Design and trial of a patient-reported experience measure for people living with moderate to advanced dementia

Hannah Sugarman

June 2016

Submitted in partial fulfilment of the requirements for the degree of Doctor in Clinical Psychology (DClinPsy), Royal Holloway, University of London

Abstract

Dementia is a progressive neurodegenerative condition resulting in global cognitive and functional impairments. People living with dementia have complex care needs and are at high risk of adverse outcomes, yet they tend to be excluded from providing feedback about their experiences of care due to dementia-related impairments which preclude them from using the feedback tools available. This is particularly true for people in the moderate-advanced stages of dementia. This study aimed to develop and trial a patient-reported experience measure (PREM) for people living with moderate-advanced dementia. A draft PREM was refined through focus groups and cognitive interviews. Healthcare professionals in an older peoples' community team then trialled the draft PREM with sixteen people living with moderate-advanced dementia. Seven professionals were then interviewed to explore their experiences of using the PREM, and the results were analysed using Thematic Analysis (Braun & Clarke, 2006). Four major themes were identified: 'The right tool for the job', 'Communicating with the person', 'How dementia can get in the way' and 'What worked well?'. The findings suggested that times when the PREM was successfully used to elicit feedback were characterised by flexible, person-centred approaches. There were several challenges in using the PREM, including symptoms affecting engagement and practical obstacles posing a challenge to the implementation of tools in services. The results indicated that a stepped approach to the collection of feedback is preferable to support everyone in the client group to participate. Implications for how feedback processes could be further developed through clinical practice and future research are discussed.

Acknowledgements

Firstly, I'd like to thank my supervisors: Guy Harman, for sharing your expertise in the area, and for your unwavering support and enthusiasm. Seeing the passion you have for improving the experiences of people living with dementia made it impossible not to stay motivated, and reminded me why projects like this are so important. Kate Theodore, for your kind and thoughtful comments and guidance throughout the process, and for helping me to remain calm and focused in the face of setbacks. I'd also like to thank Tresa Andrews for taking the time to share her ideas, work, and PREM which provided the foundations and starting point for my thesis project, and Michael Evangeli for an invaluable year of supervision that helped the project to evolve into its current form.

Thanks to my amazing fellow trainees, without whom this process would have been a lot harder, and not nearly as enjoyable. I'm glad we were able to rescue each other from the depths of despair when reading/coding/formatting threatened to overwhelm us. I look forward to many more enjoyable times with you all in the future, which hopefully will take place far from the library!

Thanks to my family for all your help along the way, including providing some vital proofreading expertise in the final stages. And to Sam, who always managed to put a smile on my face no matter what the project threw at me. I'll have to iron a lot of shirts to repay you for the support you've given me throughout this process (I hope you don't mind creases!).

Finally, I'd like to thank the service-users, carers and professionals who gave their time to share their views and experiences that made this project possible. I hope I can go some way towards acknowledging your contribution by making sure that the results influence changes that help people to live better lives with dementia.

List of tables

List of figures

Table of Contents

1.   Introduction

1.1.   Overview

The project aimed to design and conduct a small-scale trial of a patient-reported experience measure for people living with moderate to advanced dementia. This chapter provides the empirical and theoretical context for the research. Dementia, its associated symptoms and typical care needs will be briefly described, followed by an exploration of some of the challenges in the provision of care for this client group. The recommendations regarding good practice in dementia care will be outlined and methods of collecting feedback about experiences of care in the NHS will be presented. Finally, the chapter will discuss how people living with moderate-advanced dementia can be excluded from providing their subjective feedback about care using existing feedback tools, and why the beliefs that have led to this exclusion are proven to be erroneous. Finally, the rationale for the project and the research aims are outlined.

Although there is a great deal of research pertaining to the earlier stages of dementia, the introduction will focus on the moderate-advanced stages of the condition as this is the population of interest in the current project.

1.2.   Dementia

'Dementia' is an umbrella term encompassing a number of different diseases with varying symptoms and neuropathology (van der Flier & Scheltens, 2005),

all of which involve progressive neurological deterioration. Alzheimer's

disease (AD) is the most prevalent form of dementia, accounting for 62% of all

dementia diagnoses (Prince et al., 2014). The second most common disease

is vascular dementia (VaD), which accounts for 17% of all dementia

diagnoses (Prince et al., 2014). Other dementia subtypes include dementia

with Lewy Bodies, frontotemporal dementia and dementia associated with

other neurological conditions, such as Parkinson's Disease (Prince et al.,

2014). Although there is a small subset of people with early-onset dementia

(diagnosis before the age of 65), dementia tends to be diagnosed in later life,

with age as the most significant risk factor for developing the condition (van

der Flier & Scheltens, 2005). Although medication can slow the progression of

cognitive deterioration in AD (The National Institute for Health and Care

Excellence [NICE], 2011), there is currently no known cure for dementia.

Treatment therefore focuses on reducing modifiable risk factors (McVeigh &

Passmore, 2006) and providing care to manage the symptoms associated

with the condition.

The prevalence of dementia in the UK is estimated at 7.1% of the total age-

standardised population in people over 65 years of age (Prince et al., 2014).

Prevalence increases with age, and is estimated at 18.3% for people aged 85-

89 (Prince et al., 2014). There has been an 80% increase in the number of

people aged 65 and over in the UK since 1951, with a projected further 64%

increase in this age group between 2010 and 2035 (Rutherford, 2012). As a

consequence of the ageing population, the number of people living with dementia is expected to double by 2040 (Parkin & Baker, 2015).

1.2.1. Symptoms and impact of dementia

Dementia results in the progressive deterioration of cognitive abilities including memory, language, executive functioning and visual processing (Andersen, Wittrup-Jensen, Lolk, Andersen, & Kragh-Sørensen, 2004; Dubois et al., 2007). Cognitive profiles vary across different types of dementia, and presentations vary widely across different individuals (Cohen-Mansfield, 2000). The impact of dementia is multidimensional, affecting all traditional domains of quality of life (QOL; Albert & Logsdon, 2000). Difficulties with functional abilities eventually results in a need for assistance with nearly all activities of daily living (ADLs; Dubois et al., 2007). High levels of dependency and disability can lead people to feel disconnected from the social world (Phinney, 2008) and people may experience a number of negative emotional responses to the condition, including feelings of intense anger (Phinney, 2008), depression or anxiety (Clare, 2007; Edvardsson, Winblad, & Sandman, 2008; Enache, Winblad, & Aarsland, 2011).

