enhance the accuracy of questions.

Quality of diagnostic process
Several barriers to the integrity and validity of the diagnostic process were reported. These included concerns regarding the accuracy of communication relating to diagnostic testing. Where professional interpreters were unavailable and translation fell to family members, this was considered a threat to the validity of the diagnostic process. Clinicians frequently reported a lack of personal confidence in communicating the diagnosis due to perceived cultural gaps. In the some of the literature, a lack of confidence was related to stigmatising beliefs and stereotyping of migrants.

Assessment accuracy. The accuracy of assessments was widely reported as questionable across papers, forming a persistent barrier to a comprehensive diagnosis. Firstly, the reporting and interpretation of a patient’s premorbid and daily functioning was sometimes viewed as unreliable, muddying an accurate picture of historical and present-day ability. Most commonly, assessment tools were described as lacking cultural specificity. Cognitive tests requiring native knowledge were regarded as compromising the validity of assessments:

“I have often wondered about people with a foreign background that have been assessed with tests that we know are language-specific; for example, so-called verbal intelligence tests focus on the understanding of words, expressions, proverbs and so on, all of which are specific for the language that they are constructed within.” (Sagbakken et al., 2018, p. 8)

These concerns were expressed in both self-reports and observational studies. One of the worst outcomes of culturally invalid tests was reported as the misdiagnosis of dementia. Sagbakken et al.’s (2018) findings implied that this was a “frequent” occurrence in their sample of clinicians, with inappropriate assessment tools “used improperly” to inform clinical opinion. Several papers reflected that culturally appropriate assessment tools would facilitate accuracy of the diagnosis. However, one study reported that an additional barrier to good clinical practice was the lack of interest and effort clinicians invested in culturally valid tools, believing existing tests to be “fool-proof” (Sagbakken et al.,
Related to an absence of sensitive tools was the lack of appropriate testing norms for comparison:

“We estimate clinically what these norms are (for this group), we already make norms and simply take our 11 German-language norms. Then often we see that they are partly already clearly advanced if you take the German norms” (Wirz, 2022, p. 11)

The risk of misjudgement related to assessment tools and invalid norms were seen as a threat to the assessment process, although this was thought to be mitigated by the ability to assess migrants in their home environment. Assessments that took place in familiar surroundings were seen as reducing threat and therefore eliciting better cognitive performance, as well as providing the opportunity for accurate functional assessment.

Translation quality. There were several examples across papers of the complete absence of professional interpreters due to “affordable translation services” (Berdai Chaouni & Donder, 2020, p. 6). Providing language-matched interpreters was frequently presented as an unrealistic standard, although this was viewed by one clinician as “unacceptable” (Vissenberg et al., 2018, p. 8).

The quality of interpretation was reported as significantly challenging across studies. Notably, there was no evidence in the literature of positive experiences in the use of a professional interpreter. More prominently in observational studies, interpreters were observed to modify instructions or to omit instructions entirely:

“Again, it could be argued that the problems facing participants here are related to questionable practices by the interpreter, e.g., in terms of omitting parts of the original test-sentence in the rendition in Kurdish.” (Plejert et al., 2015, p.147)

In three papers, clinicians directly expressed their concerns about the quality of translation provided by an interpreter, with one clinician believing many interpreters “lack competence in assessment situations and may change sentences or their meaning to facilitate the translation” (Sagbakken et al., 2018, p. 9). An inability to know the exact exchanges between interpreters and patients was viewed as a source of frustration and worry, impacting confidence in the assessment and diagnostic process.
One study analysing several recordings of interpreter-mediated assessments noted that poor fluency of professional interpreters in either native or second languages could result in an “incorrect perception of the patients’ actual cognitive ability” (Torkpoor et al., 2022, p. 52) and was a clear barrier to effective assessment. Further, some of the literature highlighted that while interpreters may language-matched, this did not mean they shared the same dialect, and one study found that interpreters did not always share this information with the clinician (Torkpoor et al., 2022). Barriers to interpretation therefore lay not only in a mismatch of dialect, but in whether this was disclosed during the consultation.

In many studies, where professional interpreters were not available, translation often fell to clinicians or family members. Where family members provided interpretation, “emotional and personal involvement were seen as pitfalls for conscious and unconscious alterations of content” (Wirz, 2022, p. 15). Using family members for interpreting was seen to threaten the quality of content, where medical terminology may not be understood, and outcomes of the diagnosis could be altered. Even when clinicians were tasked with translation and possessed adequate medical knowledge, this did not mean that they were fluent enough “to translate ‘anticoagulants’ into my language, or ‘diuretic or blood pressure medication’. I don’t know how to translate such words.” (Czapka & Sagbakken, 2020, p. 7).

Clinician confidence. The confidence of the clinician was often seen to directly influence the quality of the diagnostic process. Reports of insecurity and hesitation in conveying the diagnosis were reported. On occasion, hesitation was the result of “a perceived distance between their own culture and that of the care recipient” (Berdai-Chouni & Smetcoren, 2020, p. 6). Where hesitation was reported, this sometimes led to an aversion of the emotional elements of the consultation, and instead a focus on practicalities such as driving-licence status (Sagbakken et al., 2018, p. 7).

It appeared that a lack of confidence was navigated in distinct ways. Lack of confidence appeared to drive either a referral to a specialist service to promote further investigation, or conversely an “underestimation of symptoms” and therefore a reluctance to refer to specialist services (Czapka & Sagbakken, 2020, p. 7). It was reported in several papers that clinicians’ “hesitancy” may be a result of stereotyping migrants, inaccurate assumptions regarding cultural norms, and overgeneralising the needs and wishes of these diverse populations. Although hesitancy itself was presented as a barrier to effective diagnostic care, the issues underlying hesitancy, such as stereotyping and
overgeneralising, were hypothesised as significant contributors to poorer quality assessments and clinician aversion to the diagnostic process.

Discussion

This synthesis examines clinicians’ reported barriers and facilitators to the assessment and diagnosis of dementia in migrant populations. The aim was to uncover the perceived barriers and facilitators to inform future clinical practice and service provision. Analytic themes represented core issues in the assessment and diagnosis of dementia in migrants related to service access, migrants’ beliefs about dementia, clinician-patient-interpreter relationships, and the quality of the diagnostic process.

The first theme constructed from the data, ‘service access’, suggests that in asking about the challenges of assessing and diagnosing dementia in migrants, clinicians report that migrants are simply not represented in their services. This underrepresentation is verified in European demographic studies (Canevelli et al., 2019; Schmachtenberg et al., 2020; Segers et al., 2013). Some clinicians attributed underrepresentation to socioeconomic factors, such as low education levels, and ranked this as a greater explanatory factor than migration status. Although further investigation is required to evidence these claims, one possibility is that this belief itself may serve as a barrier to migrant representation in services. Beliefs that neglect the impact of migration as a major life event affecting lifestyle and health (Xu et al., 2017), and therefore as a factor in service access, may affect the impetus to improve service change and outreach.

Occasionally, clinicians viewed migrant families as gatekeepers to a diagnosis of dementia. It was hypothesised that families could prevent help-seeking, related to an unwillingness to discuss uncomfortable topics. It is unclear, however, if this relates specifically to migrant families. Avoidance of diagnosis-seeking has been reported in general populations (Parker et al., 2020), related to a discomfort in acknowledging the symptoms of dementia. It may be that the views expressed by clinicians in this synthesis apply more generally to familial avoidance of diagnosis seeking, regardless of culture. Service access was thought to be impacted by linguistically insensitive services that could be off-putting for migrant families, as well as unavailability of resources catering for different languages. Some clinicians saw it as the service responsibility to develop outreach strategies, for example deploying community link workers and approaching community leaders to promote services.

The second theme concerning perceptions of migrants’ beliefs about dementia was reported more often as a barrier than facilitator to the diagnostic procedure. The findings here suggest clinicians
believe migrants to view symptoms of dementia as normal ageing. It is noteworthy, however, that in Arora et al.’s (2018) synthesis of migrant perspectives on access to healthcare, migrants considered clinicians to dismiss their symptoms as normal ageing. It is unlikely that clinicians would report dismissive practice due to social desirability bias (Pauls & Stemmer, 2003), and observational studies of diagnostic communication may illuminate aspects of direct practice. Clinicians often viewed migrants and families as holding inaccurate beliefs regarding the cause and treatment of dementia, leading to diagnostic delay. Inaccurate beliefs regarding dementia and its consequences for a timely diagnosis have been reported in larger ethnic minority communities (Brijnath et al., 2021; Kenning et al., 2017). However, by focusing on a more specific population, this synthesis indicates that migrant beliefs surrounding dementia may delay the diagnosis and affect the acceptance of the diagnosis when it is communicated. Beliefs about the role of family in this synthesis are also viewed as a barrier to timely diagnosis. Family care practices have been previously reported as impediments to timely diagnosis from patient perspectives (Nielsen et al., 2021; Shrestha et al., 2023). However, this synthesis provides triangulation with these sources, adding further weight to the argument that beliefs surrounding dementia may directly contribute to diagnostic delay.

Relationships between the clinician, patient and caregiver were viewed as integral to the diagnostic process, as were relationships between the interpreter and patient. Several clinicians reported the belief that it was their duty to gain trust with patients and families to assess and diagnose dementia. Managing the expectations of all family members involved was reported as a significant challenge, in part due to the uncertainty of caregivers’ true emotional burden. Clinicians described the need to maintain awareness of the mismatch between caregivers’ reported and actual coping, a finding that has been echoed elsewhere (Ahmad et al., 2020). A concerning finding was the evidence of poor relationships between a professional interpreter and a patient. Occasionally, clinicians reported that pre-existing links between an interpreter and the migrant community could compromise the privacy of the diagnostic process. One observational study found that a negative interaction between an interpreter and patient led to the patient becoming withdrawn, thus adding further complication to the assessment process. Concerns about pre-existing links between interpreter and migrant communities have been reported elsewhere (MacFarlane et al., 2020). In their cross-sectional survey study, MacFarlane et al. also highlighted clinicians’ views that interpreters could behave unprofessionally and negatively towards patients during primary care consultations. The findings from this synthesis indicate that services may need to go beyond the practical issue of sourcing a professional interpreter, and to consider issues of privacy and interpreter-competence in the diagnostic process.
Diagnostic tools were viewed as a consistent barrier to the valid assessment of migrants. The cultural validity of assessment tools is an extensive research area, with many Western tools considered inappropriate for those with low education levels or where English is not a first language (Jones & Gallo, 2001; Tombaugh & McIntyre, 1992). However, this synthesis suggests while culturally sensitive tools may not be readily available in services, an additional barrier may be a lack of interest in obtaining them, or a belief that Western tools are sufficient. One facilitator to a valid assessment, however, was flexibility in the mode of assessment. Clinicians reported offering cognitive assessments within the patients’ home to obtain a more reliable picture of daily functioning, and to promote engagement in the process.

A surprising finding of this synthesis is that interpreters could often be viewed as a barrier to quality assessment and diagnosis of dementia. The finding that clinicians may hesitate before requesting a translator due to service pressures has been reported elsewhere (Hadziabdic et al., 2015). However, this synthesis is the first to suggest that when interpreters are made available, there may still be issues of dialect that result in impaired communication between the interpreter and patient. The results here also highlight the perception that the interpreter’s own fluency in both languages may compromise the process. Interpreters may modify and alter the content of the clinician’s speech in ways that compromise the accuracy and validity of the diagnostic process. While the provision of interpreters is essential to quality care and cultural sensitivity, these results suggest that further thought and attention to the quality of interpreters is needed. The fluency, dialect-match, and conduct of the interpreter may need further consideration for services to be suitably culturally sensitive.

It is important to consider that the views expressed in the literature by clinicians may reflect assumptions regarding cultural practices in relation to caregiving. Clinicians may perceive migrants to be those from non-Western countries and may therefore consider migrants and their families to hold collectivistic notions of caregiving. For instance, the belief that families generally assume responsibility for a relative’s cognitive decline, and that this responsibility is rooted in duty and obligation, may reflect a bias regarding non-Western culture, rather than a genuine barrier to a dementia diagnosis. Similarly, many clinicians appeared to believe that migrants possess “non-Western” beliefs about dementia as a form of “insanity” or as a transient condition. This clinical belief may also be rooted in prejudices or assumptions about non-Western culture and attitudes towards the medical establishment.
Strengths and limitations
The authors’ clinical experience of dementia diagnosis guided the choice of this research question, and a pre-understanding of the topic may have increased the risk of bias in the synthesis. Many of the studies did not explicitly outline ‘barriers’ or ‘facilitators’ in the diagnostic process, and the researchers’ inference may have decontextualised the experiences of diagnosing dementia. Further, while the review question may be meaningful for clinicians practicing in this area, it is acknowledged an official dementia diagnosis may be less relevant to migrants who possess culturally specific understandings of dementia. A major limitation of this synthesis, therefore, is the lack of clarity and shared understanding regarding the term migrant, as well as the individual meaning of this term to the clinicians participating in each study. The small number of studies included in this review may also reflect the fact that various migrant populations within Europe are still relatively young, and not yet seeking diagnostic services. This may partly explain why several clinicians within these studies reported a lack of contact with migrant populations, even within migrant-dense areas of European countries. Additionally, given the breadth and heterogeneity of migrant populations in Europe, the themes constructed here may over-simplify barriers and facilitators for a population with disparate and divergent beliefs about dementia.

The studies in this synthesis were published between 2015 and 2022, affording the results current relevance in European diagnostic settings. The combination of interview studies and observational studies lend insight into both self-reported and observed practices, offering a degree of triangulation between perspectives. Although the quality across papers was considered adequate according to the CASP tool, many papers did not report on the relationship between the researcher and participants, and therefore biases in the formulation of the research question and data collection cannot be eliminated. Two of the studies were conducted by the same lead researcher, although the research questions were adequately distinguished and generated varied results.

Further, while this synthesis aimed to understand barriers and facilitators in the diagnostic process, on occasion data was extracted from studies that in part related to residential care. It may be that responses to questions were influenced by the range of roles clinicians undertake in dementia care, for example those who work in both diagnostic and community settings. Additionally, a limitation of this synthesis is that several studies included a combination of clinicians, patients, and caregivers. The data collection methods used, for example focus groups and dyadic interviews, may have influenced self-reports from clinicians regarding the barriers and facilitators to diagnosing dementia in migrants.
Clinicians’ perceptions of barriers to service access may be inaccurate, and the self-reported views here are not necessarily accurate. For example, the perception that service access may relate more to socioeconomic factors than migration status warrants further investigation. This view itself may serve as a barrier to diagnosis, particularly if these views divert attention from outreach efforts.

Conclusions
The analytic themes constructed from the data imply that the diagnosis of dementia of migrants is seated within issues of service access, perceptions of migrant beliefs, clinician-interpreter-patient relationships, and variable assessment quality. The findings suggest that it was not possible to discuss the diagnosis of dementia in migrants without discussing their underrepresentation in services. Clinicians perceived migrants to hold self-stigmatising and inaccurate beliefs about dementia that prevented service access and diagnostic acceptance. A prevailing view was the notion that clinicians are directly responsible for building trust and alliance with patients and caregivers to communicate the diagnosis. There was evidence of clinicians requesting training in cultural competence, as well as valid cognitive tests, to facilitate the accurate diagnosis of dementia.

Potentially, the results highlight the need for services to turn their attention to the provision of culturally sensitive tools, and to provide clinicians with education and training surrounding the importance of these. This synthesis also highlights the need for greater attention to the provision of quality interpreters within services to facilitate positive patient experiences and valid dementia assessments. Considerations regarding an interpreter’s personal links to migrant communities, as well as ensuring dialect-matched professionals, may further facilitate the diagnostic process. Although services may intend to provide culturally sensitive care, it is evident in this review that service-level constraints may impact the provision of quality interpreters and adequate assessment tools. Clinicians routinely reported low confidence in their ability to assess and diagnose dementia in migrants.

A summary of the proposed barriers and facilitators to the diagnosis of dementia in migrants in outlined in Table. 5
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<thead>
<tr>
<th>Area</th>
<th>Barriers</th>
<th>Facilitators</th>
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<tbody>
<tr>
<td>Service access</td>
<td>• Patterns of caregiving meaning migrants do not seek diagnostic services</td>
<td>• Outreach initiatives including the use of multicultural link workers</td>
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<td></td>
<td>• Social isolation preventing appointment attendance</td>
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<td></td>
<td>• Culturally insensitive services and dearth of linguistically-tailored resources</td>
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<tr>
<td>Perceptions of migrant beliefs</td>
<td>• Beliefs that dementia is a form of madness</td>
<td>• Beliefs that memory is a shared responsibility, resulting in greater acceptance of the diagnosis</td>
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<td></td>
<td>• Beliefs that dementia may be curable</td>
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<td></td>
<td>• Cultural obligations to provide care for family members without external support</td>
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<tr>
<td>Relationships</td>
<td>• Lack of integration between healthcare organisations and third sectors</td>
<td>• Active trust-building between the clinician, patient, and caregiver</td>
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<td></td>
<td>• Adverse impact of interpreter upon patient wellbeing</td>
<td>• Nonverbal language as integral to signalling inclusion and involvement</td>
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<td></td>
<td></td>
<td>• Remaining sensitive to possible caregiver burden</td>
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<tr>
<td>Quality of diagnostic process</td>
<td>• Lack of accuracy and certainty regarding historical cognitive functioning</td>
<td>• Medically trained interpreters may facilitate accuracy and quality of assessment</td>
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<td></td>
<td>• Variability in quality, fluency, and competence of professional interpreters</td>
<td>• Increase training in cultural competence and the value of culturally valid assessment tools</td>
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<td></td>
<td>• Lack of available culturally sensitive diagnostic tools</td>
<td>• Valid testing norms for migrant populations</td>
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<td>• Clinical disinterest in culturally relevant diagnostic tools</td>
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<td></td>
<td>• Professional interpreters altering content and meaning</td>
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<td></td>
<td>• Low clinician confidence in skill and ability to diagnose migrants</td>
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</tr>
</tbody>
</table>

**Table 5. Summary of main barriers and facilitators to diagnosis of dementia in migrants**

**Future Research Implications**

Clinicians attributed the underrepresentation of migrants in services to socioeconomic, familial, and service factors. Firstly, greater demographic data is needed to estimate populations of migrants in Europe to determine if they are proportionally represented in diagnostic services. Secondly, further investigation into the hypothesised barriers to diagnosing dementia is needed to target outreach campaigns. Clinicians reported reduced confidence in the diagnosis of migrants, and future research should aim to specify methods of confidence-building. Observational studies of communicating a diagnosis in the context of a language barrier are greatly lacking, and there is a need to understand how self-reported practice is implemented. Research clarifying the role and remit of interpreters in dementia diagnostic settings may be valuable, from patient, clinician, and interpreter perspectives.
References


McKenzie, E. L., & Brown, P. M. (2021). “Just see the person who is still a person (... they still have feelings”: Qualitative description of the skills required to establish therapeutic alliance with


Chapter 2. Empirical Project

Communicating a diagnosis of dementia in secondary care: a reflexive thematic analysis of multidisciplinary perspectives

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Abstract

Background: Communicating a diagnosis of dementia is regarded as a complex intervention. Existing literature shows that clinicians may struggle to balance hope with honesty, and to manage triadic expectations and attitudes within the consultation. There is a dearth of research relating to how a diagnosis of dementia is communicated in virtual settings, and how clinicians modify their practice in this format. Further, there is scant literature pertaining to communicating the diagnosis to patients from migrant backgrounds and cross-cultural practice in diagnostic communication.

Methods: A qualitative study was conducted across three NHS healthboards in Scotland. Sixteen individual interviews were conducted using a semi-structured guide. Clinicians included 9 psychiatrists, 6 clinical psychologists and one neurologist. Transcripts from interviews were analysed using reflexive thematic analysis. Data was coded via an inductive approach, and themes were constructed.

Results: Communicating a diagnosis was considered an intricate process that depended on factors within and beyond the consultation room. Four themes were constructed from the data: (1) relationships involved in the consultation (2) personalising the consultation (3) strategies and techniques involved in communication and (4) equity and risk.

Conclusions: Clinicians reported a need to balance hope with honesty, although communicating the progressiveness of the condition was considered integral. Progressiveness of the condition could be communicated with both accuracy and euphemisms. Clinicians experienced virtual diagnostic delivery during COVID-19 as an affront to professional values. There was limited experience of diagnosing migrant populations, and tensions in the use of an interpreter.

Keywords
Dementia;
Diagnosis;
Communication;
Virtual;
COVID-19;
Migrant
Introduction

There are currently an estimated 900,000 people living with dementia in the UK and 57.4 million people globally ("2020 Alzheimer's disease facts and figures," 2020). Dementia is an umbrella term for a number of progressive neurological conditions, including Alzheimer’s Disease, Vascular Dementia, Dementia with Lewy Bodies and Frontotemporal Dementia (Dening & Sandilyan, 2015). Given the increasing prevalence of dementia, the UK government has placed emphasis on developing public awareness and access to a diagnosis (Alzheimer’s Society, 2014). In tandem with the Alzheimer Society’s ‘Right To Know’ (2014) campaign, clinical and public attitudes to dementia are changing, with greater insistence on early detection and timely diagnosis (Dooley et al., 2015).

Professional Guidelines

The Faculty of the Psychology of Older People within the British Psychological Society (BPS) advocate for timely and sensitive communication of a dementia diagnosis that acknowledges the role of pre-diagnostic counselling as vital to the process ((BPS), 2014). Pre-diagnostic counselling is emphasised as the foundation of the diagnostic consultation, and an opportunity to prepare a patient for the outcome of investigations and assessments. Crucially, pre-diagnostic counselling and assessment is an opportunity to understand a patient’s wishes in relation to knowing the outcome of the assessment. Communication of the diagnosis, therefore, is not an isolated event. Rather, the consultation is part of a chain of continued understanding, adjustment and sense-checking with the patient and their family.

While BPS guidance on sharing a diagnosis is brief, the guidelines acknowledge the need to continually respect the patient’s wishes and their consent to the process. ‘Breaking bad news’ models are advised against, given their development for oncology populations and those without a cognitive impairment. Further, the guidelines advise against the use of euphemisms or technical terms that may obscure a diagnosis and understanding. An emphasis on choice and careful use of language, from assessment to post-diagnostic care, is recommended. The stigmatising impact of language is also acknowledged, with insensitive terms such as ‘demented’, ‘sufferer’ and ‘senile’ discouraged. Although the guidelines give a brief overview of best practice and ethical considerations, there is little on navigating contemporary issues in diagnostic consultations, such as cross-cultural factors and technological changes to services.

Practices in Communicating the Diagnosis

Greater awareness of dementia and diagnosis-seeking has warranted more attention to how a diagnosis is shared by clinicians. In their systematic review, Low et al. (2019) highlight divergence in
self-reported best diagnostic practice. The review highlighted that clinicians vary in their use of terminology, with some reporting an ethical duty to name dementia, and others believing euphemistic terms such as ‘memory problems’ to be permissible. The mixed findings perhaps reflect a difference in clinicians’ ethical priorities, for example in the choice to prioritise honesty or to preserve hope in diagnostic communication, and represent a departure from BPS guidelines advising against the use of euphemism. In their qualitative synthesis of findings, the authors construct ‘approaches to communicating the diagnosis’ as a subtheme within wider communicative strategies. They report that clinicians may soften a diagnosis, using a ‘spiel’ to normalise symptoms of dementia. However, Low et al.’s review is limited in terms of current clinical relevance. Many of the papers included in the review were published prior to 2010, and therefore before shifts in public and clinical discourse surrounding dementia emphasising a patient’s right to know. With increased value and importance placed upon honest communication of a diagnosis, the review may not be relevant to modern clinical settings.

In a more recent paper, balancing honesty with hope was a finding of Dooley et al. (2015) in their focus groups with psychiatrists. In their thematic analysis of transcripts, Dooley et al. reported that clinicians could often experience this as a tension and predicament, with one clinician describing the need to “say it, ‘the D-Word’... you offer the diagnosis and then you have to do some reparation”. The quote illustrates that delivering a diagnosis may not only require honesty, but emotional containment and active alliance-building, although the ‘D-Word’ hints at dementia as something shameful or unmentionable. Providing a clear diagnosis while remaining sensitive to a patient and caregiver is a task reported as challenging elsewhere (Dhedhi et al., 2014; Dickinson et al., 2013). While Dooley et al.’s findings highlight the tension between honesty and hope, the study lacked detail regarding strategies and recommendations for navigating this dilemma in triadic consultations with caregivers. Further, the views reflected in Dooley et al.’s paper belong exclusively to psychiatrists with medical training. Clinicians with different training backgrounds, such as clinical psychologists, may possess alternative practices to medically-trained professionals, and further triangulation of perspectives is needed to clarify best practice in diagnostic communication.

Specific techniques in the communication of a diagnosis were presented by Wollney et al. (2022). Using individual interviews and thematic analysis, the researchers constructed a theme of ‘using deliberate choice in diagnostic terms’. Clinicians in this study reported a combination of asking permission to communicate the diagnosis with the use of specific diagnostic language, for example referring to the subtype of dementia if it was considered appropriate. Clinicians reported that communicating uncertainty was integral, particularly in relation to the aetiology of the subtype.
Wollney et al.’s (2022) study suggests that communicating accurately, as well as openness about uncertainty, may be a key facet of diagnostic communication. The findings in Wollney et al.’s study also imply that the issue of honesty in diagnostic communication may be satisfied by seeking permission from patients to communicate the diagnosis, thus sharing this communicative dilemma. The question of why clinicians in this study regard this practice as optimal remains unclear, however. Further exploration of the perceived value of this technique may have given greater weight to whether this constitutes best practice.

Cultural Considerations
An appreciation of culture in the communication of a diagnosis is an area of developing interest due to the increasing presence of migrants in European diagnostic services (Schmachtenberg et al., 2020). In addition to cultural differences, migrants may not speak the native language, creating added complexity within the diagnostic consultation. The systematic review contained within this portfolio highlighted several challenges inherent to the diagnosis of dementia in migrants. Clinicians believed that migrants were underrepresented in services, related to culturally insensitive services and inaccurate beliefs about the cause and progression of dementia. Interpreters could be seen as negatively impacting the patient experience, as well as altering the content and meaning of diagnostic delivery. A limitation of the synthesis preceding this thesis is that clinical perspectives relating to cross-cultural challenges were often embedded within data obtained from focus groups. It is therefore unclear how self-reported practice may have been influenced by the views and opinions of others. An advantage of the present study is its individual interviews with clinicians, where details of practice and attitudes may be teased apart from other influences.

Although few studies exist relating to diagnostic communication within these populations, one study used individual and dyadic interviews, as well as focus-groups, to explore clinicians’ experiences (Sagbakken et al. (2018). Culturally insensitive tools and an absence of appropriate testing norms led some clinicians to suspect that dementia may be significantly over-estimated in this population. This view is supported elsewhere in the literature (Goudsmit et al., 2021; Schoenmakers & Robben, 2021). Sagbakken et al.’s study suggested that invalid assessments combined with a language barrier could impact confidence in communicating the diagnosis of dementia, and that interpreters could distort and alter the clinicians’ communication. The most notable finding from Sagbakken et al.’s study is that, despite interviewing clinicians working in migrant-dense parts of Norway, many clinicians had no direct experience of working with migrants and/or interpreters. The overall findings may therefore reflect inaccurate assumptions relating to the challenges in diagnostic communication. Further,
clinicians from home-based and hospital-based settings were recruited and often interviewed in focus-group settings. The mix of settings and practices in which clinicians worked may have obscured the specific experiences and communicative practices relevant to diagnostic settings.

Czapka & Sagbakken (2020) interviewed clinicians, patients and caregivers using individual, semi-structured interviews. Their thematic analysis resulted in a predominant theme relating to barriers in communicating the diagnosis effectively, such as the inability to hire professional interpreters, and variability in interpreter-skill. Their findings indicated that clinicians may lack cultural awareness and competence, as well as the impetus to remedy this. One clinician in the study reported that services often rely on bi- or trilingual clinicians to translate a diagnosis, even though their fluency in medical terminology may be limited. Czapka and Sagbakken’s study illustrate the difference between merely translating a diagnosis and providing professional, sensitive communication. Their findings suggest a need to examine in depth the ways that interpreters are perceived to aid or impede communication of a diagnosis. While Czapka & Sagbakken used thematic analysis and the theoretical perspective of intersectionality to interpret their data, the authors apply this theory ambiguously to their interpretation of the data. The authors conclude that ‘cross-cultural differences cannot be explained by ethnicity alone’, although there is little evidence or reference to additional social identities that may influence barriers to a dementia diagnosis. It remains unclear how intersectionality supports or enhances the understanding of diagnostic communication according to this theory.

Virtual Considerations
While a language barrier may impair good diagnostic communication, the rise of virtual consultations due to the COVID-19 pandemic presented another challenge to effective diagnostic communication. In the absence of face-to-face appointments, many clinicians were called to diagnose dementia virtually (Owens et al., 2020). Following the COVID-19 pandemic, services have considered the merit of virtual consultations. However, virtual diagnoses pose a threat to the central tenet of good diagnostic communication, primarily the need to do so face-to-face (Vitto et al., 2022).

A series of one-to-one semi-structured interviews with neurologists examined the experiences of delivering a diagnosis of neurological conditions in virtual consultations (Courtney et al., 2021). Several clinicians reported unease in diagnostic delivery due to the inability to offer and perceive non-verbal cues, resulting in reduced confidence in diagnostic skill. Concerningly, clinicians deemed virtual consultations riskier due to the inability to judge the emotional state of a patient. However, some clinicians believed virtual clinics could be more efficient and eliminate travel time to clinic. As these
findings relate to the experiences of neurologists working predominantly with people with epilepsy, it is unclear whether they are relevant to the communication of a dementia diagnosis, and further thought and adaptation may be required to communicate a progressive neurological condition. Further, the results from this study were collected during “lockdown” in the COVID-19 pandemic. The sudden switch to virtual services during lockdown may have influenced the diagnostic interactions that took place, with clinicians reported to experience significant stress and burden in a particular historical context (Wanat et al., 2022).

Wheatley et al. (2022) investigated the experience of virtual post-diagnostic care in dementia settings. The individual interviews with psychiatrists and clinical psychologists revealed clinicians’ discomfort in communicating a diagnosis of dementia remotely. Further, clinicians reported that the absence of non-verbal cues led to challenges in gauging the emotional impact of the diagnosis, echoing Courtney et al.’s (2020) findings and the difficulties in obtaining an accurate clinical presentation. Wheatley et al.’s study indicates the importance of non-verbal communication as central to good diagnostic practice: where non-verbal communication was missing, diagnoses could feel detached and the clinical picture incomplete. The study indicates the importance of nonverbal cues to gather a full picture of a patients’ functioning, and questions remain regarding the ways in which clinicians may navigate their absence during virtual consultations.

Summary
The literature summarised here points to the complexity of the diagnostic consultation. Clinicians report tensions between balancing honesty with hope and remaining sensitive to both the patient and caregiver during the consultation. Studies have begun to investigate the need for cultural sensitivity and competence in diagnostic practice, particularly in relation to the diagnosis of migrants. The findings from the extant literature suggest that professional interpreters may represent a barrier to quality diagnostic communication, depending on their fluency and skill. Emerging literature relating to virtual diagnostic delivery shows that consultations may result in increased risk and uncertainty. Clinicians’ inability to perceive the non-verbal and emotional cues of patients may be unnerving and lead to under-confidence in diagnostic communication. The literature outlines the challenges and complexities of the diagnostic consultation and highlights common areas of struggle.

Research Aims and Questions
The aim of this study was to investigate how a diagnosis of dementia is communicated in secondary care NHS settings, as well as the strategies used to aid this intervention. A further aim of this study is
to understand how a diagnosis is conveyed in virtual settings, and how clinicians modify their practice and communication. The final aim of this study is to understand how clinicians convey a dementia diagnosis in cross-cultural contexts, where language may not be shared and an interpreter may be required.

Methods
Setting and participants
A purposive sampling technique was used to recruit 16 clinicians working in diagnostic settings in Scotland. Clinical leads in NHS older adult and neuropsychology services were contacted in three healthboards. The researcher emailed clinical leads the Participant Information Sheet with details of the study, as well as the inclusion and exclusion criteria, which were cascaded to their team members. For three departments, the researcher was invited to give a short presentation on the nature and purpose of the study. Interested clinicians then contacted the researcher via email, following which eligibility was assessed and confirmed. Inclusion criteria for clinicians were: working as a clinical psychologist, psychiatrist or neurologist and routinely involved in the communication of a dementia diagnosis, with a minimum of one year's experience. Beyond these inclusion criteria, the researcher noted further participant details, such as age and years of clinical experience, to recruit a diverse sample of participants. The researcher conducted an initial, brief meeting with clinicians to answer queries relating to the study and to ensure all aspects of participation were understood. This process was intended to ensure fully informed consent prior to study participation. Table 1 provides further information on the characteristics of participants.

<table>
<thead>
<tr>
<th>Participant characteristics</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>8 (50%)</td>
</tr>
<tr>
<td>Male</td>
<td>8 (50%)</td>
</tr>
<tr>
<td>Clinician type</td>
<td></td>
</tr>
<tr>
<td>Consultant psychiatrist</td>
<td>9 (56%)</td>
</tr>
<tr>
<td>Clinical psychologist</td>
<td>6 (38%)</td>
</tr>
<tr>
<td>Neurologist</td>
<td>1 (6%)</td>
</tr>
<tr>
<td>No. of years working in dementia</td>
<td>Mean: 18; Range: 3-32</td>
</tr>
</tbody>
</table>

Table 1. Participant characteristics
Braun and Clarke’s (2021) guidance on reflexive thematic analysis was considered in the number of participants recruited to the study. Braun and Clarke emphasise richness of accounts, diversity of participants (for example profession and level of experience) as well as number of participants. The researcher considered the variety of clinical backgrounds and career stages, as well as the number of participants, as sufficient to reflect the aims, scope, and purpose of the research question.

Data Collection
During the development stage of the study, a semi-structured interview schedule was constructed (Appendix. H) based on the existing literature on communicating a diagnosis of dementia. A pilot interview was conducted with a research supervisor to determine the appropriateness of the schedule and its relation to the research question. Discussions with research supervisors were used to refine the schedule before a final structure was agreed upon. A priori interview themes included: (1) how a dementia diagnosis is best communicated, (2) how a diagnosis was communicated during the COVID-19 pandemic, (3) how the subtype of dementia affects communication and (4) how a diagnosis is communicated to migrants in the context of a language barrier.

Interviews were conducted one-on-one to enhance an in-depth approach. All interviews were conducted on Microsoft Teams in a location convenient to participants (e.g. NHS clinic rooms or their home). All but one participant consented to both visual and audio recordings of the interviews, while one participant requested audio only. The duration of the interviews was between 27 and 71 minutes. All interviews were recorded and transcribed verbatim, and transcripts were anonymised to remove identifiable information. Interviews were transcribed verbatim according to Braun and Clarke’s transcription guidance (Braun & Clarke, 2013).

Ethical considerations
All participants were offered a Participant Information Sheet prior to the interview to support their understanding of the nature of the study, and to aid informed consent. Before the start of each interview, a consent form was completed with each participant. This included obtaining their permission to record the interview on Microsoft Teams. Participants were offered the option to participate with audio only and were reminded that they could withdraw their data from the study up until the point of data analysis. During the study development, the research team considered the potential for emotional discomfort in discussing diagnostic communication. The researcher developed an appropriate resource and sign-posting list ahead of interviews in case of distress, and participants were informed at the start that they were free to terminate the interview at any moment. Clinicians
were made aware of the available resources during a short debrief at the end of each interview. The study was granted ethical approval from three Research and Development centres at corresponding NHS healthboards. Since the study did not involve the recruitment of NHS patients, Research Ethics Committee approval was not sought.

Data Analysis

Interview data were analysed using reflexive thematic analysis as outlined by Braun and Clarke (2021). This approach is thought to permit a rich and detailed analysis of material, allowing thematic construction to capture patterns of meaning, as well as convergent and divergent responses. Other qualitative approaches were considered for this study, including Interpretative Phenomenological Analysis, since this method aims to make detailed sense of lived experiences and inner worlds (Smith, 2009). Although using Interpretative Phenomenological Analysis would have yielded meaningful results, it may have been more appropriate for a research study investigating the meanings clinicians attach to their practice. Discourse Analysis (Fairclough, 1993) was also considered since it aims to analyse social phenomena through language and its components, including non-verbal gestures. Discourse Analysis aims to understand how people use language to achieve specific effects (Potter, 2012). Although Discourse Analysis may have provided useful insights into how a diagnosis is communicated, it may be better applied to observational studies of interactions. After discussion and reflection with supervisors, it was agreed that reflexive thematic analysis would be the most appropriate methodology, since it is not theoretically bound and provides a flexible framework within which to interpret self-reported practice and to elucidate strategies deployed in communicating a diagnosis of dementia.

Researcher Perspective

Within reflexive thematic analysis, researcher subjectivity is regarded as an analytic tool that requires acknowledgment and engagement. Although an inductive approach to data analysis was undertaken, Braun & Clarke recognise that the researcher inevitably brings their own perspective, experience, and knowledge to the data (Braun & Clarke, 2019). Good practice within qualitative research requires the researcher to outline their own characteristics and perspectives that may have shaped their interpretation of the data. The primary researcher is a white-British, middle-class female working as a trainee clinical psychologist, with prior experience working in older adult memory clinics. The researcher also has personal experience of supporting a close friend with a diagnosis of dementia, who was not told their diagnosis. The decision not to communicate the diagnosis was made by the clinical team involved in their assessment, owing to their advanced presentation by the time they had
reached professional services. This experience left the researcher questioning diagnostic decisions made within dementia care, particularly as their family believed they would have wanted to know, prior to their cognitive decline.