As dementia progresses and the cognitive abilities required to process and express emotions are compromised, people may resort to more nonverbal, behavioural mechanisms of communicating their distress. Anger may be expressed as aggressive outbursts during care, and boredom may be

expressed as agitation (Albert & Logsdon, 2000). These symptoms are said to place a significant burden on caregivers, and are typically experienced as the most stressful aspect of caring for a person with dementia (Zarit & Zarit, 2008). The Clinical Dementia Rating Scale (CDR) is an instrument designed to assess the clinical stage of dementia, based on caregiver reports (Hughes, Berg, Danziger, Coben, & Martin, 1982). Different stages are determined by the level of disability across a number of different domains. The stages of 'mild', 'moderate' and 'severe' dementia are described in table 1.

Table 1

The markers of mild, moderate and severe dementia

	Mild dementia	Moderate dementia	Severe dementia
Memory	Moderate memory loss, more marked for recent events; defect interferes with everyday activities	Severe memory loss; only highly learned material retained; new material rapidly lost	Severe memory loss; only fragments remain
Orientation	Some difficulty with time relationships; oriented for place and person at examination but may have geographic disorientation	Usually disoriented in time, often to place	Orientation to person only
Judgement and problem-solving	Moderate difficulty in handling complex problems; social judgement usually maintained	Severely impaired in handling problems, differences; social judgement usually impaired	Unable to make judgements or solve problems
Community affairs	Unable to function independently at these activities though may still be engaged in some; may still appear normal to casual inspection	No pretence of independent function outside home	
Home and hobbies	Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned	Only simple chores preserved; very restricted interests, poorly sustained	No significant function in home outside of own room
Personal care	Needs occasional prompting	Requires assistance in dressing, hygiene, keeping of personal effects	Requires much help with personal care, often incontinent

Note. From the Clinical Dementia Rating Scale by Hughes et al. (1982).

1.3. **Providing Care for People Living with Dementia**

1.3.1. Care needs of people living with dementia

Care needs vary over the course of the condition. The interplay of cognitive,

functional and behavioural impairments in dementia necessitates regular re-

assessment to determine the appropriate support (Struble, Kavanagh, &

Blazek, 2013). The complexity of peoples' needs often warrants the

involvement of a number of different professionals from health and social care

services. Once dementia has progressed to the 'moderate' stage, the person

tends to require increasing levels of emotional support and assistance with

ADLs. Family caregivers may be under a lot of stress, and evidence suggests

that they are at risk of physical exhaustion, emotional burnout, financial

hardship and social isolation (Charlesworth, 2008). Although the majority of

people live at home, many move to institutional care settings when their

needs cannot be met in the community (Charlesworth, 2008).

Admission to hospital for acute episodes of physical illness may be more likely

in the advanced stages of dementia as falls or infections become more

difficult to avoid (de Vries, 2003). Risk planning becomes increasingly

important, with reduced capacity and increased confusion placing people at

risk of abuse and neglect. As cognitive impairments become more

pronounced, peoples' capacity to make decisions can be affected. They may

disagree with the need for certain treatments or procedures and find it

challenging to engage with the recommended interventions, placing them at

risk of adverse outcomes (Carpenter, 2004). Health professionals and

caregivers are tasked with conducting ongoing risk assessments and referring

to advanced directives to make decisions in the best interest of a person with

dementia, if they are deemed to no longer have capacity to make important

decisions independently (Department of Health [DoH], 2010b). In the final

stages of dementia, decisions must be made with family members and health

professionals about end-of-life care.

1.3.2. Obstacles in the provision of dementia care

The impairments associated with dementia may pose an obstacle to the

successful provision of good quality care. Sekerak and Stewart (2014)

suggest that a unique skillset is required to manage the behavioural

symptoms of dementia alongside physical complications, and unfamiliarity

with the concurrent management of such symptoms can present an obstacle

to the provision of care. Most people will have a communication disorder as a

consequence of their dementia (Weirather, 2010) which can make it difficult

for caregivers to identify the source of unmet needs (Vasse, Vernooij-Dassen,

Spijker, Rikkert, & Koopmans, 2010). Caregivers may avoid communicating

with people living with dementia altogether due to previous failed attempts

leading to feelings of hopelessness (Tappen, Williams-Burgess, Edelstein,

Touhy, & Fishman, 1997).

Nelson et al. (2002) interviewed 1085 people over 65 living in an inner London

borough to assess the patterns and predictors of service usage in this group.

The responses indicated that people living with dementia used health services

less than their counterparts without dementia, despite frequently experiencing comorbid illnesses. The authors suggested that this could be due to their inability to voice their needs. Although these findings may not necessarily be generalisable to people in other areas of the UK, they are indicative of potential barriers in access to dementia services.

It has been suggested that societal views of dementia may have influenced commissioning of services. Banerjee (2010) suggested that misconceptions about dementia, such as the idea that it is a normal part of ageing, had resulted in dementia care being neglected by health policy makers and commissioners. Bond et al. (2005) conducted a survey across Europe to find out about key stakeholders' views on dementia care. They found that a majority of the respondents perceived their governments as indifferent to the challenges associated with dementia for service-users and carers. They acknowledged that the sample size (2500) was relatively small and potentially not representative of wider views, yet the responses indicate a concerning discourse about the level of priority given to dementia as a public health issue, considering the significant impact it has at both an individual and societal level.