As a result of the researcher’s personal and professional experiences, they considered the issue of diagnostic communication both a moral and ethical issue. The research topic was deeply personal and emotive for the researcher. Their view was that a person possesses both the right to know - and the right to refuse – knowledge of a dementia diagnosis. As such, the researcher remained aware that their personal experiences and stance may have influenced the interview process, and that they may have been particularly drawn to conversations about the ethics of diagnostic communication. Supervision was used to remain mindful of the original research question and to ensure interviews did not drift into areas of personal interest. The researcher tried to remain aware that early interpretations or conclusions regarding the data may have been influenced by their position, and reflexive journaling and supervision was used to mitigate early assumptions.

Phases of analysis
Reflexive thematic analysis requires the researcher to immerse themselves in the data from the initial stage of transcription to the final production of the report. The six stages of analysis include: (1) familiarisation with the data, (2) generating initial codes, (3) generating themes (4) reviewing potential themes, (5) defining and naming themes and (6) producing the report (Braun & Clarke, 2006, p. 87). The researcher adopted an inductive, ‘data-driven’ approach to the production of codes, meaning the analysis was not theoretically bound or conducted within a pre-existing conceptual framework. Data was therefore ‘open-coded’ to represent meaning that was free from a theoretical lens. Braun and Clarke (2013) argue that data analysed deductively may risk producing a less detailed description of the dataset. However, they acknowledge that coding and analysis inevitably may fall into both inductive and deductive approaches. Arguably, it is not possible to conduct a purely inductive approach to analysis, given that open-coding still requires a conformity to a research question (Byrne, 2022). Nevertheless, the researcher attempted a predominantly inductive approach to data analysis, where data-based meanings were emphasised.

Phase 1. Familiarisation with the data
Braun and Clarke (2006) recommend that researchers manually transcribe interviews as a way of facilitating greater familiarity with the data. The transcription stage was also an opportunity to note inflections, pauses, tone of voice, laughter etc. The researcher manually transcribed each interview,
noting inflections and tone to support the interpretation of coding in the subsequent stage. Once each interview was transcribed, the researcher read and re-read each transcript, referring to reflective logs written directly after interviews occurred. An excerpt from the reflective journal is found in Appendix L.

Phase 2: Generating initial codes

The coding process in reflexive thematic analysis is regarded as an opportunity to develop succinct labels for data items that may be relevant to the research question. Braun and Clarke recommend that researchers work systematically through the data, with each data item given equal importance. While codes should be brief, they must also be distinct enough to stand separately to other codes. An example of the coding process is outlined in Table 2. An audit trail of the evolution of codes was kept separately to the data analysis, documenting rationales for changing a code.

<table>
<thead>
<tr>
<th>Excerpt</th>
<th>Coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>And sometimes we use words that patients aren’t comfortable with or worry about but we as doctors and nurses are very familiar with using these words and then I give them a little bit of a moment to think about how they want to react to me, and then I’ll say [open inverted comma] sadly I think this does appear to be dementia [close inverted comma] so I will use the word dementia and again just take a wee moment to see what (.) happens for them. What their response is at that point. Some people are extremely relieved, some people are surprised and some people are frightened erm, and then once we’ve used the word dementia in the room I will usually look to their loved ones if they’ve got some with them and I will ask both of them you know [open inverted comma] were you expecting me to say something like that today?</td>
<td>Medical terminology and meaning to patients</td>
</tr>
<tr>
<td></td>
<td>Medical terminology and meaning to clinicians</td>
</tr>
<tr>
<td></td>
<td>Silences to aid patient involvement</td>
</tr>
<tr>
<td></td>
<td>Using the word dementia</td>
</tr>
<tr>
<td></td>
<td>Silences to further tailor communication</td>
</tr>
<tr>
<td></td>
<td>Validating the range of emotions</td>
</tr>
<tr>
<td></td>
<td>Using the word dementia</td>
</tr>
<tr>
<td></td>
<td>Validating patient and carer</td>
</tr>
<tr>
<td></td>
<td>Including everyone in the room</td>
</tr>
<tr>
<td></td>
<td>Using questions to determine insight</td>
</tr>
</tbody>
</table>

Table 2. Example of initial preliminary coding

Phase 3: Generating themes

Once codes were finalised, they were then handwritten onto pieces of card. Handwriting the finalised codes, while cross-checking the associated data, allowed the researcher to further refine and clarify codes. In conversation with another doctoral researcher, codes were organised and re-organised into tentative subthemes. The physical arrangement of codes facilitated an iterative process of
arrangement and rearrangement of codes to produce distinctive themes. While the salience of themes was not determined by the number of codes, the process nonetheless allowed the researcher to see the amount of potential data relating to each tentative theme and subtheme. This process is documented in Figures 1., 2., and 3.

![Figure 1. Codes laid out non-hierarchically](image1)

![Figure 2. Tentative construction of subthemes](image2)

![Figure 3. Tentative construction of overarching themes](image3)

**Phase 4: Reviewing potential themes**

The fourth phase of reflexive thematic analysis requires the researcher to ask critical questions regarding tentative themes and subthemes. The researcher engaged in reflexive conversation with another doctoral researcher and research supervisor, asking whether proposed themes were in fact
codes, and how potential themes related to the research question. Tentative themes were assessed for their breadth or meagreness, and whether they captured a coherent account of the codes.

Once a tentative construction of themes was created, the themes were considered again in relation to the codes, the data set, and the research question. The analysis in this phase required the researcher to move between two levels of analysis. The first level required the researcher to consider the tentative subthemes and themes in relation to the data set as a whole. The researcher reviewed the relationships between the data items and assessed whether codes sufficiently informed each subtheme and overarching theme. Where codes appeared to form coherence, it was assumed that there was a logical argument underscoring a subtheme and theme. Initial descriptors of subthemes and overarching themes were revised to better capture the inherent codes and corresponding data. For example, the theme ‘Personalising the consultation’ was reached via several iterations, including ‘Personal factors’ and ‘Individual attitudes’.

During the second level of analysis, overarching themes were revisited. Byrne (2022) recommends assessing themes for their density and coherence at this stage. For example, the theme ‘Strategies and techniques in communication’ appeared dense and sprawling, reflecting a muddled and unspecific account of the techniques clinicians deployed in effective communication. This theme was subsequently teased apart and refined, resulting in separate subthemes ‘clinician emotion’ and ‘individual style’ that eventually informed the theme ‘Personalising the consultation’. While clinician emotions and individual style may still have been considered strategies in effective communication, the researcher felt they were best represented in relation to building positive connections with patients and caregivers. The way this data was previously understood, therefore, was fundamentally altered in this process. The reconceptualisation of this data was thought to add greater specificity to the narrative of the data, and to answer the overarching research question more meaningfully.

Table 2. provides an example of how the data and coding related to subthemes within the overarching theme ‘Strategies and techniques in communication’.
<table>
<thead>
<tr>
<th>Quote</th>
<th>Code</th>
<th>Subtheme</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would kind of say it's not that they're a different person... you know from the person that walked in the room today, they've not changed just because I've kind of given them this label</td>
<td>Reminding patients of what remains true</td>
<td>Instilling hope and softening bad news</td>
<td>Strategies and techniques in communication</td>
</tr>
<tr>
<td>I will usually say and now... we've done all of this what do you now think now that you've had time to think about that? What... do you or your wife or your family... think might be going on here?</td>
<td>Asking questions to elicit understanding</td>
<td>Facilitating patients' understanding and awareness</td>
<td></td>
</tr>
<tr>
<td>what I would cover is the reason why we were doing a neuropsychological assessment ... what, how many sessions we met for and that this appointment was going to cover what they did really well during their test, what they didn't do quite so well in their test, what that meant, what we as a clinical team felt the diagnosis would be</td>
<td>Laying out a structure</td>
<td>Setting the scene</td>
<td></td>
</tr>
</tbody>
</table>

Table 2. Example of the analytic process for the theme ‘Strategies and techniques in communication’

Phases 5 and 6: Defining and naming themes; Producing the report

The goal of thematic analysis is to produce a ‘lucid narrative’ of the data; to tell a story that reliably informs the research question and captures the dataset. Within the fifth stage, the researcher settled upon final iterations of themes. This stage also requires the researcher to select illuminating extracts from the dataset to sufficiently represent each subtheme. While the last two stages of reflexive thematic analysis are often blurred, the sixth stage required the researcher to adopt a recursive approach to writing. The researcher was required to move between stages five and six and to question how quotes illustrated themes, and whether quotes were adequately analysed. The themes presented in this report attempt to present a logical ‘order’. Relationships were presented first, for example, as positive connections between the clinician, patient and caregiver were regarded as the seat or cornerstone of effective communication.

Reflexivity and Rigour

The research team included four members with academic and clinical backgrounds in clinical psychology, neurology, and neuropsychology. Each member possessed skills and experience in qualitative research methodologies. The primary researcher for this study was an NHS Trainee Clinical Psychologist with direct (although modest) experience in communicating a diagnosis of dementia,
positioning them as an ‘insider’ (Asselin, 2003). It is recognised that the primary researcher’s pre-
understanding of the diagnostic consultation may have biased the interview approach and analysis of
data. However, the dual position of the researcher as both an insider and a trainee, i.e. a novice, may
have permitted them to attend to interviews and the data analysis with a fresh perspective.

Noble and Smith (2015) recommend steps to mitigate the influence of bias upon the research process.
For example, recording the interviews allowed the researcher to return to the data to check their own
understanding and participants’ meaning; changes to codes were documented and decisions for
changes recorded; a reflective journal for each interview was referred to throughout the interview
process and, finally, supervision with another researcher gave way to different interpretations of
codes and themes in the analytic journey. The goal was not to eliminate bias entirely, but rather to
create transparency in the research process by acknowledging the various influences upon the
research process. Further, while biases may have informed the data collection and analytic process,
within reflexive thematic analysis, the researcher’s subjectivity and pre-understanding are viewed as
resources in constructing meaning (Braun & Clarke, 2019).
Results

Themes

Four themes were constructed from the data (1) Relationships involved in communicating a diagnosis; (2) Personal factors in communication; (3) Strategies and techniques in communication and (4) Equity and risk. The themes and subthemes are summarised in Table 1.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Description of subtheme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationships involved in communicating a diagnosis</td>
<td>Connecting with the patient</td>
<td>Building positive connections by getting to know a patient on their individual terms</td>
</tr>
<tr>
<td></td>
<td>Prizing the patient-caregiver relationship</td>
<td>Fostering connection between the patient and caregiver and validating each perspective</td>
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Theme 1: Relationships involved in communicating a diagnosis

Communicating the diagnosis effectively was seen to depend upon positive connections between the clinician, patient, and caregiver. Clinicians strived to understand a patient’s uniqueness and personhood and regarded caregivers as vital recipients of the diagnosis. Relationships with other professionals were viewed as instrumental in the communication of the diagnosis, although a disconnect with other professionals could result in challenging diagnostic consultations. The following subthemes elucidate the relationships involved in communicating a diagnosis of dementia.

Connecting with the patient. Clinicians viewed connecting with the patient as fundamental to good diagnostic communication. Communicating the diagnosis was viewed as an interactive rather than didactic process, where patients were encouraged to actively participate. Many clinicians used the consent process as a way of signalling the importance of the patient’s involvement, and often the patient’s wishes were prioritised where conflicts between family members emerged. For many, connecting with the patient meant encouraging the patient to share important aspects of their personal history. This was a way of maintaining sight of the patient as an individual, rather than a diagnosis:

“people are not the numbers people are (.) how they tell you their story, people are (.) you know the... things that they get upset about” [HCP 13]

Clinicians connected with patients by conveying their unique importance and making them “the centre of my attention and world” [HCP 13]. Connecting with a patient could involve equalising a power imbalance. Conveying the patient’s agency and authority was one clinician’s approach:

“I’ll actually say to them, “well you’re the boss, what do you want to do?” ... I really don't want a patient walking out... being unhappy that they haven't had a say in things” [HCP 10]

Clinicians viewed the use of silences as meaningful communication that fostered connection. Silences were used to allow patients time to process the diagnosis and respond emotionally, providing clinicians with cues to proceed. For some, silences were deployed more deliberately during virtual diagnostic delivery to bolster engagement by ensuring patients had the opportunity to contribute. One clinician described “paus[ing] more during the process to give people a bit more opportunity to
feedback” [HCP 1], and to ensure patients and families would not be “overloaded with information” [HCP 8].

Offering patients choice was seen as an essential method of building alliance, signifying patient involvement. Unsurprisingly, therefore, the inability to offer choice regarding the mode of consultation during COVID-19 was viewed as an impediment to connecting with the patient. Some clinicians reported discomfort knowing that many patients would “not have chosen” [HCP 12] a virtual consultation. Virtual delivery was also regarded as an impediment to a personalised consultation and a barrier to understanding a patient’s “hopes and wishes... their fears how they describe themselves” [HCP 11]. Another clinician commented on the inability to determine whether a consultation felt “odd” due to its remoteness or something that related more to a patient’s presentation:

“there’s also the... few occasions where actually (.) you realise an interaction is just a bit odd (.) and you just need to say something about it and you need to find out why it’s odd that actually on the telephone you just yeah (.) You just couldn’t tell” [HCP 7]

Prizing the patient-caregiver relationship. Clinicians were aware of the need to value caregivers during the consultation and to engage the “social unit” [HCP 1]. This related to an acknowledgement that dementia may affect the wider system as well as the patient. Clinicians acknowledged that caregivers may present with a range of emotions, including “relief” [HCP 14], “distress” [HCP 7] or “indifference” [HCP 4] and that a fundamental skill in diagnostic communication was to normalise this range. Engaging caregivers was typically seen as a requisite to conveying the condition as an evolving process of adjustment for everyone involved:

“it feels like [for] families there's no resting ground... there’s constant tasks involved in the human condition to adjust and live with dementia... it’s a journey that no one would pick to go on.” [HCP 7]

Clinicians reported that expectations of patients and caregivers could be divergent, although many were keen to facilitate shared understanding where possible. Creating patient-caregiver unity by navigating differences of opinion was often regarded as another skill required for diagnostic communication. One clinician felt that communicating the validity of both perspectives was key:
“Your brain is telling you that everything’s fine and what your family are saying is just another perspective. You’re all telling the truth; it’s just another viewpoint” [HCP 10]

A frustration of virtual delivery could be the inability to determine the nature and quality of dynamics within the consultation room. The inability to witness “the little non-verbal things you see between a loved one and their… patient” or to accurately understand the “complex… systemic and functional factors” [HCP 6] could affect the ability to understand patient-caregiver dynamics and unite the social unit.

For clinicians with experience of diagnosing dementia in migrants, the presence of an interpreter was occasionally regarded as a challenge to facilitating the patient-caregiver relationship. However, one clinician viewed the presence of a professional interpreter as essential to relieve the “emotional burden that you’re placing on the family member” [HCP 10] to provide translation. This clinician viewed the diagnostic consultation as a forum in which patients and caregivers required space to share and understand the impact of the diagnosis, without the additional task of providing translation for the clinician.

**Clinician-interpreter discord.** Clinicians described challenges in fostering a working relationship with an interpreter, including the inability to meet prior to the consultation and in keeping a “consistent” [HCP 9] interpreter across appointments. The inability to build a working relationship was experienced as frustrating, creating unfamiliarity and “randomness” [HCP 9] in the consultation room. Clinicians were conscious of wanting to build rapport quickly with an interpreter and made efforts to make interpreting as smooth as possible, by offering shorter chunks of information at a time:

> “with interpreters it’s doing that a lot more slowly, giving time and prompting questions… just to make sure [they are] understanding the things in smaller chunks.” [HCP 11]

Some clinicians acknowledged that while this may have facilitated the relationship with the interpreter, it may have affected the rapport with the patient and companion.

Clinicians saw interpreters as ranging in skill and quality. One clinician expressed concern about untranslated exchanges between interpreters and patients, and another that the diagnosis was not translated accurately. Several views expressed by clinicians implied that the role of the interpreter was to translate “word for word” [HCP 4] and that deviation from this role could generate uncertainty.
One clinician reported their experience of an interpreter “who found it very difficult to ask someone about suicidality” [HCP 2]. The inability to determine the emotional state of the patient was regarded as an issue of risk, and a barrier to a safe consultation. Clinicians were unable to judge whether reports of daily functioning were accurate and had less time to cover important details in the consultation. Another clinician reflected on the need for medically trained interpreters who could accompany appointments with an awareness of the emotional consequences of the diagnosis, as well as fluency in the translation of medical terminology. One clinician discussed the impact upon “the amount of detail you can go into” due to the extra time needed for translation of the diagnosis and its symptoms.

Professional dynamics. Clinicians recognised that “the interplay of team dynamics” [HCP 8] could affect the way a diagnosis was communicated. Where diagnoses were communicated jointly between different professions, tensions were occasionally reported in the conclusions of the diagnosis. One clinician believed these tensions “impact the patient experience” and extend “that period of uncertainty for the patients which contributes to their distress” [HCP 8].

Theme 2: Personal factors in communication
Clinicians reflected on how their emotional responses and clinical persona could be assets in communicating the diagnosis, facilitating authentic expression. There was a need to have certainty about the diagnosis, and to communicate uncertainty where present. Clinicians demonstrated different levels of cultural competence and perceived migrants to hold beliefs about dementia that could complicate the diagnostic process.

Clinician emotion. It was clear that, for many clinicians, communicating the diagnosis generated significant discomfort. Discomfort stemmed from the idea that a dementia diagnosis was analogous to a terminal diagnosis. The diagnosis was compared to a “death sentence” [HCP 15] with the job of communicating the condition akin to “being an undertaker” [HCP 7]. One clinician commented that they “still feel a bit sick before... [a] diagnostic session after all these years” [HCP 8]. Underpinning the discomfort of communicating the diagnosis appeared to be a sense of guilt or responsibility for conveying the diagnosis, as though clinicians were on some level to blame for a patient’s dementia. One clinician used supervision to alleviate feelings of guilt for conveying the diagnosis, describing how she is not “giving” someone dementia but rather an “explanation” [HCP 8]. Only two clinicians described feeling comfortable communicating the diagnosis and attributed this to significant experience in diagnostic communication. A psychiatrist commented that “you get used to giving these diagnoses or otherwise you wouldn’t be in the business” [HCP 13]. In contrast, several clinicians
regarded an emotional reaction to communicating the diagnosis as a facilitator to good communication, since it “just shows that you’re human” [HCP 9] and permits a genuine demonstration of empathy.

Virtual delivery of the diagnosis was sometimes associated with frustration, largely due to the inability perceive and demonstrate non-verbal language. The inability to give or perceive typical non-verbal communication left one clinician feeling “very angry” [HCP 4] and dissatisfied with their communication. The same clinician highlighted that silences could feel unnerving, leading to repetitive communication:

“But I found myself in that “are you still there? Are you still there? Are you still there? Can yo- can you hear me?” You just don’t know” [HCP 4]

Personal discomfort surrounding both telephone and virtual diagnostic delivery was equally related to an inability to “attune” [HCP 8] with patients and to adequately contain distress. Remote delivery was regarded as interfering with the process of intuition and dynamism required for communicating a diagnosis.