Kitwood and Bredin (1992) suggested that the emphasis on neuropathology in dementia has led to a disproportionate focus on the technical consequences of the condition which minimises the personal consequences. Although people living with dementia may have complex physical care needs, an

excessive focus on these can lead to the neglect of peoples' emotional needs (Moyle, 2010). Carers may presume that service-users have little awareness of their social environment, despite evidence that people with dementia retain awareness of their situation even into the later stages of the condition (Clare, Rowlands, Bruce, Surr, & Downs, 2008a). If this is the case, addressing shortfalls in care provision may not be seen as a priority. There is evidence to suggest that level of impairment alone does not predict levels of awareness in early dementia (Clare, 2010a), and in a review of people in the moderate-advanced stages of dementia, Clare (2010b) found that if care environments are depriving or lack stimulation, service-users are less likely to express their awareness. This perpetuates a cycle of carers believing that people require less interaction and interacting with them less (Clare, 2010b).

Kitwood (1997) pioneered a movement towards a new perspective on dementia care. He suggested that a 'malignant social psychology' can arise in care settings due to a narrow understanding of dementia symptoms in terms of organic pathology. This means the 'personhood' ("the attributes possessed by human beings that make them a person"; Dewing, 2008, p. 3) of the service-user is not prioritised. Kitwood's theory proposes that observable impairments are a consequence of a dialectical interplay between dementia-related neuropathology and the social environment (Kitwood, 1997). Rather than symptoms manifesting only as a direct consequence of neuropathology, Kitwood proposed that the way people are treated can diminish their personhood, which results in their dementia symptoms becoming more salient

to those around them (Dewing, 2008). This process can lead to a culture of care which, without malicious intent, engenders interactions that infantilise, ignore or stigmatise the person with dementia (Kitwood, 1997).

An example of how the processes described by Kitwood could arise is as follows: Memory impairments could cause someone to forget a recent interaction, leading people around them to believe that they no longer wish to or are able to communicate (Astell & Ellis, 2006). This event may discourage further attempts at communication and increase the likelihood that the person will be viewed primarily in terms of their disabilities (Henwood & Ellis, 2015). Kitwood suggested that viewing people in this way leads to 'excess disability', defined as disability beyond that which would be predicted by the extent of neuropathology (Sabat, 2001). There has been criticism of the suggestion that altering the culture of care could influence the irreversible decline associated with dementia, a notion which has been consistently disproved in research findings (Dewing, 2008). However, Kitwood's theories have undoubtedly encouraged a perspective that dementia is an experience to be lived meaningfully (Hubbard, Cook, Tester, & Downs, 2002).

In summary, people living with dementia are a heterogeneous client group with a high level of service usage. Attempts to address complex care needs are further complicated by social and cultural influences. The predominant theoretical framework pertaining to the culture of dementia care indicates that

if caregivers attend only to impairments, this can lead to diminishment of the personhood of people living with dementia which may have an impact on the manifestation of their symptoms (Kitwood, 1997). The numbers of people living with dementia in the UK will continue to rise as a result of the ageing population, and health and social care agencies are tasked with ensuring that good standards of care are maintained.

1.4. Good Practice Guidance and Current Standards of Care

1.4.1. Recommendations about provision of good quality care

The principles of good practice in dementia care have been significantly influenced by the social-psychological theories of Kitwood and colleagues. Kitwood and Bredin (1992) proposed a number of essential factors for people to maintain a relative level of wellbeing, from which the concept of 'person-centred care' (PCC) arose. PCC is defined as care which offers and respects choices, focusing on what the person can do rather than what has been lost as a consequence of dementia (Edvardsson, Winblad, & Sandman, 2008). PCC is increasingly considered to represent good quality care in dementia (Chenoweth et al., 2009; Edvardsson, Fetherstonhaugh, & Nay, 2010) although through a review of research regarding PCC for people living with advanced dementia, Edvardsson, Winblad, and Sandman (2008) concluded that there were few existing studies of PCC in advanced dementia that were conducted with empirical rigour. This could be attributed to the challenges of establishing robust measurement systems to determine whether or not there have been clinically significant changes. The authors highlighted a need for

more tools to be developed to measure PCC for people in the later stages of dementia.

The existing guidance draws on a broad range of sources to guide good practice in dementia care. It states that the principles of PCC should be adhered to across all services. (NICE, 2010). This should take into account the person's values, their individuality, personality and life experiences. It should acknowledge the perspective of the person living with dementia and their carer, as well as focusing on relationships and their potential to promote wellbeing (NICE, 2006). The overarching recommendation, taking into account the diverse needs of the client group, is for professionals to work together to deliver integrated care in order to provide consistency and minimise the number of professionals service-users encounter (National Collaborating Centre for Mental Health [UK], 2007).

1.4.2. Care inequalities for people living with dementia

Evidence from the literature suggests that there may be discrepancies in standards of care for people living with dementia compared to their cognitively intact equivalents. A number of UK and non-UK studies have found differences between care provided to people with and without dementia. US-based studies have found that nursing home residents who died with advanced dementia were not provided with optimal palliative care (Mitchell, Kiely, & Hamel, 2004), people living with dementia were offered half the level of pain medication compared to cognitively intact counterparts with the same

medical conditions (Ahronheim, Morrison, Baskin, Morris, & Meier, 1996), and

six month mortality rates were increased fourfold in people living with

advanced dementia, compared with their cognitively intact counterparts, with

survival rates comparable to those seen in serious physical illnesses such as

metastatic cancer or advanced liver disease (Morrison & Siu, 2000). In a

Swedish study, Ekman, Norberg, Viitanen, and Winblad (1991) found that less

time was used to help patients with dementia compared to patients without

dementia in a geriatric clinic, and nursing staff tended to avoid all but task-

oriented communication with individuals with advanced dementia. This finding

was attributed to nurses perceiving people with advanced dementia as unable

to communicate.

Research in the UK has indicated a similar trend. A Royal Commission report

by the House of Commons reported that people with dementia receive sub-

optimal palliative care. It was speculated that this is due to the uncertainty in

prognosis in the cases of many people living with dementia (House of

Commons Health Committee, 2004). Sampson, Blanchard, Jones, Tookman,

and King (2009) found that three times as many people with dementia and

five times as many people with severe cognitive impairment (indicated by their

score on a cognitive screening test) died during their index admission

compared to people without dementia. Additionally, only half of the people in

the dementia group had a diagnosis of dementia at the time of admission.

Although a screening test may not be the most reliable method of determining

whether impairments are sufficient for a diagnosis of dementia, the results

indicated that there may have been people with severe cognitive impairments who had not received a dementia diagnosis and therefore may not have had access to the services that could meet their individual needs.

Sampson, Gould, Lee, and Blanchard (2006) examined the case notes of 122 people with and without dementia who had died on acute medical wards over a one-year period. They found that people with dementia had received significantly fewer palliative interventions than people without dementia. For both patients with and without dementia, there was little consideration of spiritual needs when planning end-of-life care. For people living with dementia, information about religious preferences was rarely recorded. There may be a bias in making inferences about quality of care from the information that was recorded in case notes, as it may be that spiritual and religious needs were merely not prioritized in the recording of information. However, it is also possible that service-users' preferences had not been attended to, which is particularly concerning given the importance of spiritual and religious needs for some individuals at the end-of-life. This raises concerns that services may not be adhering to recommendations about offering and respecting the choices of service-users.

There is also evidence to suggest that the quality of residential dementia care may be compromised. Ballard et al. (2001) assessed the quality of care in 17 residential care facilities in the UK using an observational tool. They

concluded that care was rated as needing radical improvement in every

facility, noting that people living with dementia spent only 14% of their time

communicating with staff or other residents. Although this research indicated

concerns about the standards of care from the perspective of observers, it did

not capture the subjective experiences of service-users. Clare et al. (2008a)

sought to do this by interviewing 81 people living with moderate to severe

dementia. Their reports indicated that conversations with staff were mainly

brief, task-focused or superficial, and there were limited opportunities for

residents to engage in appropriate activities. Hancock, Woods, Challis, and

Orrell (2006) examined the level of unmet needs for 238 people living with

dementia in care homes in the UK. They found that although physical and

environmental needs were usually met, a number of other areas of need were

unmet, including sensory, mental health and social needs. Overall, these

findings suggest that dementia care may not be meeting the needs of service-

users or adhering to recommendations about PCC.

The National Dementia Strategy (Department of Health, 2009) was

implemented to address inequalities in care by encouraging early diagnosis,

improving the quality of care in hospitals and care homes and reducing the

use of antipsychotic medication to manage behavioural symptoms

(Department of Health, 2010b). Despite the implementation of this strategy, a

2013 report reviewing the quality of care across England discussed significant

disparities in standards of care (DoH, 2013). This report used indicators such

as diagnosis rates and post-diagnostic support as reflections of quality, with

limited exploration of the quality of care from the perspective of the service-user. A 2014 report by the Care Quality Commission also highlighted the variable standards of care in services, suggesting that "a person living with dementia is likely to experience poor care at some point along their care pathway" (Care Quality Commission, 2014, p. 44).

Another complicating factor for initiatives to improve dementia care lies in the relative shortage of available information about the quality of services, compared to nationally available data for other client groups. The available data regarding the quality of dementia care are said to be limited and variable in quality (DoH, 2010a). A 2014 report reviewing progress in dementia care following the National Dementia Strategy stated that "there is currently no mechanism available to check that services are helping people with dementia to live well" (All-Party Parliamentary Group on Dementia, 2014, p. 9).

In summary, despite the existence of guidance about care quality that is grounded in theory and empirical evidence, care for people living with dementia may not be meeting the recommended standards. It is known that poor quality care can be extremely damaging, yet there is a dearth of accepted mechanisms to evaluate care quality, particularly from the perspective of people who use dementia services. This means that there are limited means for ensuring that services are accountable for delivering good quality care.

1.5. Clinical Governance and Methods of Measuring Quality in the NHS

The concept of clinical governance is defined as "a system through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care can flourish" (Scally & Donaldson, 1998, p. 62). Implementing frameworks for clinical governance ensures that services strive for continual improvement (Department of Health, 1997; Scally & Donaldson, 1998). As a consequence of investigations into serious failings by services (DoH, 2014), changes were made in how services measure outcomes and define quality. Whelan, Andrews, Patel, and Lewis (2010) summarise the transition in clinical governance processes. They detail how targets were set for mental health trusts to encourage them to record information, such as information about diagnoses and care planning meetings. However, these targets had no direct link to quality of care. Next, targets were focused on clinical outcomes, and routine clinical outcome measures (RCOMs) such as the Health of the National Outcome Score (HoNOS; Wing et al., 1998) were used by clinicians to record outcomes (Whelan et al., 2010).

Although the introduction of RCOMs encouraged the collection of data about outcomes, they rely on the judgement of the clinician completing them, neglecting the subjective experience of the service-user. The identification of this shortfall prompted a movement towards user-defined 'patient-reported measures', which aim to capture the voice of the service-user to reflect the

quality of services (Whelan et al., 2010). A focus on patient experience has

continued in more recent government reports, with the suggestion that patient

experience should be as important as clinical outcomes (DoH, 2014).

Research has indicated that service-user experience is positively associated

with safety and clinical effectiveness across a wide range of disease areas

and settings (Doyle, Lennox, & Bell, 2013). This has prompted the

development and use of 'patient-reported measures' that measure the

service-user's experience of care.

1.5.1. Patient-reported measures

Patient-reported outcome measures (PROMs) aim to capture health status

and health-related QOL (Marshall, Haywood, & Fitzpatrick, 2006). Over the

past few years, a number of PROMs have been developed and implemented

in an effort to increase professionals' awareness of concerns and streamline

the processes of tailoring care to the needs of service-users (Marshall,

Haywood, & Fitzpatrick, 2006). PROMs are distinguished from patient-

reported experience measures (PREMs), which aim to find out about the

service-user's views about the experience of receiving care (Monmouth

Partners, 2014). Both PROMs and PREMs can be generic, intended for use in

any health setting, or specific to particular services or conditions. The process

of developing PROMs and PREMs usually commences with the need for an

instrument being identified, followed by draft versions of a measure being

progressively refined by collaborating with relevant stakeholders (Slade,

Thornicroft, & Glover, 1999). Next, it is recommended that a pilot is conducted

with a small number of service-users (Basch et al., 2014). Finally, a formal psychometric study is carried out to establish reliability and validity of a measure before it is released and disseminated (Slade, Thornicroft, & Glover, 1999).