**Individual style.** Clinicians viewed their own personality as a resource in diagnostic communication. Clinical personas “can’t be that detached from who you really are” [HCP 1] according to one clinician, indicating a key component of communication to be authenticity. Although some clinicians possessed training in breaking bad news, two clinicians reported a need for further training and a concern about “drift” [HCP 6] from best practice. Some saw value in providing the diagnostic headline nearer the start of the consultation to reduce anticipatory anxiety, a strategy they had acquired from medical training. Many clinicians formed their style of communicating a diagnosis via observation of colleagues. One clinician framed it as “being a bit of a magpie” [HCP 10]; selecting and disregarding practices according to personal taste. The same clinician reflected on how their observations of poor practice could be instructive:

“It's like almost giving a weather report. You know, it's sometimes as blunt as that as like “oh, look, it's raining outside, ohh look, you've got cancer” you know and so it's it's erm(.) yeah… it's made me very conscious of what not to do” [HCP 10]
Several clinicians regarded their clinical psychology training as an asset in communicating the diagnosis dynamically, with enhanced awareness of the need to attune to emotion in the room. There was a sense that communicating the diagnosis was an intuitive process, involving “feeling your way” [HCP 4] and “formulating… very quickly and on the hop” [HCP 8].

Clinicians described how their diagnostic approach was inextricably linked to their professional values. Values could be considerably challenged during COVID-19, where methods of diagnostic delivery could clash with views of ethical practice. One clinical psychologist described their “ugh feeling” during a virtual diagnostic consultation, related to a belief that they had “not done things completely in line with… [their] value base” [HCP 6]. The need to communicate the diagnosis in person was related to issues of respect and professional integrity. One clinician believed virtual diagnoses to be fundamentally immoral:

“Yeah, it feels wrong, doesn’t it… if somebody’s gonna break a a life-changing diagnosis to you it should be done face to face really… there’s something about respect there and, I dunno, it just feels wrong doesn’t it?” [HCP 5]

Clinician Certainty. Clinicians often reported a personal need for certainty regarding the accuracy of the diagnosis to instil confidence in communicating it. A need for certainty was weighed with the acknowledgement that dementia could be an inherently “murky” [HCP 15] diagnosis. A particular area of concern for one clinician was communicating a diagnosis of mild cognitive impairment, which they regarded as a “heterogenous rag bag” [HCP 2]. A lack of certainty in the diagnosis could be experienced as a dissonance, resolved by openly communicating doubt directly to the patient and caregiver. An openness about uncertainty was considered good practice, and terms such as “borderline” or “early dementia” [HCP 1] were used by one clinician to qualify their doubt. Another clinician reported using phrases such as “we’re not able to give you clarity” [HCP 13] and another “there’s not really a clear answer” [HCP 8]. In addition to self-reported doubt, there was equally an acceptance that a degree of doubt was natural when communicating the diagnosis. Clinicians recognised that they won’t “always get it entirely right” [HCP 9] and that communicating a diagnosis of dementia could involve a continual process of reflecting on practice and learning from each diagnostic consultation.

Cultural competence. Clinicians sometimes reported a lack of understanding and awareness about the meaning of a dementia diagnosis to patients with migration backgrounds. At times, this led to
difficulties communicating the dementia diagnosis and prognosis, resulting in greater focus on practical implications such as driving and medication. Clinicians sometimes speculated that migrants may expect a more “paternalistic” [HCP 11] approach to communication which may have altered their style:

“it’s very authoritarian it’s, you do what the doctor says, you don’t ask questions, you go away” [HCP 11]

It was notable that in response to an interview question concerning migrants, one clinician responded in relation to the travelling community. This clinician believed that patients from minority backgrounds relied more on their communities for the management of dementia. These beliefs appeared to make the communication of the diagnosis more abrupt:

“I have a travelling site in my area erm well as static travelling site, if you know what I mean, and erm again they’re very clear often they want the diagnosis and then, “that’s fine, doctor, go away” [HCP 2].

There was evidence that clinicians did not believe communicative practice should be altered when communicating the diagnosis to a patient with a migrant background. Five clinicians felt that they would communicate the same content using the same terminology, regardless of culture or language. One clinician expressed the enhanced communicative skill from working with migrants. They felt it prevented “falling into rote diagnosis” [HCP 10] and challenged them to actively reflect on their practice.

Patient and carer attitudes. Clinicians reported a range of patient and caregiver attitudes towards dementia as affecting their diagnostic communication. One clinician commented on the “greater awareness of dementia” [HCP 2] as a facilitator to communication, resulting in patients and families attending with greater awareness of the benefits and consequences of a diagnosis. Conversely, one clinician believed that previous adverse experiences could “contribute to a degree of psychological denial” [HCP 1] making the diagnosis harder to impart. On occasion, caregiver attitudes towards dementia could result in wishes for the diagnosis not to be communicated at all. Two clinicians reported this experience in relation to families with medical backgrounds, who believed their relative may not “cope” [HCP 13] with the diagnosis.
Patient and carer attitudes toward the mode of consultation varied. One clinician reflected that patients could see virtual and telephone appointments as more casual modes, akin to “a parcel being delivered or…. A gas engineer coming” [HCP 5]. This could lead to late arrivals resulting in shorter appointment slots and a more pressured diagnostic consultation and/or non-attendance. Attitudes towards a virtual appointment could also be seen to affect levels of engagement. One clinician believed that patients could be more “ambivalent” towards a virtual appointment, and that an effective virtual consultation depended upon “an engaged patient” to facilitate good diagnostic communication.

**Theme 3: Strategies and techniques for communication**

Clinicians relied upon specific strategies to aid their communication, including setting expectations early in the session. Honesty was viewed as important, although clinicians balanced this with sensitivity to a patients’ emotional and cognitive state, as well as the drive to instil hope. There was an awareness of the impact and importance of nonverbal language, as well as the need to delicately facilitate awareness and insight.

*Setting the scene.* Laying out the structure of the consultation was often used to provide containment and to manage expectations for the communication of the diagnosis. Twelve clinicians recognised that they had a “spiel” [HCP 4], a “standard pattern” [HCP 5] or a “gambit” [HCP 1]. Several clinicians began by outlining the consent process, orienting the patient and caregiver to the previous assessment sessions, and outlining the purpose of the diagnostic consultation. Although many clinicians utilised a pre-existing script, many reflected on the need to modify and improvise this. Scripts could be tailored to emotional reactions, education levels and degree of insight. However, two clinicians expressed opposition to the idea of a pre-existing script.

Setting the scene virtually was found to be particularly important where other factors, such as nonverbal communication, were impaired. One clinician mentioned the need for an “agenda” [HCP 8] for virtual appointments, and two clinicians described the need to communicate the availability of follow-up support, or additional consultations, in case the patient and caregiver had not understood the outcome of the consultation. Setting a clear structure for virtual communication was used to “make it as close to the clinic appointment as possible” [HCP 11]. One clinician believed in being “very careful” [HCP 10] in selecting patients for a virtual diagnosis. Patients considered to have straightforward presentations were considered more suitable for virtual appointment. Clinicians reported the need to
ascertain who was in the room with the patient and the emotional support they had access to, as well as checking that sound quality was sufficient for each person to hear.

**Honesty and directness about diagnosis.** Clinicians reflected on the terminology they used as well as the timing of their language. Many clinicians used the word “dementia” early in the diagnostic consultation to ensure the diagnosis was not “coloured by everything else you’re about to discuss” [HCP 2]. Using the term ‘dementia’ was important to most clinicians, although others used terms such as “brain change” [HCP 8] and “deteriorating condition” [HCP 16]. There was evidence of clinicians balancing honesty with how terminology may be understood. For example, one clinician weighed the use of the word “dementia” with the question “what do we want to get across?” [HCP 6]. Using terminology that would more clearly convey the “progressiveness and irreversibility” [HCP 16] of the condition was occasionally viewed as more important than using specific diagnostic terms. Clinicians identified terminology they considered inappropriate. The word “terminal”, for example, was regarded as inappropriate by four clinicians due to its association with conditions such as cancer. Terms such as “brain damaged” [HCP 9] and “senile” [HCP 10] were avoided and considered stigmatising. Notably, one clinician believed that the word “dementia” was also a “horrible, horrible word” [HCP 15] and viewed communicating the subtype of dementia as preferable.

**Importance of non-verbal language.** The congruence of verbal and non-verbal language was often regarded as integral to good communication. One clinician expressed their desire to remain aware of “whether there’s a mismatch between my non-verbal communication and what I’m actually saying to people” [HCP 1]. They discussed the difficulty of balancing a “benign manner” with “really hard news”, and how this could be experienced as a communicative dilemma. Non-verbal approaches such as “softness in how we speak” [HCP 10] was viewed as facilitator of authentic expression, and there was a perception that softness of speech could be soothing. One clinician reflected on the importance of appropriate touch to aid genuine empathy in communicating the diagnosis, such as a hand on the arm to soften the news.

Unsurprisingly, several clinicians noted their frustration at the inability to offer non-verbal communication during virtual consultations. Several clinicians reported attempts to demonstrate extra non-verbal language, for example through “a lot of gestures” [HCP 12] and “modulat[ing] my voice to sound softer” [HCP 10]. Alterations to the tone and cadence of voice could be a facilitator to communicating the diagnosis, and an attempt to evoke familiarity:
“start[ed] speaking like Mary Poppins [laughing]... my voice becomes so crisp and clear...
I wonder if I’m trying to (. ) make myself more of a familiar, a familiar voice from you know how people may have sounded before or delivered medical information before” [HCP 4]

In settings where clinicians used an interpreter, there was a view that a language barrier could be ameliorated using non-verbal language. Clinicians regularly used gestures and tone of voice to communicate empathy where language was not shared. One clinician hoped that “hearing the tone of my voice... they’re aware that there’s a kindness” [HCP 10] while another used gaze to reinforce the importance of the patient: “I always talk to the person in English and erm look at the person” [HCP 14]. Several clinicians reflected on the need to maintain eye contact with the patient and caregiver, rather than the interpreter, when imparting the diagnosis. Eye contact was used to convey the importance of the patient within the context of the language barrier.

Facilitating patient understanding and awareness. Clinicians frequently reported that diminished insight could hamper communication. Depending on the patient’s presentation, clinicians believed that a diagnosis may not “mean much” [HCP 16]. In the absence of insight, clinicians anchored the diagnosis to concrete medical tests and evidence of biomarkers to foster understanding and awareness. One clinician believed that orienting a patient to memory difficulties could support them to understand:

“I’ll actually say to the patient that by the very nature of having memory problems people forget that they forget and and it’s such a simple way of putting it and you can see for a second there’s a light bulb moment” [HCP 10]

Asking patients questions about their condition was used to determine insight and to encourage a patient to name the diagnosis themselves. Linking the diagnosis with patients’ real-world experiences and examples was also used to consolidate understanding. Phrases such as “it ties up with what you’ve told me” [HCP 12] were thought to allow patients to consider links between the diagnostic consultation and their day-to-day life. Several clinicians reported the use of videos, “drawings of the brain” [HCP 3] and the use of metaphors to reinforce understanding of the diagnosis.

Instilling hope and softening bad news. Instilling hope was considered a central skill in communicating the diagnosis. Advances in targeted medication provided clinicians were used to foster optimism. Hope could be instilled by reminding patients of what remained constant following a diagnosis. One
clinician would communicate “that they’re not a different person... from the person that walked in the room today” [HCP 9] and to convey that the essence of person remained constant despite the diagnosis. Although many clinicians valued honesty, this was not incompatible with softer phrases such as “memory problems” or “forgetting” [HCP 12]. The use of appropriate humour was regarded as a communicative aid to combat the seriousness of the consultation. Humour could be used to “bring... a little bit of lightness” [HCP 10] to a difficult situation. In virtual settings, humour was used to enhance consultations that could feel detached or disconnected. The use of humour was also reported in consultations involving interpreters acting as a bridge between the clinician and patient.

**Theme 4: Equity and risk**

Although clinicians were interviewed about how a diagnosis of dementia was communicated, issues of service access and risk were reported as salient in question relating to migrant populations and virtual delivery. Clinicians generally regarded provision for migrants as inequitable, attributing underrepresentation to service barriers, cultural beliefs, and family caregiving patterns. Several clinicians considered virtual diagnostic delivery as an unethical mode of delivery, where risk could not be adequately contained, and privacy concerns emerged.

*Migrant exclusion.* Collectively, there was a sense that migrants were underrepresented in services, preventing the diagnosis of this population. A clinician involved in the triage process in their service felt that triage served as a point of exclusion for migrants, where patients were screened according to their proficiency in English. The same clinician saw a lack of readily available interpreters as another barrier to the assessment and diagnosis of this population. One clinician believed that services could be alienating or meaningless to migrants, with systems lacking cultural interest and competence:

“We have a terrible (.) engagement with people from diverse populations and it’s something we’re working on” [HCP 7]

The same clinician saw it as incumbent on services to develop outreach initiatives to improve access for this population:

“we keep expecting minority groups to engage with us, we should be engaging with them. We should be going out to their communities, we should be... marketing through their community leaders... we need to engage better with the communities” [HCP 7]
There was curiosity about why migrants were underrepresented in services, and speculation that this could be related to cultural beliefs as well as service barriers. One clinician believed that dementia was regarded as “taboo” [HCP 7] in migrant communities and another that dementia “is the same as madness” [HCP 5] to migrant populations. It was notable that many clinicians remained reflective and curious about the issues preventing migrant access, and were keen to avoid stereotyping or cultural assumptions.

Risk issues. Many clinicians expressed a strong dislike of virtual diagnostic delivery relating to the issues of risk and harm they could generate. During COVID-19, one clinician experienced this as a tension between doing “something” or “nothing” [HCP 2]. The same clinician summarised that, during COVID-19, they “did things then that would... previously be thought of as very poor practice” [HCP 2], including assessing cognition over the telephone. Clinicians regarded the impaired ability to accurately assess and diagnose dementia as a “danger” [HCP 11], resulting in a greater potential for missed and delayed diagnoses. One clinician reported that they ensured their healthboard were exempt from virtual diagnostic appointments, believing virtual appointments to cause more harm than good owing to the validity of a diagnosis. Remote consultations were often viewed as inherently riskier with patients considered more “vulnerable” [HCP 12] due to lack of social support in the room. There was a lack of procedure in place to support patients who became emotionally distressed, as well as a lack of experience in “offering comfort remotely” [HCP 9]. The issues of risk arising from virtual diagnostic consultations could leave clinicians feeling that they had engaged in poor practice, resulting in a mutually dissatisfying consultation.

Discussion

Communicating a diagnosis of dementia was regarded as a complex and multi-faceted process influenced by multiple factors within and beyond the consultation room. Optimally, good diagnostic communication was seated within strong connections with patients, caregivers, and other clinicians. Participants in this study acknowledged that their values, emotions, and training experiences could influence the ways they imparted the diagnosis, and many considered honesty as key. The experience of communicating a diagnosis virtually was routinely perceived as conflicting with professional values and regarded in at its most extreme as morally wrong. In relation to migrants, few clinicians had direct experience of diagnosing dementia is this population. Of those who did, uncertainties related to the quality of interpretation were reported, as well as privacy concerns connected to interpreters links to migrant communities. The four themes constructed from the data postulate several obstacles to diagnostic communication, as well as strategies thought to constitute best practice. Importantly, these
results extend findings from the extant literature by examining self-reported practices in the context of technological and language barriers.

General Practices in Communication
Explicitly naming the diagnosis of dementia was imperative for many clinicians in this study, contrary to Low et al.’s (2019) findings that general practice was to euphemise a diagnosis. Nevertheless, there was evidence that some clinicians may soften the diagnosis with terms such as ‘memory problems’ (Dooley et al., 2015; Kissel & Carpenter, 2007). Choice of language was often determined by a patient’s cognitive ability, educational background, and emotional presentation. The tactical and personalised use of terminology echo practices reported in Dooley et al.’s (2015) study. Some clinicians, however, viewed the diagnostic consultation as an opportunity to communicate the progressive and irreversible nature of dementia, regarding this as more important than accurate terminology. Softening the diagnosis could also be viewed as more responsive to a patient’s emotional state. These findings imply that diagnostic consultations may be too variable to apply a binary approach to the question of honesty in imparting a diagnosis. A nuance of this study that extends previous research is the finding that clinicians valued authentic expression. The need to develop a personal style of communication consistent with professional values was considered integral. How this translates into observable practice remains unknown, however, and how authenticity is viewed by patients and caregivers requires further investigation.

Instilling hope was important to many clinicians, a view reflected in the literature (Del Vento et al. 2009). Clinicians frequently commented on advances in medication options as a useful point of optimism. Others believed in communicating the constancy of personhood and saw this as a technique to reduce distress and provide containment for patients and caregivers. Concerningly, several clinicians in this study described the task of communicating a diagnosis as comparable to an “undertaker”, believing dementia to be a “death sentence”. There was evidence that the diagnostic consultation could leave clinicians feeling guilty, responsible or ‘causing’ dementia. The findings here echo opinions expressed elsewhere, for example comparing delivery of a diagnosis to acting as “the grim reaper” (Dooley et al., 2015), and equating dementia to a “living death” (Gove et al. (2016). Views of dementia as a death sentence are also reflected in media portrayals of the condition as a fearful and catastrophic diagnosis to be avoided (Milne, 2010). Analogies likening dementia to a living death reflect an aversive, stigmatised attitude towards the condition, and contravene the principles outlined in BPS guidance to remain attentive to the language used to convey and conceptualise dementia. How these aversive beliefs and attitudes unfold within the chain of assessment and diagnosis is not known
in this study, and Gove et al.’s research indicates that further training may be required to support clinicians to understand the ways in which their own beliefs may perpetuate the stigma of dementia and hinder timely diagnosis.

Despite professional guidelines emphasising the role of pre-diagnostic counselling as preparation for a diagnosis, clinicians demonstrated variable awareness of the importance of this in this study. Although the practice of consent-taking was indicated by a few participants, there was evidence that clinicians viewed this as cursory or superficial. There appeared to be a lack of awareness of the consent process as inherently valuable and inextricably linked to a patient’s right to know (or not to know). While the third theme constructed in this analysis, ‘Strategies and techniques involved in communication’, offers useful suggestions on methods used within the consultation room, they imply that a dementia diagnosis is an atomised event disconnected from the thread of clinical care. This directly opposes the recommendations set out within professional guidelines underscoring the value of previous consultations, history checking and permission-taking as the seat of good diagnostic communication. The strategies and techniques outlined in this study cannot be separated from the primary importance of obtaining a patient’s permission to use them.

Communicating uncertainty was a palpable issue for many clinicians, a finding reflected in Wollney et al.s (2022) study, suggesting overlap in global practice. However, in this study, where clinicians felt uncertain in the accuracy of the diagnosis, hesitancy was reported in their communication. Uncertainty related to accuracy, prognosis and genetic implications is reportedly prevalent in memory clinics (Visser et al., 2019). In recordings of clinicians communicating a dementia diagnosis, Visser et al. (2019) observed that uncertainty about the course and progression of dementia was routinely conveyed to patients. Comparably, in this study, many clinicians described communicating their uncertainty directly to the patient. Often, the need to communicate uncertainty related to the professional value of honesty, although there was an acceptance that a diagnosis of dementia could be inherently tentative. In NHS contexts, where values are embedded in systems, it may be that clinicians develop and evolve their practice according to professional principles.