The remainder of the introduction will focus on tools aiming to measure the experience of care (PREMs) and their use in services for people living with dementia, in line with the aims of the current study.

1.5.2. What constructs should PREMs capture?

Previous research has sought to elucidate important aspects of the care experience to give an indication of the constructs that PREMs should seek to capture. (Goodrich & Cornwell, 2008). In conjunction with the Harvard School of Medicine, the Picker Institute generated eight primary principles of patient-centred care as a result of focus groups with service-users, carers and professionals, combined with a literature review (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993). These are outlined in table 2. The Picker principles are considered to reflect the aspects of care that are felt to be important for service-users in general. However, if a PREM is designed for a specific service or client group, it should seek to capture elements of the care experience that are important to people in that group.

Table 2

Mapping statements from people with dementia onto the Picker Institute framework

Domains in the Picker Institute framework	Domains identified through statements from research (HIN, 2014)
Communication and education	Learning about dementia
Access to care Physical comfort	Using services
Respect for patient-centred values, preferences and expressed needs	Dignity and empathy
Emotional support	
Involvement of family and friends	Involvement
Coordination and integration of care	Ongoing support
Transition and community	
	Support to maintain some independence

Note. From "What is important to people with dementia? Statements to help assess healthcare quality based on empirical research", by the Health Innovation Network (2014). Reproduced with permission.

Previous research has reported efforts to tailor the content of PREMs to capture the unique experiences of specific client groups. Whelan et al. (2010) report the development of a combined PROM/PREM for an older adults' mental health service. They produced a user-defined pen-and-paper questionnaire that sought to capture the experiences of care of everyone who used the service, including people living with dementia. This work demonstrates a well-intentioned attempt to capture the aspects of care that are important to older people. Unfortunately, the format is likely to be unsuitable for people in the later stages of dementia. Impairments in areas such as in working memory (Baddely, Logie, Bressi, Della Sala, & Spinnler, 1986), language (Potkins et al., 2003) and attention (Perry & Hodges, 1999) are well-documented in these individuals, and these are likely to pose an obstacle to the completion of lengthy pen-and-paper questionnaires. Additionally, despite people living with dementia belonging to a wider demographic of 'older people', the aspects of care that are important to them are likely to be unique, given the complexity of their needs.

In order to capture what is important for people living with dementia, the Health Innovation Network (HIN) reviewed the empirical evidence focusing on the experience of dementia to extract a list of statements reflecting key themes about important aspects of care (HIN, 2014). They grouped the themes into six domains, which were then mapped onto the principles from the Picker Institute framework (see table 2). Although this project provides a unique, empirically-based insight into the important aspects of care in this

group, the methodology used runs the risk of 'cherry picking', where data to support a given perspective are selected to endorse that perspective (Morse, 2010), rather than acknowledging the context and the aims of the original research giving rise to the findings.

The authors of the review highlight potential biases that could limit the generalisability of the statements. They state that the majority of the research pertained to the views of carers, rather than people living with dementia (HIN, 2014). Additionally, very few of the studies focused specifically on the advanced stages of dementia, which could dispute the suitability of the statements for people in the more advanced stages of dementia. The authors acknowledge that the review cannot state the aspects of care that are most important to service-users, as these conclusions could only be drawn following empirical testing (HIN, 2014). It may therefore be prudent to use the domains as broad indicators of what may be important to people living with dementia, providing an indication of the constructs that a PREM for this client group should seek to measure.

If the important aspects of experience (as indicated by the Picker principles and statements from the HIN) are cross-referenced with the principles of PCC, commonalities emerge. The principles of respect, dignity, empathy and support to maintain independence clearly align with the values asserted by Kitwood about approaches to care that seek to enhance personhood. By

producing a PREM that specifically aims to measure the quality of the care experience with reference to these principles, feedback obtained from the PREM could be used as an indicator of the degree to which PCC is being delivered in services.

In order to investigate whether efforts had been made to produce PREMs specifically for people living with dementia, searches were conducted using Pubmed, JStor, Sciencedirect, Psychnet and Google Scholar using the terms "patient experience", "patient-reported experience measure(s)", "PREM", "dementia", "alzheimer's", "patient consultation", "patient-reported experience". The search demonstrated that although there is a body of research aiming to learn about the experiences of people living with dementia, much of the research does this through capturing the experiences of carers or professionals, or people in the early stages of dementia. To the knowledge of the author, there were no published efforts to produce a PREM for use with people in the moderate to advanced stages of dementia, despite concerns that they may not be able to use the tools for capturing experiences of care that are available in services.

1.5.3. Problems with existing experience measures in the NHS

Although measures of experience have been in use for many years, they have not been formally used to evaluate the quality of services until relatively recently. A programme of national patient surveys has reported to the Healthcare Commission since 2004 (Goodrich & Cornwell, 2008). In 2013, the

Friends and Family Test (FFT) was introduced as a national standardised

satisfaction measure (Monmouth Partners, 2014). This involves asking

service-users a single question about whether they would recommend a

service to friends or family if they needed similar input from health

professionals. Although the implementation of the FFT represents an

encouraging movement towards routinely using feedback from service-users

as a reflection of care quality, problems have been raised with it. It has been

suggested that FFT responses are vulnerable to bias from demographic

factors and the mode of administration (Sizmur, Graham, & Walsh, 2015).

Furthermore, global measures of satisfaction like the FFT can disguise varied

views about particular aspects of services (Bauld, Chesterman, & Judge,

2000) as service-users are required to "reduce their entire history of

interaction with a service to a single rating" (Willis, Evandrou, Pathak, &

Khambhaita, 2015, p. 7).

As a generic measure of satisfaction, the FFT may not adequately capture the

specific aspects of care that are important to particular client groups. This is

particularly true of people living with dementia, who require complex and

varied input from services. Research involving people with learning disabilities

suggests that the wording of the FFT is not easily comprehensible for people

with cognitive impairments (Raczka, Williams, & Theodore, 2014). Although

there is guidance on adopting a 'stepped' approach to using the FFT with

people living with dementia (NHS England, 2014), this may still be insufficient

for people in the more advanced stages of dementia who have significant

difficulties with verbal communication. The universal implementation of generic tools can exclude people who are unable to use them due to cognitive or communication impairments, as most tools have not been adapted or validated for people with these impairments (Kroll, Wyke, Jahagirdar, & Ritchie, 2012). Before tools are put into practice, they should be tested with the eventual target users (Jahagirdar, Kroll, Ritchie, & Wyke, 2012), but people who do not have the cognitive capabilities to take part in the trialling phase of measure development are frequently excluded from this process, and as a result the final measures may not be accessible to them (Jahagirdar et al., 2012).