Many clinicians were aware of the need to facilitate the triadic nature of consultations. This could involve settling disagreements by validating each perspective in the room and acknowledging a spectrum of caregiver emotions from indifference to distress. The need to balance the perspectives and emotions of a triad is a view reflected in both observational (Karniele-Miller, 2012; Peel, 2015) and self-reported diagnostic communication (Dooley et al., 2015). The findings from this study provide
additional insight into navigating a triad. Specific phrases such as ‘everyone is telling the truth’ could be useful for engendering consensus. Further, clinicians indicated that the dynamic between the patient and caregiver was used as a rich source of information in the consultation room. Nonverbal exchanges between patients and caregivers could be used to determine the quality of social support outside the room, for example, and as emotional gauges to further tailor communication.

Virtual Considerations

Given the complexities and triadic demands of in-person diagnostic consultations, it is unsurprising that an inability to detect nonverbal exchanges during remote consultations was a source of frustration and concern. The findings here reflect Wheatley et al.’s (2022) in that the inability to convey and detect nonverbal cues was a source of discomfort for clinicians. In this study, however, clinicians could compensate for this by modulating their tone of voice, using additional gestures, and leaving extra time to allow patients to process and respond. In their study of communicating a dementia diagnosis during COVID-19, Kinnaird & Russ (2021) found that the inability to detect who was present with a patient was a significant source of apprehension for clinicians. The findings here, however, shed further light on why this may be disconcerting for professionals. Clinicians felt that missed nonverbal exchanges between patients and carers could form a barrier to ascertaining a patient’s level of social support. Nonverbal exchanges between patients and carers were thought, ordinarily, to provide clinicians with cues to tailor their communication further. In their absence, interactions could feel stilted and more uncertain. Similarly, while silences were typically used in face-to-face settings to develop connections with patients, silences in virtual and telephone consultations could be experienced as unnerving. Pauses were perceived as ambiguous, where clinicians struggled to detect the emotional impact and understanding of the diagnosis.

The rapid shift to virtual formats during COVID-19 was experienced by some clinicians as a moral dilemma; a question of offering ‘something’ or ‘nothing’. Several clinicians refused to conduct virtual diagnostic sessions or, if they did, considered it morally wrong. Virtual consultations were often considered an affront to professional values. The findings here point to the possible moral injury experienced by clinicians delivering virtual diagnoses, with moral injury defined as a feeling that an individual or institution has failed to provide a certain duty of care, or that care practices have violated deeply-held values (Litz & Kerig, 2019). Other studies have pointed to the moral injury experienced by clinicians working in healthcare settings during COVID-19 (D’Alessandro et al., 2021). The inability to provide previous standards of care was experienced as uncomfortable for several participants, and whether this constitutes moral injury is a question worthy of further investigation. In the Scottish
context, where virtual delivery may become more standardised for rural populations (Innes et al., 2012), supporting clinicians to work in ways that align with their value base is imperative.

Clinicians in this study also reported increased uncertainty and lack of confidence in communicating the diagnosis virtually, a finding also reported by Courtney et al. (2021). Decreased confidence in the accuracy of the diagnosis stemmed from the virtual assessment process preceding the consultation, where the validity of assessments was considered questionable. The inability to gather adequate clinical information during telephone consultations has been reported previously as a significant barrier to accurate neuropsychological diagnoses (McKinstry et al., 2010). In this study, clinicians also experienced video consultations as providing an incomplete clinical picture, despite prior research suggesting video appointments may be safer (Duncan et al., 2010). If communicating a dementia diagnosis ordinarily depends upon strong personal connections, physical proximity, and a threshold for certainty, it may be that virtual consultations are less appropriate for communicating a progressive neurological condition.

Cultural Considerations
In relation to the diagnosis of migrants, the findings from this study validate several issues highlighted in the systematic review at the start of this portfolio. The first is the sense that migrants may experience unique barriers to accessing dementia services that are poorly understood (Sagbakken et al., 2018; Czapka & Sagbakken, 2020) resulting in limited experience in diagnosing this population. Secondly, clinicians in this study believed that the use of an interpreter could be challenging and expressed concerns regarding the accuracy and nuance of translation. There were reports that exchanges between the patient and interpreter may be untranslated, and that interpreters may struggle to probe patients about their emotional state. Thirdly, the findings also suggest that the presentation of migrants’ may be more advanced by the time they reach services (Chejor et al., 2022; Czapka & Sagbakken, 2020; Vissenberg et al., 2018). There was speculation that this could relate to patterns of caregiving that were different in migrant communities. However, patterns of caregiving were considered an explanatory factor for delayed diagnoses in more socioeconomically deprived areas of Scotland. Socioeconomic status as a greater explanatory factor in service access was also reported in the preceding systematic review. More advanced presentations in migrant patients could lead to more certainty about the diagnosis; however, the diagnosis regarded as less meaningful to a patient who was more severely cognitively impaired.
The findings from this study raise questions regarding the role of the interpreter in diagnostic consultations. Clinicians expressed concerns when information was not translated verbatim and took a traditional view of interpreters as conduits for precise translation (Flores, 2005). Increasingly, however, interpreters in medical settings may regard their role as one of cultural mediation and patient advocacy (Latif et al., 2022). Latif et al. (2022) highlighted that interpreters could struggle to bridge the gap between clinicians’ terminology and patients’ understanding. Clinicians here reported infrequent and brief contact with interpreters, as well as limited opportunities to jointly prepare or debrief. Further, some clinicians felt that the content of their communication remained the same, regardless of cultural or linguistic background. Latif et al.’s (2022) findings and those outlined here underscoring the need to examine and standardise the views of clinicians and interpreters regarding the function of diagnostic consultations. Clinicians may need further training and support to communicate a culturally sensitive diagnosis via an interpreter, considering adaptations to their terminology and cultural implications of the diagnosis.

Limitations

Owing to the design of the interview schedule, it is possible that the interview questions constructed the diagnosis of dementia as a singular event disconnected from pre-diagnostic counselling. That clinicians failed to mention the importance of pre-diagnostic counselling may therefore be an artefact of the schedule itself, rather than an inherent lack of value or awareness of this aspect of the diagnostic process. Alternative interview questions probing further into the value clinicians place upon the entire assessment and diagnostic process may have resulted in more nuanced conversation regarding the role of preparation and consent-taking prior to the diagnostic consultation. To better understand the stigmatising references to dementia as a “living death”, an alternative methodology such as Content Analysis or Interpretative Phenomenological Analysis may have been more appropriate. Understanding clinicians’ specific perceptions, fears and judgements surrounding dementia may better clarify the training needs and support needed to reduce stigmatising beliefs about dementia.

This study is limited by its small sample size, and the findings may not be generalisable to settings outside of Scotland. The study aimed to include the views of neurologists, clinical psychologists, and psychiatrists, however only one neurologist was recruited to the study. It is unlikely that the findings adequately reflect the views of the neurology profession. In addition, Advanced Nurse Practitioners (ANPs) are increasingly involved in diagnostic communication. The exclusion of nursing perspectives
may also be a limitation of this study. Nevertheless, the representation of views from clinical psychologists and psychiatrists constitutes useful data to reflect the convergence and divergence of practice across two disciplines.

Due to the self-selecting sample recruited to this study, the sample may be biased towards clinicians with higher motivation. This may mean that the practices reported here are reflective of those particularly invested in diagnostic communication. Findings regarding virtual diagnoses may be influenced by the context of COVID-19, and there is a risk of conflating attitudes towards remote delivery with attitudes towards forced innovation in the context of a global pandemic. Findings relating to the diagnosis of dementia in migrants are limited by the fact that some clinicians possessed no experience in this area. The interpretation of the term ‘migrant’ may also be understood differently across clinicians, and there is a risk of homogenising the challenges of diagnosing a culturally and linguistically diverse population.

**Future Implications**

It is unknown whether clinicians’ self-reported practice is implemented in their clinical work, and further observational studies are needed to determine the application of practice. Moreover, the views outlined here do not necessarily constitute best practice, and conclusions regarding diagnostic communication are tentative without triangulating the views of patients and caregivers in similar settings. A concerning finding of this study is the potential stigma reflected in clinical attitudes to giving a dementia diagnosis, and the cursory regard for consent-taking and pre-diagnostic counselling. Clinicians may need greater support and training to understand their own prejudices and assumptions regarding a diagnosis of dementia. A significant finding within this study is that diagnostic communication was often inextricably linked to professional values. Communicating a diagnosis virtually was routinely experienced as an affront to these values. Further research is needed, therefore, to understand how to support clinicians to work in alignment with their principles in virtual diagnostic settings, particularly when virtual formats are increasingly deployed by the NHS. Clinicians reported a lack of contact with migrant populations. Demographic data may provide greater clarity on the prevalence and age of migrants within Scotland. Research exploring clinicians’ and interpreters’ views on the role of medical interpretation is needed to standardise expectations and practice in diagnostic settings. The views of migrants, caregivers and families are also required to develop greater insight into the possible barriers to diagnostic access, as well as the experience of receiving a diagnosis where language is not shared.
References


Parker, M., Barlow, S., Hoe, J., & Aitken, L. (2020). Persistent barriers and facilitators to seeking help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and
people with dementia. *International Psychogeriatrics*, 32(5), 611-634. https://doi.org/10.1017/S1041610219002229


Appendix A. Author guidelines for the Journal of Dementia

From: https://journals.sagepub.com/author-instructions/dem

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Dementia, please ensure you have read the Aims & Scope.

1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia. Biomedical and overly clinical research articles will not be accepted.

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

The journal also publishes book reviews. We send out a list of books to review twice a year in September and March.

If you would like to receive this list please e-mail Sarah Campbell, Book Review Editor at and you will be added to our reviewer list. We welcome suggestions of books to review at any time. Also, if you have read a book that you think would be of interest to the journal and would like to review it, we also welcome unsolicited contributions.

Book reviews are usually around 1000 words in length but it will vary depending on the book. Providing a book review is not a guarantee of publication.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

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2. Editorial policies

2.1 Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer’s name is withheld from the author and, the author’s name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission,
- The reviewer should not have recently collaborated with any of the authors,
- Reviewer nominees from the same institution as any of the authors are not permitted.

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student’s dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Any acknowledgements should be placed on the title page. Your main text should include a Declaration of Conflicting Interests (if applicable), any notes and your References but should be completely anonymized.

2.3.1 Third party submissions

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual’s name, company and level of input
• Identify any entities that paid for this assistance
• Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

Where appropriate, SAGE reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

2.4 Funding

Dementia requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of Dementia to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a ‘Declaration of Conflicting Interests’ statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that ‘The Author(s) declare(s) that there is no conflict of interest’. For guidance on conflict of interest statements, please see the ICMJE recommendations here.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient’s actual written informed consent with your article, as this in itself breaches the patient’s confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for
example in a patient’s hospital record. The confirmatory letter may be uploaded with your submission as a separate file.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants.

2.7 Research data

The journal is committed to facilitating openness, transparency and reproducibility of research, and has the following research data sharing policy. For more information, including FAQs please visit the SAGE Research Data policy pages.

Subject to appropriate ethical and legal considerations, authors are encouraged to:

- share your research data in a relevant public data repository
- include a data availability statement linking to your data. If it is not possible to share your data, we encourage you to consider using the statement to explain why it cannot be shared.
- cite this data in your research

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3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics’ International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

Dementia and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author’s institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material
can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor’s Publishing Agreement. SAGE’s Journal Contributor’s Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit the SAGE Author Gateway.

3.3 Open access and author archiving

Dementia offers optional open access publishing via the SAGE Choice programme. For more information on Open Access publishing options at SAGE please visit SAGE Open Access. For information on funding body compliance, and depositing your article in repositories, please visit SAGE’s Author Archiving and Re-Use Guidelines and Publishing Policies.

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4. Preparing your manuscript for submission

Dementia requires authors to submit a short author biography. You will be asked to upload this as a separate file.

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)TeX templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

Dementia requires authors to submit a short author biography. You will be asked to upload this as a separate file.

4.2 Language

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dement). Language that might be deemed sexist or racist should not be used. All submissions should avoid the use of insensitive or demeaning language. In particular, authors should use ‘dementia-friendly’ language in positioning people living with dementia in their article and avoid using pejorative terms such as ‘demented’ or ‘suffering from dementia’.

Please also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have common usage,
please try to avoid unnecessary abbreviations in the submission of your manuscript, such as PWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

Useful websites to refer to for guidance

We recommend that authors refer to the Dementia Engagement and Empowerment Project (DEEP) guidance which was developed by people living with dementia and offers a range of advice and support, including writing dementia-friendly information.

Alternatively, Alzheimer’s Australia sets out guidelines for dementia-friendly language, as do the Alzheimer Society of Canada, both of which are useful for guidance.

4.3 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE’s Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.4 Supplemental material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.5 Reference style

Dementia adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal’s specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

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5. Submitting your manuscript
Dementia is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit http://mc.manuscriptcentral.com/dementia to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

Book reviews must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Sarah Campbell

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID iD to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication’s metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID iD please follow this link to create one or visit our ORCID homepage to learn more.

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. The affiliation listed in the manuscript should be the institution where the research was conducted. If an author has moved to a new institution since completing the research, the new affiliation can be included in a manuscript note at the end of the paper. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

Dementia requires authors to submit a short author biography. You will be asked to upload this as a separate file.
5.3 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway.

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article’s progress throughout the production process. Proofs will be made available to the corresponding author via our editing portal SAGE Edit or by email, and corrections should be made directly or notified to us promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate.

6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

6.3 Access to your published article

SAGE provides authors with online access to their final article.

6.4 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the Promote Your Article page on the Gateway for tips and advice.

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Dementia editorial office as follows:

dem.pra@sagepub.com
Appendix B. Ethical Approval from NHS Lothian Research & Development

Lothian NHS Board

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ

FMILD/approval
10 February 2022

Miss Siobhan Hurley
University of Edinburgh
Old College
South Bridge
Edinburgh
EH8 9YL

Research & Development
Room E1.16
Tel: 0131 242 3330

Email: accord@nhslothian.scot.nhs.uk

Director: Professor Alasdair Gray

Dear Miss Hurley

<table>
<thead>
<tr>
<th>Lothian R&amp;D Project No: 2021/0272</th>
<th>REC No: N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Title of Research:</strong> Communicating a diagnosis of dementia in secondary care: a multi-disciplinary perspective</td>
<td></td>
</tr>
<tr>
<td><strong>Participant Information Sheet:</strong> Version 1.0, dated 15 November 2021</td>
<td><strong>Consent Form:</strong> Version 1.0, dated 15 November 2021</td>
</tr>
<tr>
<td><strong>Protocol:</strong> Version 1.0, dated 15 November 2021</td>
<td></td>
</tr>
<tr>
<td><strong>Approved Location(s) within NHS Lothian:</strong> Royal Edinburgh Hospital</td>
<td></td>
</tr>
</tbody>
</table>

I am pleased to inform you this letter provides Site Specific approval for NHS Lothian for the above study and you may proceed with your research, subject to the conditions below.

*Please be aware that ACCORD has issued COVID-19 Clinical Research Plan and Guidance that includes instructions for restarting/commencing non-COVID-19 clinical research, and also advice on what to do if there is a requirement to halt recruitment of new participants to an active study, what to do if the study design needs to be amended or if there is a resource issue within the study team in light of the ongoing COVID-19 pandemic.*

*The ACCORD guidance is available on the ACCORD website; [http://www.accord.scot/about-accord/accord-news/covid19-planning-and-guidance-research-0](http://www.accord.scot/about-accord/accord-news/covid19-planning-and-guidance-research-0)*

*The guidance detailed here applies to research projects Sponsored by NHS Lothian and/or the University of Edinburgh and to NHS Lothian hosted studies until further notice.*

Please note that the NHS Lothian R&D Office must be informed of any changes to the study such as amendments to the protocol, funding, recruitment, personnel or resource input required of NHS Lothian.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where applicable.
Lothian NHS Board

Data controllers and processors have a legal obligation to hold a register of all its information assets (e.g. personal information (data) and/or special categories of personal data held in paper or electronic format for the purpose of clinical research). This R&D management approval is given on the understanding that you, as a potential information asset owner, will register any information assets associated with this research project with your employing organisation (where the data is held) in accordance with the Data Protection Act 2018.

Please keep this office informed of the following study information, which is a condition of NHS Lothian R&D Management Approval:

1. Date you are ready to begin recruitment, date of the recruitment of the first participant and the monthly recruitment figures thereafter.
2. Date the final participant is recruited and the final recruitment figures.
3. Date your study / trial is completed within NHS Lothian.

I wish you every success with your study.

Yours sincerely

Fiona McArthu
Deputy R&D Director

cc Dr Tom Weavers, Principal Investigator, UoE
Clara Cala, Academic Advisor, UoE
Tracey McKie, Services Director, Psychiatry, RIE
David Hood, General Manager, Medicine, RIE
James Powell, Consultant HPB and Transplant Surgery, NHS Lothian
Lothian NHS Board

Insert 1 - Contracts

1a We note that this project includes a researcher(s) who will require a Letter of Access from NHS Lothian. The individual(s) concerned <insert names> should contact our offices with a view to applying for the necessary documentation. Please note all final paperwork will have to be signed and returned to our R&D offices before the researcher(s) can commence work on the project.

1b We note that this project includes a researcher(s) who will require an Honorary Research Contract from NHS Lothian. The individual(s) concerned <insert names> should contact our offices with a view to applying for the necessary documentation. Please note all final paperwork will have to be signed and returned to our R&D offices before the researcher(s) can commence work on the project.

Insert 2 – GCP Training

Please note that ACCORD policy for GCP & SOP Training requires you to have undertaken documented GCP training within the previous 24 months, before commencing activities with respect to the Project listed above. ACCORD policy also states that the Principal Investigator is responsible for ensuring that local research site staff members have undertaken GCP training before beginning Project specific activities.

Insert 3 – Externally Sponsored Clinical Trial of an Investigational Medicinal Product (CTIMP) or Clinical Investigation of a Medical Device (CIMD) or a clinical trial of an Advanced Therapy Investigational Medicinal Product (ATIMP) (delete as appropriate)

Please note that it is your responsibility as Principal Investigator for this externally sponsored Clinical Trial of an Investigational Medicinal Product (CTIMP) or Clinical Investigation of a Medical Device (CIMD) or a clinical trial of an Advanced Therapy Investigational Medicinal Product (ATIMP) (delete as appropriate) to maintain a record of all Serious Adverse Events (SAEs) occurring in participants you recruit to the study. You are also responsible for reviewing trial safety data sent to you by the Sponsor and it is recommended that you alert the ACCORD office if you have any concerns regarding the safety data or conduct of the trial.

Insert 4 – Participant Identification Centre Studies

We note that NHS Lothian is participating in this trial as a Participant Identification Centre (PIC).

Insert 5 – EudraCT

Results of Clinical Trials of Investigational Medical Products (CTIMPs) must be uploaded to the European Clinical Trials Database (EudraCT) within 12 months of the ‘end of trial’ or within 8 months of the ‘end of trial’ for paediatric studies. This task is delegated to Chief Investigators of CTIMPs co-sponsored by the University of Edinburgh and NHS Lothian. Further instruction can be found at www.accord.scot or by contacting the ACCORD Office at enquiries@accord.scot.

Insert 6 – Patient Identifiable Information & Information Governance

We note that this study has obtained Caldicott approval or approval from the Public Benefit and Privacy Panel (PBPP) and/or approval from NHS Lothian Information Governance/IT Security for those aspects of the study that involve collection and/or transfer of identifiable information (delete as appropriate). You are responsible for informing the NHS Lothian R&D Office if there are any changes to the study that impact the terms of this approval or these approvals (delete as appropriate).
Approval - LOT (2021.0272), 10.02.22

"Approval - LOT (2021.0272), 10.02.22" History

Document created by Lliaur Downie (v1llaur@exseed.ed.ac.uk)
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Document e-signed by Fiona Mc Ardle (fiona.mcardle@nhslothian.scot.nhs.uk)
Signature Date: 2022-02-10 - 1:22:09 PM GMT - Time Source: server - IP address: 62.253.82.229

Agreement completed.
2022-02-10 - 1:22:09 PM GMT
Appendix C. NHS Fife Participant Identification Centre Agreement

Medical Director

Miss Siobhan Hurley
University of Edinburgh
Old College
South Bridge
EDINBURGH
EH8 9YL

Date: 24 August 2022
Our Ref: 21-080
IRAS/REC: 301374
Enquiries to: Fife Research Approvals
E-mail: fife.fiferesearchapprovals@nhscot
Telephone: 01383 623 623 Ext 20940
Website: www.nhsscot.org

Dear Miss Hurley

**Project Title: Communicating a diagnosis of dementia: an MDT perspective**

Thank you for your application to carry out the above project. Your project documentation (detailed below) has been reviewed for resource and financial implications for NHS Fife and I am happy to inform you that NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>IRAS R&amp;D Form</td>
<td>5.21</td>
<td>6 December 2021</td>
</tr>
<tr>
<td>Study-Wide Governance Report</td>
<td>21 January 2022</td>
<td></td>
</tr>
<tr>
<td>Protocol</td>
<td>2.0</td>
<td>7 February 2022</td>
</tr>
<tr>
<td>PIC Agreement</td>
<td></td>
<td>11 August 2022</td>
</tr>
</tbody>
</table>

I understand that NHS Fife are acting as a ‘Participant Identification Centre’ in this case. Dr Audrey Espio and Dr Nancy Attalla are the local contacts.

I note that review by an NHS Research Ethics Committee has not been necessary since the study involves NHS staff only.

The joint sponsors for this study are University of Edinburgh and NHS Lothian. Please note that it is the responsibility of the Sponsor to ensure that adequate and appropriate insurance is maintained throughout the course of the study.

Details of our participation in studies will be included in annual returns we are expected to complete as part of our agreement with the Chief Scientist Office. Regular reports of the study require to be submitted. Your first report should be submitted to Professor Frances Quirk, Assistant R&D Director, R&D Department, Queen Margaret Hospital, Whitefield Rd, Dunfermline, KY12 OSU (Frances.Quirk@nhscot) in 12 months time and subsequently at yearly intervals until the work is completed. A copy of the REC Annual Progress Report (where relevant) is acceptable. A Lay Summary will also be required upon completion of the project.

In addition, approval is granted subject to the following conditions:-

NHS Fife was awarded the Carbon Trust Standard in February 2010 and is the first Scottish NHS Board to achieve this accolade

Any amendments which may subsequently be made to the study should also be notified to Fife Research Approvals: [ffe.fiferesearchapprovals@nhs.scot](ffe.fiferesearchapprovals@nhs.scot) as well as the appropriate regulatory authorities. Notification should also be given of any new research team members post approval and/or any changes to the status of the project.

This organisation is required to monitor research to ensure compliance with the UK Policy Framework for Health & Social Care Research and other legal and regulatory requirements. This is achieved by random audit of research. You will be required to assist with and provide information in regard to monitoring and study outcomes (including providing recruitment figures to the R&D office as and when required).

As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT Security Policies, until the destruction of this data.

Permission is only granted for the activities for which a favourable opinion has been given by the REC (and which have been authorised by the MHRA where appropriate).

The research sponsor or the Chief Investigator or 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 [ffe.fiferesearchapprovals@nhs.scot](ffe.fiferesearchapprovals@nhs.scot) 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.

I would like to wish you every success with your study and look forward to receiving a summary of the findings for dissemination once the project is complete.

Yours sincerely

Pp DR CHRIS MCKENNA  
Medical Director  
NHS Fife  

Cc : Fife Research Approvals, NHS Fife [ffe.fiferesearchapprovals@nhs.scot](ffe.fiferesearchapprovals@nhs.scot)
Appendix D. NHS Lanarkshire Participant Identification Centre Agreement

Miss Siobhan Hurley
Trainee Clinical Psychologist
University of Edinburgh
Old College
South Bridge
Edinburgh
EH8 9YL

R&D Department
David Matthews Building
University Hospital Monklands
MonksCourt Avenue
AIRDRIE
ML6 0JS

Date 18 August 2022
Enquiries to Elizabeth McGonigal,
R&D Facilitator
Email Elizabeth.mgonigal@lanarkshire.scot.nhs.uk

Dear Miss Hurley

R&D ID: L21118_PIC

NHS NUMBER: NRS21/301374

PROJECT TITLE: Communicating a diagnosis of dementia in secondary care: a multi-disciplinary perspective

I am writing to you as Chief Investigator of the above study to advise that R&D Permission has been given for NHS Lanarkshire to act as a Participant Identification Centre (PIC) that will refer potential subjects to Miss Siobhan Hurley, Trainee Clinical Psychologist in Royal Edinburgh Hospital, NHS Lothian. The local contact in NHS Lanarkshire is Leigh Whitnall, Consultant Clinical Psychologist.

NOTE: As a PIC, NHS Lanarkshire’s involvement in the study is strictly limited to identifying and referring potential participants to the study team in Royal Edinburgh Hospital for assessment and possible recruitment into the study.

NHS Lanarkshire staff are not authorised to carry out any other study related procedures such as taking consent, carrying out investigations, taking samples, etc. – all such activities must be carried out at Royal Edinburgh Hospital.
For the study to be carried out you are subject to the following conditions:

**Conditions**

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and relevant UK-GDPR and Data Protection 2018 legislation.

- The research is carried out in accordance with the Scottish Executive’s Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: http://www.cso.scot.nhs.uk/ or the Research & Development Intranet site: http://firstport2/staff-support/research-and-development/default.aspx)

- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research & Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.

- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.

- You must contact the Lead Nation Coordinating Centre if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.

- You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire.

- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.

- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.

- If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for a criminal records check. If this is the case, please contact the R&D Department to discuss.

I trust these conditions are acceptable to you.

Yours sincerely,

Raymond Hamill, Senior R&D Manager

cc.

<table>
<thead>
<tr>
<th>NAME</th>
<th>TITLE</th>
<th>CONTACT ADDRESS</th>
<th>ROLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leigh Whitnall</td>
<td>Consultant Clinical Psychologist</td>
<td><a href="mailto:Leigh.Whitnall@lanarkshire.scot.nhs.uk">Leigh.Whitnall@lanarkshire.scot.nhs.uk</a></td>
<td>Local Contact</td>
</tr>
<tr>
<td>Charlotte Smith</td>
<td></td>
<td><a href="mailto:scahss.res.ethics@ed.ac.uk">scahss.res.ethics@ed.ac.uk</a></td>
<td>Sponsor Contact</td>
</tr>
<tr>
<td>Dr Clara Celia</td>
<td></td>
<td><a href="mailto:c.celia@ed.ac.uk">c.celia@ed.ac.uk</a></td>
<td>Academic Supervisor</td>
</tr>
<tr>
<td>Dr Patricia Graham</td>
<td>Director of Psychology Services</td>
<td><a href="mailto:Patricia.Graham@lanarkshire.scot.nhs.uk">Patricia.Graham@lanarkshire.scot.nhs.uk</a></td>
<td>Other</td>
</tr>
</tbody>
</table>
Appendix E. University of Edinburgh Favourable Opinion, HiSS

School of Health in Social Science Research Ethics Application
The supervisor or primary investigator must complete and sign this form after checking that all relevant sections are completed, and relevant documents are attached. For all undergraduate (UG) and MSc student projects, it is the supervisor’s responsibility to submit this form and all attachments. Please note that failure to do this will result in the application being returned (and not processed) causing your research to be delayed.

Supervisor (name and UUN): Dr Clara Calia, Lecturer in Clinical Psychology and Deputy Director of Research and Ethics Integrity
Primary Investigator (name and UUN): Siobhan Hurley (Trainee Clinical Psychologist)
List of all collaborators (with affiliated institutions in brackets): Siobhan Hurley (University of Edinburgh & NHS Lothian), Dr Clara Calia (University of Edinburgh), Dr Tom Wearvers (Clinical Psychologist, NHS Lothian)
Student’s programme of study (if applicable): Doctorate in Clinical Psychology
Project Title: Communicating a Diagnosis of Dementia in Secondary Care: A Multi-Disciplinary Perspective
Case Number (if known assigned by Administrator at time of 1st submission):

| Proposed Project Start Date: 01/12/2021 | Proposed Project End Date: |

Please indicate whether the primary investigator on this project is staff or student and select your subject area:

- ☐ Staff
- ☐ UG or MSc Student
- ☒ DC n Student
- ☐ PhD Student
- ☐ CPASS
- ☒ C n ca Psycho ogy
- ☐ Nurs ng Stud es

This is a:

- ☒ New app cat on for eth ca rev ew – f rst subm ss on
- ☐ Resubm ss on fo ow ng rev ewer comments
- ☐ Resubm ss on w th requested amendments

Has been reviewed by an external ethical board, such as NHS IRAS or a UK HEI (multi-site studies only) with a favourable opinion? Level 1 *

- ☒ IRAS (NHS research eth cs)
- ☐ Other: ____________________

Please tick one option that best describes your application:

- ☒ Co ect ng or generat ng new data nvo v ng other peop e: Leve  2
- ☐ Extract ng, re-cod ng and ana y ng ex st ng data that conta ns sens t ve nformat on (.e. dent f ab e nformat on): Leve  2
- ☐ Ana y ng secondary (arch va ) data that s rout ne y co ected or s an ex st ng anonym sed dataset: Leve  1
- ☒ Co ect ng new data BUT an externa eth ca rev ew board (such as NHS IRAS; UK HEI – for mu t-s te stud es; etc) has fu y rev ewed th s project and generated a favourab e op n on: Leve  1

This application is complete with the following attachments (tick all that apply):

| Advert/f yer ☐ | Ca d cott app cat on stat ng what data was requested ☐ | Ca d cott s gned approva ☐ | Consent form/s ☐ | Data co ect on too s (e.g. nterv ew gu des) ☒ | Debr ef w th s gnpost ng ☐ | IRAS app cat on ☒ | IRAS op n on etter ☐ | NGO or oca author ty etters ☐ |

*If your project has been reviewed and generated an opinion by an external agency with a full ethics board, for example IRAS approval from the NHS, you only need to complete the questions related to university regulations covered in the Level 1 section of this form to ensure you are following University policies and guidelines. Please also attach the externally reviewed application and decision letter. Please note that your project will not undergo a full additional ethical review by the School of Health in Social Sciences REC, however we need to ensure your project is adhering to university regulations before you begin collecting data.
Other attachments (please specify):
IRAS Fu Data Set

---

To be completed by primary investigator or project supervisor

By signing this front sheet, I confirm that I have prepared and/or reviewed this ethics application and related documents in accordance with ethical guidelines. I also confirm I have checked that all relevant sections of the application form are completed and relevant documents are attached.

Supervisor or PI Signature:

Student signature: Siobhan Hurley

Date: 6th December 2021

On completion, this Word document along with the relevant attachments should be submitted to eth.cs.hss@ed.ac.uk.

Note: Please note all undergraduate and MSc applications MUST be signed and submitted by the project supervisor.
This section is to be completed after review only

ISSUES ARISING FROM THE PROPOSAL to be completed by EthicsReviewer

Thank you for your app cat on. The rev ew process has generated the fo ow ng quer es regard ng your app cat on. Please address the fo ow ng items, and provide a note underneath each comment if not us know how you have addressed them:

Q3. Presumably you w a so co ect part c pant ena address when they contact you? There s no consen sity as to whether the target recruitmen ts 20 or 10 20. 

The target s 20 part c pants. Now amended with tracked changes

Q8. The answer here should be ‘yes’ as the persona y der fab e data (e.g., enma s, names, raw vdeo) w be stored wth n the NHS. Now amended

Q30. and Q31. need a response Now amended

Q43. There s d screpancy here on how the intervews w take pace: “It s expected that the intervews w take p ace face to face, at the servce n wch the c nc a s work ng. Intervews w be conducted on ne us mg Crossf Teams.” E see where on Teams s mentoned. Now amended to ref ect on ne intervews on

W thdraw t wou d be standard to p ace some mt on t the after the intervw., e, up unt ana y s s comp eted. It’s not c ear how someon cou d mean ngfu w th draw after you have g, submt ted your theses. Update on PIS n ne w th what you do de. Now amended throughout the proposal and on PIS

Consent I’m not c ear practca y how consen w be obta ned. Whh s be ema ed to part c pants? How ong w they have to cons der part c pat on? The researcher will email details of the study to the leads within NHS services and disseminate study information during team meetings. Participants will be emailed a PIS following meeting. If they are interested there is no of f cme fram e regarding contact with the researcher. On the PIS t states: “Als informd consen w be taken on ne us mg Crossf Teams, you w be ema ed your comp eted form to serve as a copy of your informd consen.” What do you mean that you w co ect consent v a Teams? How w the researcher and part c pants gn the consent form t th s s be ng done d g ta y? W th s be done durg the intevw? Consent w be taken at the start of the intevw, s gned e ctn ca y and ema ed between NHS ema addres ses. Th s has now been amended on the PIS

Data storage and management more informt on s needed on where the data w be stored at each stage. W th s be d rectly on the a ptoe or on NHS Laptop not servers

Data storage f consent s be ng taken d g ta y then why do you have hard cop es of consent forms be ng stored? Th s d oesn t seem necessary. I have now removed storage of hard cop es from PIS

Q46. Th s a so needs to re ate to the record ngs and transcr pts of the intervews.

Comments on the PIS:

PIS make t cear wether they can conduct the intervew on NHS prems or n the owne home/out s de home. I assume intervews w take p ace outs de of (the r) workng ours. I have now car ed th at intervews may take p ace at home or from an NHS s te

PIS Are there any r s/st s... th s sect on moves nto the th rd person whereas the rest s n the second person makes the PIS consen st n the second person throughout. Th s has now been corrected on PIS

PIS “How w we use...” add ema addres Name Th s has now been corrected on PIS

PIS “If you consent to be ng vdeo recorded, a record ngs w be destroyed once they have been tranms d, it’s not c ear wether they can part c pate w thout consent ng vdeo record ng. Th s has now been updated to ref ect that they may part c pate w thoud o record ng on y IS type “by sending an ema to the Un vers ty of Edneg Data Protect on Offce r at dpo@ed.ac.uk th ” Now corrected

PIS comp mats I’m not sure th th Abbott shou d be s ted here Now removed

PIS super visor contac t informt on s needed. Now added

Miss ng documents th s no conf mat on of spons orship p from the un vers ty

Miss ng documents I assume th th s has recevd R&D approva from each s te. Or conf mat on that th w be obta ned or to data co ect on s needed. Th s ref eence to an IRAS app cat on but th s n’t nc ued and c ear y f u IRAS approva sn’t needed. R&D approva has so far been granted from NHS Loth an. St awa ng approva from NHS F fe and NHS Lansarksh fe and w not recruit from these s tes unt approva s granted

Miss ng documents doeb of r informt on
Query: The form says "IRAS Fu Data Set" is an attachment, but this isn't included and I'm not sure what it is. Now attached.

Signature: Ingrid Obsuth (s g)

Position: Ethics & Integrity Lead

Date: 11 Feb 2022

APPLICANT'S SIGNATURE FOLLOWING REVISIONS to be completed by applicant

I confirm that I have addressed all of the queries generated during the ethical review process of my application. I have outlined in the box above each comment how each request was addressed and/or provided further clarification.

Supervisor/PI Signature: Dr Clara Calla

Student signature: Siobhan Hurley

Date: 23/02/2022

CONCLUSION TO ETHICAL REVIEW to be completed by Ethics Lead

The applicant's response to our request for further clarification or changes has now satisfied the requirements for ethical practice and the application has therefore been given a favourable opinion.

Signature: Ingrid Obsuth (s g)

Position: Ethics & Integrity Lead

Date: 23 Feb 2022

NOTE: Once reviewed please mark the page on which the box appears as a formal document demonstrating that the favourable opinion has been provided for this project (for example as an attachment to MSc dissertations).
# Appendix F. Research 1 Proposal

**Doctorate in Clinical Psychology**

**Thesis Research Proposal**

(Research 1 Assessment)

This form should be completed and submitted as the assessment for Research 1. It will then be reviewed by a member of the academic team and will receive a grade and detailed feedback. The feedback will include an evaluation of the viability of the project and any recommendations. If there are significant concerns about viability, the project will be flagged to the research director and the research committee will decide whether the project can proceed in its current form.

<table>
<thead>
<tr>
<th>Exam Number</th>
<th>B186269</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provisional Thesis Title</td>
<td>Communicating a dementia diagnosis: a multidisciplinary perspective</td>
</tr>
<tr>
<td>Proposed Setting</td>
<td>NHS Older Adult Services</td>
</tr>
<tr>
<td>Allocated Thesis Project Supervisors</td>
<td></td>
</tr>
<tr>
<td>Clinical</td>
<td>Dr Tom Weavers</td>
</tr>
<tr>
<td>Academic 1</td>
<td>Dr Clara Calla</td>
</tr>
<tr>
<td>Academic 2</td>
<td></td>
</tr>
<tr>
<td>Others Involved</td>
<td></td>
</tr>
</tbody>
</table>

**Anticipated Month / Year of Submission**

Must be final year for full-time trainees. For flex trainees, the month and year of submission will depend on the individual Training and Development Plan. Trainees from 2011 intake onwards must submit in May. Trainees who started in 2010 or earlier are advised to submit in May to reduce potential for HCPC registration difficulties.

May 2023

**Please Note:** Whilst this is not an ethics review process, where questions have some similarities to questions contained in the NHS IRAS Research Ethics form, the corresponding IRAS question numbers are given in parentheses. This is intended to facilitate completion of NHS ethics where such approval is needed.