If PREMs are the platform for people to provide feedback about services, people living with moderate-advanced dementia who are unable to complete them in their current form are excluded from taking part in the feedback process. This introduces a risk of further increasing health inequalities by excluding people from quality improvement mechanisms (Kroll et al., 2012), highlighting a requirement for the development of measures that are accessible for people who struggle to use the feedback tools that are routinely available.

1.5.4. Efforts to enhance the accessibility of PREMs

Examination of previous research reveals efforts to adapt measures to support people to participate in feedback processes. People with learning disabilities are often excluded from providing feedback due to lack of

reasonable adjustments to the feedback process (Mander & Rigby, 2014), in spite of an increased vulnerability to a range of additional physical and mental health problems (Alborz, McNally, & Glendinning, 2005). The format and complexity of existing measures can be a barrier to accessibility for people with learning disabilities (Jahagirdar et al., 2012). The Central London Community Healthcare NHS partnership reported on the development of accessible PREMs for community learning disability services, in response to reports that PREMs were not being used due to the majority of service-users being unable to use the existing PREMs. Easy-read PREMs were produced which used visual stimuli to support service-users to respond (Central London Community Healthcare, 2012).

Raczka, Williams, and Theodore (2014) trialled an accessible version of the FFT which could be administered via an app, and found that this could be successfully used to gain feedback on experiences of care from individuals who would otherwise have been excluded from providing their feedback. By doing this, the project helped to initiate a longer-term process for capturing feedback about services that could be used to increase satisfaction, improve engagement and reduce health inequalities (Raczka, Williams, & Theodore, 2014). These projects demonstrate that it is possible to adapt existing PREMs to assist people with cognitive impairments, yet there appear to be no similar published efforts to adapt tools for people living with dementia. This leads to consideration of why an exploration of this possibility has been neglected,

particularly given the high level of engagement with care services and the importance of positive experiences of care for this client group.

1.6. Capturing the Views of People Living With Dementia

Some of the prevailing assumptions about dementia may explain why few efforts have been made to directly capture their subjective experiences. Godwin and Waters (2009) suggest that previously, asking people living with dementia what they thought would be seen as misguided and a fundamental misunderstanding of the reality of dementia. Lindow and Morris (1995) conducted a review of service-user involvement in social care, from which they reported that social care agencies had not elicited the views of people living with dementia as they found communication with these people difficult and believed that they could not give an opinion. Instead, it was believed that professionals were best placed to comment on the services available (Goldsmith, 1996) and 'proxy' reports from carers or family members should be used as a substitute for the views of service-users. These ideas help to explain the reliance on the views of professionals or carers. However, there is evidence to suggest that proxy reports may not always be concurrent with the views of people living with dementia.

1.6.1. Criticism of proxy reports
A number of studies have demonstrated the differences between the perspectives of people living with dementia and their carers. One study found that a caregiver may underestimate a service-user's QOL due to their position

as a 'healthy person'. Meanwhile, the person with dementia may have found new meanings in life and perceive their QOL to be quite high, unbeknownst to the caregiver (Ettema et al., 2005). Arons, Krabbe, Schölzel-Dorenbos, van der Wilt, and Rikkert (2013) found a number of biasing factors that could affect carers' views of the health-related QOL of service-users. The results indicated that carers may project part of their own health-related QOL onto their relatives living with dementia. The authors concluded that proxy views should not be used as a direct substitute for health-related QOL ratings, even when service-users are no longer able to meaningfully assess their own QOL. According to ratings on the CDR, none of the participants in the study had 'severe' dementia, which limits the applicability of findings to people in the more advanced stages of dementia.

Hoe, Hancock, Livingston, and Orrell (2006) used the Quality of Life in Alzheimer's Disease (QoL-AD) measure to rate service-user and professional perceptions of QOL in residential homes in the UK, alongside measures of depression and anxiety. Professionals' and service-users' ratings of the service-users' quality of life were only significantly correlated for five of thirteen items on the QoL-AD, suggesting that professionals and service-users can perceive QOL quite differently. Although the correlational nature of the research does not allow for any conclusions to be drawn about the mechanisms by which changes in perceived QOL occur, the results demonstrate that there are disparities between the views of service-users and professionals that may be causing important areas of need to be neglected in

care processes (Hoe et al., 2006). However, once again, the QoL-AD could not be completed with people with advanced dementia, which excluded just under half of the service-users in the study from providing a subjective rating of their QOL. This is a methodological challenge in research seeking to compare proxy and service-user views, as people are, by definition, unable to answer for themselves if a proxy report is required (Bjertnaes, 2014). Although conclusions can therefore not be generalised to people in the more advanced stages of dementia, the results do indicate that caution should be exercised when relying on proxy views, and the subjective views of people living with dementia should be sought wherever possible.

1.6.2. Obtaining the views of people living with dementia

It was assumed for a long time that it was not possible to access the subjective views of people living with dementia beyond the early stages of the condition. However, a body of evidence has emerged which suggests that people living with dementia are able to express awareness of their situation and communicate, even in the later stages of the condition. Goldsmith (1996) conducted a literature review, consulted healthcare professionals in the field and conducted interviews with people living with dementia and their relatives. From this, he concluded that even people in the advanced stages of dementia who are not thought to be able to communicate have a great desire to do so. He suggested that as it has been proven that communication is possible, it is the task of professionals working to acquire the skills that enable them to

understand and interpret the views of people who struggle to make themselves heard (Goldsmith, 1996).

Through analysing tape-recorded conversations with 23 people with AD, Tappen, Williams, Fishman, and Touhy (1999) concluded that even people in the more advanced stages of the condition were able to use the first person indexical, thus demonstrating an intact sense of self (Sabat & Harre, 1992). Mayhew, Action, Yauk, and Hopkins (2001) found that although understanding communication can involve wading through extra sounds or words and incorporating nonverbal communications in the interpretation of meaning, people with advanced dementia were still able to communicate their views about their dementia. Although this research was small-scale, it provides promising initial evidence that it is possible to conduct meaningful interactions with people who are in the advanced stages of dementia, despite the challenges that may be inherent in interpreting interactions. Tappen et al. (1997) found that even in light of very low scores on cognitive screening tests, people living with dementia were able to provide responses that were relevant, or related to the preceding statement in the conversation. This demonstrates that even significant cognitive impairments do not preclude people from participating in meaningful interactions. The researchers observed that most of the literature in this area is based on clinical experience rather than empirical evidence, which implies a need for further investigation (Tappen et al., 1997).

38

Beattie, Daker‑White, Gilliard, and Means (2004) demonstrated that by asking people living with dementia for their views directly, it is possible to obtain unique insights that otherwise would be difficult to access. For example, participants noted that professionals can become quite fixated on issues of risk and danger, which they felt compromised their independence without making significant improvements to their safety. The researchers noted that as part of identifying their sample, staff had previously expressed doubts about the ability of the two participants with advanced dementia who were ultimately included in the study (Beattie et al., 2004), providing an example of how assumptions about communication abilities may be erroneous. However, as very few of the participants had advanced dementia, the findings may not be generalisable to people in the more advanced stages of the condition. This highlights a need for research which seeks to find ways of accessing the views of people in the later stages of dementia. Researchers have a responsibility to try to find ways of including people who may be otherwise judged as incapable due to the obstacles presented by cognitive and communication difficulties (Goldsmith, 1996).

1.6.3. Consulting people living with dementia about their experiences of care

It is likely that preconceptions about communication in dementia precluded efforts to capture information about the subjective experiences of care from the perspective of people living with dementia. However, there is evidence to suggest that it is possible to do this. In a small-scale project, Allan (2001)

aimed to explore the ways in which professionals can consult with people living with dementia about their views of services by trialling different methods of consultation with service-users, many of whom were in the more advanced stages of dementia with significant communication difficulties. The overall conclusion from this exercise was that communication was possible, and even people in the advanced stages of dementia had the ability and will to express their needs and preferences. Although this project provided useful insights into the topic of asking people for their views about services, it cannot be regarded as robust empirical evidence due to the informal, unplanned nature of the study. Allan encouraged further research examining the process of consulting with service-users about their experiences using structured empirical methodologies.

Aggarwal et al. (2003) analysed semi-structured interviews with 27 service-users with dementia (with varying degrees of severity) and 28 relatives in residential care homes and day centres. They video-recorded each service-user's social encounters for one week, conducted observations and examined participants' care plans. They found that service-users were able to communicate their experiences of care, most of which were corroborated by the data from video recordings and observations. They also noted frequent disparities in the views of service-users and their relatives regarding how service-users felt about their care, supporting evidence from other studies about the unreliability of proxy reports. The researchers concluded that the direct views should be sought from service-users wherever possible. The

research was carried out within the Jewish voluntary sector which the authors identified to be well financed and resourced compared to other care settings (Aggarwal et al., 2003). It may be that higher levels of support facilitated the process of service-users expressing their views, which could be more problematic in settings where resources are scarcer. It is important to explore whether it is possible for people to communicate their experiences of dementia care in other settings, including statutory settings where people may not have access to as much support.

In summary, although prevailing assumptions about dementia historically led to a reliance on the views of carers and professionals, research indicates that these proxy views may not accurately reflect the views of people living with dementia. In addition, the evidence suggests that with adequate support, people living with dementia are capable of expressing their own subjective views about care, even in the moderate-advanced stages of the condition. This refutes the historical assumption that there is no value in consulting them about their care. Despite this, quality indicators in dementia services remain focused on objective, clinician-defined outcomes. The absence of direct consultation with people living with dementia about their subjective experiences of care contradicts government directives that recommend service-user consultation in the delivery of services (Beattie et al., 2004).

Capturing service-user preferences and experiences is in line with the values asserted by Kitwood (1997) and the available guidance about dementia care, which promotes PCC as best practice. Providing individualised care requires continuing to consider the person's own story and how they are experiencing and reacting to their current situation, even in the advanced stages of the condition (Holst & Hallberg, 2003). Understanding a person's experience using only medical, cognitive and functional assessments adds to the risk of delivering poor quality care (Cohen, 1991). Given that tools have been adapted for other client groups who are unable to use PREMs that are routinely available in services, there is a strong case for striving to adapt tools to capture feedback about experiences of care from people living with dementia.

1.7. **Current Study**

The current study sought to design and trial a PREM to gather feedback about experiences of care from people who are in the moderate-advanced stages of dementia and who are unable to engage with typical PREMs available due to cognitive impairments. An iterative process was used, based on the guidance about the development of measures (Streiner, Norman, & Cairney, 2014) and methods adopted in the development of existing PREMs (Bobrovitz, Santana, Kline, Kortbeek, & Stelfox, 2015; Royal College of Paediatrics and Child Health, 2011).

Qualitative methodologies are useful in exploring areas where there has been little substantive research previously, or to gain in-depth understandings of areas that are difficult to understand quantitatively (Strauss & Corbin, 1990). Given that the project aimed to explore a novel area by capturing peoples' views to contribute to the development of a new PREM, a quantitative approach could have prematurely imposed a structure that constrained peoples' responses. Qualitative methods have previously been employed successfully to support people living with dementia to participate in research (e.g. Aggarwal et al., 2003; Beattie et al., 2004; Prorok, Horgan, & Seitz, 2013; Tappen et al., 1999). In addition to this, qualitative methods are recommended in the initial stages of scale development, and have been used widely in previous efforts to develop new PREMs (Bobrovitz, Santana, Ball, Kortbeek, & Stelfox, 2012; Bosworth et al., 2015; Pusic et al., 2009; Taylor et al., 2015). In light of the apparent absence of previous efforts to investigate this area, a qualitative methodology was used.