Once complete to the satisfaction of both supervisors, submit via Learn with the filename:

ExamNumber_DateSubmitted_R1
Section 1: Introduction

1.1 Provide a brief critical review of relevant literature, which should clearly demonstrate the rationale and scientific justification for the research

1000 – 1500 words

Relevant to IRAS A12

Recent figures suggest that there are 850,000 people living with dementia in the UK, and this number is expected to double by 2040 (Wittenberg et al., 2020). Given the increasing prevalence of dementia in the UK, The Prime Minister’s Challenge in 2009 (Department of Health, 2016) sought to improve the timeliness and frequency of a diagnosis, as well as access to post-diagnostic services and support. Dementia diagnoses are delivered in a variety of settings in the UK and by a range of different specialists including GPs, neurologists, psychiatrists and clinical psychologists. The range of professionals involved in assessment and diagnosis, as well as research with service users and carers, has led to significant debate on the value of a diagnosis (Hansen et al., 2008). For example, service users receiving a diagnosis have described the process as a “key point of disempowerment” (Low et al., 2019) due to lack of information provided at the time of diagnosis, as well as limited treatment options. Time-restricted appointments have been shown to be distressing for service users, who are given little time to emotionally process the diagnosis (Xanthopoulou & McCabe, 2019). Clinicians have also identified negative consequences of a diagnosis, including increased anxiety around therapeutic alliance and how to break the news while containing distress (Zaleta & Carpenter, 2010). Conversely, a diagnosis is thought to offer several benefits to service users and carers, especially when the diagnosis is ‘timely’ (Moore & Cahill, 2013).

It is clear that delivering a diagnosis is challenging for clinicians. Service users may experience language decline, a reduction in conversational interest or initiation, as well as reduced speech output (Blair et al., 2007), and these communicational barriers may be in addition to impaired memory, mood, attention or capacity to understand the diagnosis (Mormont et al., 2014). Further, clinicians frequently deliver diagnoses within a triad, in essence delivering a diagnosis to two people. Clinicians may also diagnose young-onset dementia where worries about heritability are present (Robinson et al., 2010), or they may (Draper et al., 2016). Dementia diagnosis may also require the presence of a translator, who may inadvertently change sentences and meaning, adding further uncertainty or misunderstanding (Sagbakken et al., 2018). Given that participants in Sagbakken et al.’s study were all general practitioners working in primary care, however, the views of those working in multidisciplinary, secondary care services may not be reflected. There is very little research exploring how clinical psychologists, for example, perceive or reflect on cultural issues present in dementia-diagnosis sessions.

The assessment and diagnostic process within dementia is described as a key, complex intervention by the British Psychological Society (BPS, 2018) which may lay the foundation for future engagement with services. However, the guidelines provided by the BPS for communicating a diagnosis are brief and unspecific. The article promotes ‘good practice’ in pre-diagnostic counselling with families, but does not elaborate on the components of good practice. In the absence of formal guidelines, delivering a dementia diagnosis has been conceptualised as a form of ‘breaking bad news’ (Rosenzweig, 2012), with clinicians in healthcare relying on the SPIKE protocol, a six-step framework for delivering bad news in the context of cancer care Baile et al. (2000). The SPIKE acronym stands for Setting Up, Perception, Invitation, Knowledge, Emotions and Summary and, when implemented correctly, has been shown to increase confidence and improve communication skills for clinicians (Back et al., 2007). The SPIKE-Dementia (SPIKES-D) adapted model was recently proposed by clinicians (Peixoto et al., 2020) to provide a framework for communicating a diagnosis of dementia. However, this model is not currently implemented in UK services, and there are several drawbacks. The SPIKE-S-D approach is predominantly didactic, and based upon a singular interaction between one clinician and one service user. In dementia diagnosis,

Once complete to the satisfaction of both supervisors, submit via Learn with the filename: ExamNumber_DateSubmitted_R1
service users are often accompanied by another person, and the SPIKES-D therefore may not successfully accommodate a triad. Further, the SPIKES-D model does not account for the dementia-specific dilemma of “truth-telling versus conserving hope” (Begley & Blackwood, 2000). Although the ‘breaking bad news’ model outlined by Rosenweig, for example, promotes a person-centred approach to communication, it may be more suited to physical health diagnoses rather than dementia (Murphy & Gair, 2013). Although a model does exist for delivering a dementia diagnosis, the model is arguably much too generic, and does not represent the views of current clinicians in dementia care, nor the added challenge of online diagnosis.

Observational studies of diagnostic delivery have yielded mixed results, and none to date have investigated the implementation of framework-specific guidelines. Karnieli-Miller et al. (2007) observed diagnostic encounters between neurologists and service users with a diagnosis of Alzheimer’s disease (AD), finding that clinicians employed strategies such as ‘standardisation’, with phrases such as “everyone suffers from cognitive decline; however yours is worse”. A crucial finding of the study was that practitioners often used euphemisms such as ‘cognitive decline’ rather than naming the diagnosis explicitly, and that incomplete disclosure was attributed to clinicians’ fears of upsetting patients or rupturing therapeutic alliance. While the study uncovered aspects of assessment and diagnosis that clinicians find challenging, it did not shed light on any solutions to clinicians’ fears or strategies for communication. Further, the findings may not necessarily be representative of larger clinical populations, given that interactions were explored exclusively between neurologists and service users with a diagnosis of AD.

More recent studies, however, have generated different findings. Dooley et al. (2018) found that clinicians tended to name a diagnosis explicitly, although avoided answering questions from service users regarding prognosis. A strength of this study was the methodological approach: using conversation analysis (CA) identified the naming of the diagnosis during sessions. Additionally, CA identified hesitations and fractured sentences during the naming process, leading to conclusions that although diagnoses were named, clinician hesitancy may have clouded understanding. While the study gave insight into the style of diagnostic naming, the study gave little insight into clinicians’ reflections on this process, for example where explicit naming may be most effective, useful or even inappropriate. Further research is needed to determine perspectives on the utility of explicitly naming a diagnosis.

Despite the increasing need for timely and effective dementia diagnosis, there is little evidence-based guidance on strategies for delivery. This may be due, in part, to the complex and overlapping nature of dementia as a medical and psychological condition, with multiple teams and professionals involved. Clinicians’ perspectives on delivering a diagnosis of dementia have rarely been explored. Nonetheless, Bailey et al. (2019) conducted focus groups with doctors in order to explore different clinical perspectives on the diagnostic process. They also found that diagnoses were often delivered within a triad, and balancing hope with honesty was especially difficult in these contexts. The study highlighted the need for a communicative framework that considers the triadic nature of diagnostic delivery. However, given that focus groups contained specialist consultants, the authors acknowledge this may have limited freedom of expression from clinicians. Arguably the current research project, which aims to interview individuals rather than dyads, may resolve this particular issue. The study acknowledged that communication of Mild Cognitive Impairment (MCI), for example, may have been ‘bewildering’ both for service users and clinicians, given the variable prognosis of MCI. However, research exploring communication strategies in relation to a wider range of dementia subtypes may be useful and needed, given the heterogenous presentation, abilities and prognosis for this population.

The outbreak of coronavirus disease 2019 (COVID-19) has given clinicians the additional challenge of online assessment and diagnosis of dementia. There is little guidance on breaking bad news remotely, however,
the British Medical Journal released a short article offering direction. Recommendations included making use of the SPIKES protocol, using the video function where possible, paying attention to tone of voice and ensuring a quiet environment for delivery (Collini et al., 2021). Although the article provided generic tips for remote delivery, the use of the SPIKES model in dementia care has been previously criticised for its lack of specificity and failure to account for a triadic delivery. Exploring clinicians’ perspectives and consideration for online delivery may be useful for future service delivery, particularly when dementia assessment and diagnosis may be increasingly delivered remotely. Guidelines may also improve remote delivery for service users and carers living in remote areas (Barth et al., 2018).

It is clear that a comprehensive framework for diagnostic delivery is desperately needed for clinicians. Though frameworks for breaking bad news do exist, there is no evidence that these are implemented in UK services or that a dementia diagnosis is best conceptualised as a form of breaking bad news. The existing literature on clinicians’ views of diagnosis delivery has also tended to focus on service users as a homogenous group rather than a heterogeneous population with different communicative needs. No research to date has explored clinicians’ perspectives on the challenges of communicating a diagnosis when factoring, for example, young-onset dementia, dementia sub-type, whether a translator is present, or the difficulty of remote diagnosis. Shedding light on these intricacies could contribute to an evidence-based framework for communicating a diagnosis effectively and empathically, in line with person-centred care.

Section 2: Research Questions / Objectives

2.1 What is the principal research question / objective?

IRAS A10

What communication strategies do clinicians use when communicating a diagnosis of dementia?

2.2 What are the secondary research questions / objectives, if applicable?

Keep these focused and concise, with a maximum of 5 research questions

IRAS A11

How do these communication strategies vary according to culture?

How do these communication strategies vary according to dementia subtype?

How did these communication strategies vary during online delivery?

Section 3: Methodology

3.1 Give a full summary of your design and methodology

It should be clear exactly what will happen at each stage of the project

IRAS A13

Design

A qualitative design will be deployed in order to understand in greater detail the strategies used in delivering a diagnosis of dementia, as well as clinicians’ views and reflections on these strategies. The
research will aim to identify common themes across the strategies reported during interviews. It will also investigate the commonalities or differences when factoring in the differing demographic or clinical variables of services users. The researcher will use semi-structured interviews in order to gain detailed insight into how a diagnosis is delivered, strategies used, and the efficacy of these strategies.

**Ethics**

The University of Edinburgh will be approached in order to obtain ethical approval for the study, and the researcher will also request that The University of Edinburgh act as a sponsor for the research. In addition, the researcher will request Research and Development approval from participating NHS healthboards, including Lothian, Lanarkshire and Tayside. This will be done via the Integrated Research Application System (IRAS), although the study will not need Research Ethics Committee (REC) approval as it does not involve service users or carers recruited through the NHS. The project will, however, require approval from the REC based at the School of Health in Social Science (HiSS) at the University of Edinburgh. The researcher will apply for this alongside completing an IRAS application.

**Research population**

Participants will be NHS clinicians involved in the dementia diagnostic process, and recruited from NHS older adult services in Lothian, Lanarkshire and Tayside. It is thought that clinical psychologists, neurologists and psychiatrists are predominantly involved in the dementia diagnosis journey, and as such the project will recruit individuals working in these roles.

**Pilot interview**

An initial pilot interview will be conducted with Dr Tom Weavers, a clinical psychologist working in the NHS Lothian Older Adult service and the researcher’s clinical supervisor. It is hoped that this interview will serve to enhance, clarify and guide the interview schedule, as well as identify preliminary codes and themes in the dementia diagnosis process.

**Procedure**

Clinical leads in NHS Older Adult services will be contacted by the researcher in order to convey the purpose and aims of the study. It is hoped that clinicians may also pass details of the study to other colleagues. The researcher will also devise a study information leaflet, to be disseminated at team meetings, with contact details available. The leaflet will contain details of the procedure, the expected length of the interview, and the potential benefits of participating in the research. The leaflet will also detail the inclusion and exclusion criteria.

The study will aim to recruit between 10 and 12 participants from a range of professions: neurology, clinical psychology and psychiatry, as these are the professionals most routinely involved in the diagnostic journey. It is expected that clinicians will represent a range of clinical characteristics. For example, some clinicians will have considerably more experience than others and may hold differing views on breaking bad news.

Interested clinicians will be encouraged to contact the researcher via secure NHS email. The researcher will then explain the expected topics to be covered during the interview, the expected duration and location of the interview. It will also be an opportunity to privately discuss concerns or queries about the study that clinicians may not have felt able to express during the initial presentation. It is expected that the interviews will take place face to face, at the service in which the clinician is working. Interviews will be conducted online using Microsoft Teams. Microsoft Teams is used by NHS staff routinely following COVID-19, and is a secure platform. The researcher will explain the process of informed consent, and explain that a written
consent form will be provided prior to the interview. It will be explained that the participants have the right to withdraw at any point before, during or after the interview takes place.

The interview will be delivered in a semi-structured format, according to a pre-planned interview schedule, and is expected to last between 45 and 60 minutes. The interview will explore communicative strategies adopted when delivering a dementia diagnosis, as well as reflections on how these adapt or change according to different clinical presentations. The interview will also aim to understand how this delivery is adapted according to differing service user characteristics, such as age and dementia subtype, as well as during the COVID-19 pandemic, where many services operated remotely.

Interviews will take place either face-to-face, and audio-recorded, or on Microsoft Teams and video-recorded. The researcher will follow the latest COVID-19 guidance in order to determine which option is safest and most appropriate. The consent form will explain this process and capture informed consent for the recording of the interview. Prior to analysis, all transcripts will be anonymised. The data will then be stored securely, in line with local NHS policy and the University of Edinburgh’s procedures.

**Analysis**

The data will be analysed using thematic analysis (TA), and transcripts will be coded using Nvivo-11. Since the project seeks to understand the strategies used by clinicians in the delivery of diagnosis, and importantly to interpret clinicians’ perspectives on these, a qualitative approach was thought most appropriate. Other qualitative analyses were considered, including Interpretative Phenomenological Analysis (IPA). IPA aims to make detailed sense of lived experiences and inner worlds (Smith, 2009) and is frequently used to understand elusive or emotionally-laden experiences such as pain (Smith & Osborn, 2015). Although investigating clinicians’ experiences of delivering dementia care would undoubtedly yield interesting data, the research question aims to understand communicative strategies used, as well as clinicians’ reflections and insights on these. IPA, however, may be more appropriate for a research question exploring the meaning clinicians attach to their communication. Similarly, Discourse Analysis (DA) was considered for the project. DA is the analysis of social life through language and its components, including non-verbal gestures, and is a suitable method for investigating status and systems of knowledge within conversational encounters (Potter, 2012). Arguably, therefore, DA may be more suited to research projects seeking to understand power and hierarchy within interactions. Although power discrepancies between clinicians and service users do exist, and may well inform communicative strategies, reflexive TA may allow the issue of power to arise organically alongside other themes. Using DA, with its arguably more politicised lens, may have pre-emptively guided the analysis from a stance of power inequality.

TA is a widely used qualitative analytic method, although researchers have acknowledged TA historically as ‘poorly demarcated and rarely acknowledged’ (Braun & Clarke, 2006). In more recent years, however, TA has been given greater empirical attention and definition, with Braun and Clarke developing a reflexive TA method (2019). An advantage of using reflexive TA is that it is not theoretically bound, allowing the researcher to immerse themselves fully in the data and ‘develop an understanding of patterned meaning across the dataset’ (Braun & Clarke, 2019). It is hoped that finding ‘patterned meaning’, particularly within a dataset containing multi-disciplinary perspectives, will produce findings that are helpful for a range of professions and contribute to a communicative framework for clinicians. Central to reflexive TA is the art of ‘storytelling’ or compelling interpretation of the findings. Arguably, this methodology is fitting for a project that aims to discover reflections and insights on the process of diagnostic delivery, as well as infer conclusions about future guidance on communicating a dementia diagnosis.

Although TA is often used to describe or summarise experiences (Guest et al., 2020) it has also been used
in healthcare research to examine factors underpinning, for example, nurses’ values in relation to compassionate care (McSherry et al., 2016) as well views about phenomena underpinning children’s care (Hill et al., 2017). Using reflexive TA within this project will go beyond a description of communicative strategies, examining how these strategies are shaped and regarded by clinicians.

### 3.2.1 In which aspects of the research process have you actively involved, or will you involve, patients, service users and/or their carers or members of the public?

<table>
<thead>
<tr>
<th>Design of the research</th>
<th>Analysis of results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Management of the research</td>
<td>Dissemination of findings</td>
</tr>
<tr>
<td>Undertaking the research</td>
<td>None of the above</td>
</tr>
</tbody>
</table>

### 3.2.2 Give details of involvement, or if none, please justify the absence of involvement

Given the impact of COVID-19 and the increased vulnerability of the older adult population, it was felt that minimising harm was a key priority in the undertaking of this project. As such, recruiting older adults in much of the research process was thought to be a greater harm than good, given the current status and uncertainty of the pandemic. It was also questioned whether ethical approval would currently be granted to recruit older adults to the research process, given their increased vulnerability. At the time of submitting this proposal, Scotland is also increasing lockdown measures in select parts of the country as a result of the outbreak of a new variant of COVID-19. This consequences of this for the older adult population are currently unknown. Given this added uncertainty, prioritising the safety of older adults at this time was considered paramount.

Depending on the status of COVID-19 by the completion of the thesis, the researcher will aim to disseminate the findings amongst service users and carers. For example, the researcher may approach charities such as Alzheimer’s UK in order to meet with groups of service users and carers and disseminate findings. Feedback on the findings will be invaluable in their own right, but may also inform additional research projects beyond the scope of this thesis. It is acknowledged that any evidence-based communicative framework for clinicians would include thoughts, responses and reflections from service users and carers.

### 3.3 List the principal inclusion and exclusion criteria

**Inclusion**
- Clinical psychologists, neurologists or psychiatrists who is routinely involved in service users’ diagnostic journey, including diagnosis
- A minimum of one year’s experience in assessing and diagnosing dementia

**Exclusion**
- Other healthcare professionals working in dementia but not involved in the assessment and diagnostic process, such as nurses, occupational therapists and speech and language therapists
- Relevant professionals based at NHS sites but working solely or predominantly in private practice

### 3.4 How will data be collected?

Once complete to the satisfaction of both supervisors, submit via Learn with the filename: ExamNumber_DateSubmitted_R1
If quantitative, list proposed measures and justify the use of these measures. If qualitative, explain how data will be collected, giving reasonable detail (don’t just say “by interviews.”)

The researcher will devise a semi-structured interview schedule to encourage open responses. The schedule will aim to elicit detailed responses via main questions, follow-up questions (to expand on themes and concepts), as well as probes. This is consistent with guidance on structuring qualitative interviews to ensure a significant level of depth (Rubin & Rubin 2005). According to Rubin & Rubin, interview schedules usually consist of a maximum of 6 main questions, and it is common that interviewers do not ask all of these questions. The researcher will aim for open-ended ‘what, how, why’ questions and avoid leading language (Dejonckheere & Vaughn, 2019).

After explaining the purpose of the interview, explaining participants’ rights to withdraw at any time, and ‘breaking the ice’, the interview will follow the same format for each participant.

An example of an interview schedule may be:

<table>
<thead>
<tr>
<th>Main Question</th>
<th>Follow-up Questions</th>
<th>Probes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you tell me about your experience of delivering a dementia diagnosis?</td>
<td>What went well about the experience?</td>
<td>How do you know if it went well or not?</td>
</tr>
<tr>
<td>What communicative strategies did you use?</td>
<td>Why do you use these strategies?</td>
<td>How did you know to use them?</td>
</tr>
<tr>
<td>How did your communicative strategies change according to dementia subtype?</td>
<td>Was there anything you did differently with different subtypes?</td>
<td>Why were your strategies different?</td>
</tr>
<tr>
<td>How did you communicate a diagnosis remotely during COVID-19?</td>
<td>Was anything different compared to face-to-face delivery?</td>
<td>How did it compare to face-to-face delivery?</td>
</tr>
<tr>
<td>How do your strategies vary according to different cultures?</td>
<td>What strategies are effective?</td>
<td>How did you know?</td>
</tr>
</tbody>
</table>

Section 4: Sample Size

4.1 What sample size is needed for the research and how did you determine this?

For quantitative projects, outline the relevant Power calculations and the rationale for assuming given effect sizes. For qualitative projects, outline your reasoning for assuming that this sample size will be sufficient to address the study’s aims

IRAS AS9 and IRAS A60

Sample size in qualitative research is heavily debated (Hanson et al., 2019) since the standards for quantitative research may often not apply. The most frequently used criterion therefore is “saturation”: collecting data until no new information is generated (Guest et al., 2006). The concept of saturation, however, will be treated with caution, since the judgement that saturation has been reached is often based on surface-meaning observations of the data (Hennink et al., 2016). Hennink et al. argue that code-saturation is more often reached after deeper analysis of the data, with samples of between 16 and 24, while Guest (2006) argue that this is normally achieved with 12. Braun and Clarke urge scepticism of the concept of saturation, as well as any ‘magic formula’ for participant numbers in qualitative research (2019). They do recommend, however, a sample of at least 5 or 6 for very small projects that are not aiming for publication.
development of a codebook specific to the project, in order to test inter-rater reliability of codes (Roberts et al., 2019). The researcher will develop this in the initial stages of coding, and work with another independent rater to determine a Cohen’s kappa efficient. Providing a figure of inter-rater reliability for the process of generating codes may provide greater empirical support for the construction of themes.

**Trustworthiness: Credibility, Transferability, Dependability and Confirmability**

Lincoln and Guba (1985) established the idea of ‘trustworthiness’ of qualitative data by creating four categories to parallel the constructs of reliability and validity applied to quantitative research. Credibility corresponds to the “fit” between participants’ views and the researcher’s interpretation of them (Nowell et al., 2017). The researcher will aim to achieve this via regular dialogue with academic and clinical supervisors, as well as comparing notes and observations. The researcher will ensure this process is thorough and analytical, rather than tokenistic, as it is recognised that cursory discussion of data interpretations may undermine credibility. Notes will also be kept of discussions regarding the data, developments from those conversations and changes in perspective on the data.

Transferability refers to the ability to ensure that the findings may be transferred easily to other sites. Although it is not known which sites may use the findings, the researcher will ensure the write up is thorough and transparent. Including a codebook, for example, may bolster transferability. Tobin et al. (2004) argue that dependability is demonstrated through the inclusion of a decision trail: ensuring each of the steps taken is clearly justified and explained. The researcher will keep notes on this throughout the research process, and include (where relevant) details in the appendix. For example, detailed notes on how themes were constructed, altered or revised will be included.

Finally, confirmability is thought to be achieved if the preceding three constructs have been demonstrated. Outlining in detail methodological, theoretical and analytical choices, as well as how these choices were altered or influenced, will be an integral part of the write-up.

### Section 6: Project Management / Timetable

<table>
<thead>
<tr>
<th>6.1 Outline a timetable for completion of key stages of the project</th>
</tr>
</thead>
<tbody>
<tr>
<td>E.g. ethics submission, start and end of data collection, data analysis, completion of systematic review</td>
</tr>
</tbody>
</table>

Once complete to the satisfaction of both supervisors, submit via Learn with the filename: ExamNumber_DateSubmitted_R1
Section 7: Management of Risks to Project

7.1 Summarise the main potential risks to your study, the perceived likelihood of occurrence of these risks and any steps you will or have taken to reduce these risks. Outline how you will respond to identified risks if they should occur.

<table>
<thead>
<tr>
<th>Potential Risk</th>
<th>Likelihood of Risk</th>
<th>Steps to reduce risk / response if risk occurs</th>
</tr>
</thead>
<tbody>
<tr>
<td>The most immediate risk to the project is the impact of COVID-19 upon participants' ability to take part. Participants may become affected by COVID-19 in a number of ways. For example, they may become unwell with the virus prior to the interview, or they may be unable to participate due</td>
<td>Medium</td>
<td>In order to mitigate the impact of this, there will be the option to conduct the interviews remotely on Microsoft Teams, to ensure that participants are able to attend in a way that is flexible and without risk of transmitting the virus. The researcher will also take steps to ensure that clinicians feel well enough, physically and psychologically, to participate before the</td>
</tr>
</tbody>
</table>
Once complete to the satisfaction of both supervisors, submit via Learn with the filename: ExamNumber_DateSubmitted_R1
| Professionals may feel discouraged from participating due to uncertainty about anonymity, freedom of expression or threat to reputation. | Low | Advertisements for the project will make it clear that all data will be anonymised during the process of transcription, and no identifiable information will be available in the write up and dissemination of the project. Participants will also be assured of this during the initial stages of interest, and the researcher will be clear that they may withdraw from the research at any time. |

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Section 8: Knowledge Exchange

8.1 How do you intend to report and disseminate the results of the study?

*IRAS A51*

This study will be reported in the form of a thesis for the Doctorate of Clinical Psychology at the University of Edinburgh. The thesis will be available to the general public via the Edinburgh Research Archives. In addition, it is expected that the results of the study will be submitted to a reputable, peer-reviewed journal that is relevant to the field of dementia care.

The findings will also be disseminated at departmental meetings with the participating older adult services, and the researcher will actively invite feedback, comments and reflections on the project. These meetings may also provide an opportunity to think about future projects and directions for the findings.

The researcher will aim to disseminate the findings with groups of service users and carers when it is safe to do so. This may be, for example, by approaching third-sector charities supporting service users and carers and discussing appropriate events to share the findings at. It may also be that there are opportunities within the NHS, for example on the researcher’s clinical placement, at service user meetings or events.

The Faculty for the Psychology of Older People, who are a division of the BPS, will also be approached. Their annual conference, which promotes advances and findings in the psychological care of older adults, may also be an appropriate place to share the findings of the project.

8.2 What are the anticipated benefits or implications of the project?

*E.g. if this is an NHS project, in what way(s) is the project intended to benefit the NHS?*

Research has demonstrated that the assessment and diagnostic process in dementia can lead to poorer outcomes for service users and carers, as well as concerns for clinicians regarding therapeutic alliance. While the BPS promotes assessment and diagnosis as a key, complex intervention, there is no specific guidance on how to deliver this, nor is there any specific communicative framework designed to support clinicians. This study will offer a multidisciplinary perspective on communicating a diagnosis of dementia, which is hoped will inform more specific guidance for professionals working in this field, and potentially...
BPS guidelines for clinical psychologists.

Whilst developing evidence-based communication strategies within dementia diagnosis may support key clinicians in their practice and confidence, it may also build a greater therapeutic alliance with service users and carers. This may secure greater service user and carer engagement beyond the diagnostic process, facilitating engagement for post-diagnostic support and intervention.

**8.3 Are the any potential costs for the project?**
Outline any potential financial costs to the project, including the justification for the costs (why are these necessary for the research project?) and how funding will be obtained for these costs (how will they be met?) Please separate these into potential costs for the University and potential costs for your NHS Board and note that you should ask your NHS Board to meet stationery, printing, postage and travel costs.

Given that most interviews are expected to be conducted remotely, the costs of the project are predicted to be low. There will be a small cost in order to cover the printing of participant information sheets, consent forms and posters to advertise the project. There may be small costs if face-to-face interviews are preferred at participating NHS sites, for example to cover researcher travel expenses.

**Section 9: Any Other Relevant Information**
The researcher and supervisors acknowledge that including service users and carers throughout the proposal has been restricted. This is ultimately due to the uncertainty of COVID-19 and how it may affect this population, including their ability to participate safely. However, it is acknowledged that although the research aims to inform an evidence-based framework for clinicians, this framework would be incomplete without the views of service users and carers. It is hoped that the findings from this thesis may inform later projects that involve service users and carers, and that their views are not only heard but actively shape future guidelines.

**Section 10: Key References**


Blair, M., Marczinski, C. A., Davis-Farquhar, N., & Kertesz, A. (2007, Mar). A longitudinal study of language...
Appendix G. Excerpt from Thematic Synthesis Coding

<table>
<thead>
<tr>
<th>Excerpt from Sagbakken et al. (2018)</th>
<th>Initial coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>One of the main findings was that although the participants worked in areas with a high density of immigrants, many had limited experience with older immigrants with cognitive impairment or dementia and experienced difficulties related to the need to involve family and/or an interpreter. The participants described consultations in which they lacked confidence in terms of how to communicate suspected cognitive impairment, and some GPs mentioned that they missed concrete signs, such as family members expressing concern regarding their relatives’ driving skills. Discussing driving-licence status was a common and concrete strategy for addressing symptoms of cognitive impairment among older persons with an ethnic Norwegian background, while older immigrants often do not possess a driver’s licence. Limited experience combined with language barriers seemed to create a feeling of insecurity and hesitation in managing this group of patients, and most of the participants, including the hospital-based specialists, emphasized the need for increased competence in responding to the needs of immigrant patients with dementia.</td>
<td>Lack of direct contact with migrants</td>
</tr>
<tr>
<td></td>
<td>Uncertainty in navigating dynamics</td>
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<tr>
<td></td>
<td>Lacking confidence in communication</td>
</tr>
<tr>
<td></td>
<td>Confidence impacting accuracy</td>
</tr>
<tr>
<td></td>
<td>Using concrete signs to facilitate communication</td>
</tr>
<tr>
<td></td>
<td>Concrete strategies not culturally relevant</td>
</tr>
<tr>
<td></td>
<td>Lack of direct contact with migrants</td>
</tr>
<tr>
<td></td>
<td>Language barrier impacting confidence</td>
</tr>
<tr>
<td></td>
<td>Clinicians requesting training</td>
</tr>
<tr>
<td></td>
<td>Focus on concrete signs</td>
</tr>
<tr>
<td></td>
<td>Lack of direct contact with migrants</td>
</tr>
<tr>
<td></td>
<td>Language barriers related to confidence</td>
</tr>
<tr>
<td></td>
<td>Direct requests for cultural competence</td>
</tr>
</tbody>
</table>
PARTICIPANT INFORMATION SHEET

Delivering a diagnosis of dementia in secondary care: a multi-disciplinary perspective

You are being invited to take part in research on dementia in secondary care. Sharon Hurley, Trainee Consultant Psychotherapist at the University of Edinburgh, is leading this research. Before you decide whether to take part it is important you understand why the research is being conducted and what it will involve. Please take the time to read the following information carefully.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of the study is to understand the ways in which a diagnosis of dementia is delivered in secondary care in Scotland. The aim is to understand the ways in which this approach is effective and the ways that may be improved upon. Gathering perspectives from clinicians working in different disciplines, including consultants, neurologists, and psychiatrists, may contribute to comprehensive guidelines to support multi-disciplinary teams in future.

WHY HAVE I BEEN INVITED TO TAKE PART?

You are invited to participate in this study because you are a clinician (a consultant psychotherapist, neurologist, or psychiatrist) involved in delivering a diagnosis of dementia to patients in secondary care in either NHS Lothian, NHS Lanarkshire or NHS Fife. You have been working in secondary care for at least one year.

DO I HAVE TO TAKE PART?

No – it is entirely up to you. If you do decide to take part, you are free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect your employment.

Please note that your data can only be withdrawn before data analysis is completed, which will be around December 2022.

WHAT WILL HAPPEN IF I DECIDE TO TAKE PART?

If you do decide to take part, please keep this Information Sheet. You will be asked to complete an Informed Consent Form at the start of the interview to show that you understand your rights in relation to the research, and that you are happy to participate. As informed consent will be taken on a Microsoft Teams and signed electronically, you will be emailed your completed form to serve as a copy of your informed consent. Consent will be reconfirmed verbally at the start of the interview.
Delivering a diagnosis of dementia in secondary care v3.0 17/03/2023

You will be invited to an online interview with the researcher where you will be asked a number of questions regarding the techniques and methods you use to deliver a diagnosis of dementia. The interview will take place in a safe environment on Microsoft Teams at a time convenient to you, and you may partake from home or from an NHS site. Ideally, we would like to video record your responses (and we require your consent for this), so the location should be a fairly quiet area. You may also choose to participate with an audio-record only. The interview should take around 45 minutes to complete.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

There are no direct benefits, but by sharing your experiences with us, you will be helping Sobhan Hurley and the University to better understand the most effective methods and strategies to deliver a diagnosis of dementia.

ARE THERE ANY RISKS OR DISADVANTAGES ASSOCIATED WITH TAKING PART?

There are no significant risks associated with participation. However, you will be informed prior to the interview that any disclosure of issues relating to risk or confidentiality will be taken further. Should you believe this to be an unreasonable condition of participation, you may decide not to take part in the interview.

You may feel some distress or discomfort regarding difficult experiences of communicating a dementia diagnosis. A further debrief will be given at the end of the interview, as well as information regarding services to support you if you feel you need.

WILL MY TAKING PART BE KEPT CONFIDENTIAL?

The information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage.

HOW WILL WE USE INFORMATION ABOUT YOU?

We will need to use information from your recorded interview on Microsoft Teams for this research project.
- Ths
- In t a s
- Name
- Ema address
- Age
- Occupat on

We will keep all information about you safe and secure.
People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

If you consent to be aud or video recorded, a record will be destroyed once they have been transcribed. Your data will only be viewed by the researcher/research team.

All electronic data will be stored on a password-protected computer file on an NHS laptop. Your consent information will be kept separate from your responses in order to maintain your privacy.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- At [https://www.ed.ac.uk/records-management/privacy-notice-research](https://www.ed.ac.uk/records-management/privacy-notice-research)
- by asking one of the research team
- by sending an email to the University of Edinburgh Data Protection Officer at dpo@ed.ac.uk

The University of Edinburgh is the sponsor for this study based in Scotland. We will be using information from you in order to undertake this study and will act as the data controller for this study. NHS Lothian will act as a data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Edinburgh and NHS Lothian will keep data about you for up to 6 months after the study has finished and your anonymised data for a minimum of 4 years. Your anonymised data may be used in future ethical research.

**WHAT WILL HAPPEN WITH THE RESULTS OF THIS STUDY?**
The results of this study may be summarised in published articles, reports and presentations. You will not be identifiable from any published results. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name. A summary of the findings from the study will be made available to participants. This summary will be sent to participants by email.

WHO IS ORGANISING AND FUNDING THE RESEARCH?

This study has been organised by Sobhan Hur (Trainee Clinical Psychologist) under the School of Health and Social Science, and as part of the Doctorate in Clinical Psychology training programme.

WHO HAS REVIEWED THE STUDY?

The study proposal has been reviewed by the School of Health and Social Science Ethics Committee at the University of Edinburgh. NHS management approval has also been obtained.

WHO CAN I CONTACT?

If you have any further questions about the study, please contact the lead researcher, Sobhan Hur.

If you would like to discuss the study with someone independent of the study please contact

If you wish to make a complaint about the study, please contact the Human Tissues and Social Sciences Research Governance Team at the University of Edinburgh (cahss.res.eth.cs@ed.ac.uk).

You may also contact Dr Sue Turnbull ( ), Academic Supervisor, or Dr Tom Weavers, Clinical Supervisor ( ) for further information about the study.
Delivering a Diagnosis of Dementia in Secondary Care: A Multi-Disciplinary Perspective

Interview Schedule

Introduction
Thank you for agreeing to take part in this research. We are interested in gathering opinions and perspectives on delivering a diagnosis of dementia.

We expect the interview to last between 45 and 60 minutes, but we can stop to take a break at any point, and you can finish the interview at any time without giving an explanation.

[If participant has consented to be recorded, switch on the recorder]
May I double-check that you are happy for this interview to be recorded?

[Continue recording, if participant has confirmed their consent.]

<table>
<thead>
<tr>
<th>Main Question</th>
<th>Follow-up Questions</th>
<th>Probes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you tell me about your experience of delivering a dementia diagnosis?</td>
<td>What went well about the experience? What didn’t go well?</td>
<td>How do you know if it went well or not?</td>
</tr>
<tr>
<td>How do you communicate a diagnosis of dementia?</td>
<td>What language and phrases do you use?</td>
<td>How did you know to use them?</td>
</tr>
<tr>
<td>How did your communication change according to dementia subtype?</td>
<td>Was there anything you did differently with different subtypes?</td>
<td>Why were your strategies different?</td>
</tr>
<tr>
<td>How did you communicate a diagnosis remotely during COVID-19?</td>
<td>Did you experience any challenges in communicating a virtual diagnosis?</td>
<td>How did it compare to face-to-face delivery?</td>
</tr>
<tr>
<td>How have you communicated a dementia diagnosis to people with a migration background?</td>
<td>Have you used an interpreter? How did you experience that?</td>
<td>What helped or aided using an interpreter?</td>
</tr>
</tbody>
</table>

Closing question
Is there anything else you would like to discuss that has not already been covered?
Appendix J. Participant Consent Form

Delivering a diagnosis of dementia in secondary care v2.0 27/06/2022

Delivering a Diagnosis of Dementia in Secondary Care: A Multi-Disciplinary Perspective

PARTICIPANT CONSENT FORM (on ne research)

Study Title: Delivering a diagnosis of dementia in secondary care

Researchers' name and contact details:
Sobhan Huray (Tra nce C n ca Psycho og st)

Participant ID:

1. I confirm that I have read and understood the Participant Information on Sheet (vers on 2.0 dated 27/06/2022) for the above study.

2. I have been given the opportunity to consider the information provided, ask questions and have had these questions answered to my satisfaction.

3. I understand that my participation is voluntary and that I can withdraw from the study at any time without giving a reason and without my employer or any other party being affected.

4. I understand that my data will be stored for a minimum of 4 years and may be used in future ethically approved research.

5. I agree to my interactions being recorded on Microsoft Teams.

6. I understand that relevant sections of my data collected during the study may be used at by the Sponsor (University of Edinburgh), where the sponsor is the developer of the research. I gave permission for these data to have access to my

7. By ticking this box I agree to take part in the above study.

Participant Signature: ___________________________ Date: ___________________________

Researcher Signature: ___________________________ Date: ___________________________

Original (x1) to be retained in site file. Copy (x1) to be sent to participant.
Appendix K. Excerpt from Reflective Journal for Thematic Synthesis

Thematic Synthesis Reflections

Assessment of thematic synthesis and analysis on cultural diversity and access. Lack of data availability and access for certain cultural groups. Reliance on non-verbal cues and body language in communication. Attempting to deconstruction and understanding different cultural perspectives.

Experiences and data relating to barriers and facilitators of cultural diversity. Lack of access? How can I access this data? What is the impact of cultural beliefs on access? Are there cultural beliefs that hinder access? Hard to know how to take these claims.
Appendix L. Excerpt from Reflective Journal for Reflexive Thematic Analysis

Reflective Journal 16th November 22

Journal entry for post

Hearing patient talk about how diagnosis is communicated generated a significant enthusiasm about the positive but also the negative. Diagnostic practice seemed to be as much about what you don't do as much as what you do. There was a sense that hospital was used to soothe and an implication that some actions might be better than others at this. It made us question the kind of natural aptitude some clinicians may have for this process versus what you can teach or learn from a model. The description of 'braking behaviour' being particularly striking. The idea of something life-changing presented so bluntly or neutrally implied that the diagnosis must be infused with genuine support. I started to regard diagnostic practice as something instinctive or inherent to personality - who you are outside the room, and how you care, mentally influence the way you convey something or diagnosis.