The project consisted of four stages. At the first stage, focus groups were conducted with service-users with early dementia, carers and health professionals working in an older peoples' community team. The aim of the focus groups was to consult with "experts by experience" who could advise on the preferences of people in the moderate-advanced stages of dementia. An initial draft measure was produced based on the focus group discussions and the available literature about improving the accessibility of questionnaires. In the second stage, cognitive interviews (Willis, 2005) were conducted with

service-user/carer couples and health professionals to further refine the PREM by verifying the meaning of the items and accessibility of the format for people living with dementia (Bobrovitz et al., 2015).

Following the cognitive interviews, the PREM was revised, and a second draft PREM was produced. In the third stage, professionals were trained in the administration of the PREM and asked to trial it with up to three service-users who meet the specified criteria. At the final stage, semi-structured interviews were conducted with clinicians who had trialled the measure with service-users. The interviews were audio-recorded and transcribed, and the transcripts were analysed using thematic analysis (Braun & Clarke, 2006). The aim of this stage was to discover the successes and challenges clinicians had experienced when trialling the measure and determine how it could be used to capture feedback about experiences of care that could drive improvements.

The overall aim of the project was to conduct a small-scale trial of an initial version of a new PREM to gain more insight into the successes and challenges of using a tool to collect feedback from people living with moderate-advanced dementia about their subjective experiences of care. Through doing this, the project sought to generate new knowledge about methods of measuring the quality of care in services for people living with dementia to facilitate the process of meeting the needs of this client group.

The project also aimed to add to the growing evidence base that people living with moderate-advanced dementia are able to provide meaningful feedback about their care if supported to do so using appropriate tools and interactions. Throughout the project, service-users and carers were consulted for their views to try to ensure that the PREM was user-defined and tailored to the needs of the target respondents.

1.8.   **Research Questions**

1. What are the successes in using an adapted PREM to collect feedback from people living with moderate-advanced dementia?

2. What are the challenges in using an adapted PREM to collect feedback from people living with moderate-advanced dementia?

3. How could feedback be used to drive improvements in care?

2. Method

The study used a mixed-methodology qualitative design. The process of developing the PREM involved an iterative process with four distinct stages:

1. Focus groups with professionals, service-users and carers from community services for older people, results from which were used to produce a draft PREM;

2. Cognitive interview pretesting of the PREM with healthcare professionals, service-users and carers to inform further amendments to the PREM;

3. Pilot of the PREM with service-users living with moderate-advanced dementia by professionals in the community team for older people;

4. Interviews with professionals who had trialled the PREM to explore their experiences.

2.1. **Ethics**

2.1.1. Ethical approval

Ethical approval was granted by Harrow Research Ethics Committee (REC; Ref. 15/LO/1369) and the Royal Holloway Psychology Departmental Ethics Committee (Ref 2015/156R1; Appendices 1 and 2). Research and Development (R&D) approval was gained at the NHS Trust where the research was set (Appendix 1).

Following the initial favourable opinion from the REC, two minor amendments were approved (Appendix 2). The first was for research activities to be conducted in the homes of service-users and carers in order to further support people to participate if travel to the research site was problematic. The second was to remove the phrase "people with dementia" from information sheets and consent forms as professionals suggested that this term could be distressing for people who did not identify with the diagnosis.

2.1.2. Ethical issues

The most pertinent ethical issue raised in the project related to capacity to provide informed consent. Due to the nature of the conditions, it was anticipated that some service-users might not have capacity to consent to their involvement in the research. This was particularly true of service-users with moderate-advanced dementia. Although the project did not involve any activities that were likely to incur distress or harm, the query around capacity to consent in this client required careful consideration. The consent procedure is detailed below in section 2.4.3.1.2.

2.2. Setting

Participants were recruited through a community service for older people in an outer London borough. This is comprised of a memory service and a community mental health team. These services consist of a number of different health professionals including doctors, clinical psychologists, occupational therapists, nurses and support workers. The memory service

provides comprehensive assessments for people with suspected dementia and post-diagnostic support to help people to continue to live independently. The community mental health team offers assessment, treatment and consultation for older people with short-term mental health issues and long-term input for people with complex needs.

2.3. Recruitment

2.3.1. Rationale for the chosen sample

When choosing a sample in the initial stages of scale development, it is recommended that participants are members of the target population (DeVellis, 2012). In this case, the target population (people living with moderate-advanced dementia) have significant cognitive impairments by virtue of the stage of their condition. Although there is evidence that qualitative methods can be used with people with cognitive impairments in the process of scale development if disability accommodations are used (e.g. Garcia et al., 2015), it was felt that the demands placed on memory, sustained attention and executive functioning would make it difficult for people in the moderate-advanced stages of dementia to engage in the focus groups. This was also true of the cognitive interviews, which require relatively intact higher-level cognition to enable reflection on the thought processes that are evoked by each question, alongside the ability to recall and communicate views on these topics. However, it was felt that the sample should still consist of people

with experiences and knowledge of dementia that would enable them to comment on the development of the PREM.

Guidance indicates that when it is difficult to involve people with more severe forms of a condition in research, involving someone with a less severe form of the condition is an alternative option (Mental Health Research Network, 2013). This led to the recruitment of service-users with early dementia, carers and professionals working with people living with dementia.

2.3.2. Recruitment of healthcare professionals

Recruitment of professionals involved engagement with the service at an early stage of the project. The researcher attended regular team meetings to introduce the project and keep the professionals informed of relevant dates so that they could plan their involvement where possible. Information sheets (Appendix 3) were distributed to professionals both in person and via e-mail, and professionals were asked to notify the field supervisor if they wished to be involved in the research. Written informed consent was obtained from the professionals (Appendix 4).

The inclusion criteria for professionals were as follows:

1. Experience of clinical work with people living with dementia
2. Work in the older adults' community team for a minimum of three months

49

All of the professionals working in the team at the time the research was being conducted met these criteria.

2.3.3. Recruitment of service-users and carers

2.3.3.1.   Stage 1 (focus groups) and stage 2 (cognitive interviewing)

Figure 1 displays the process initially used to recruit service-users and carers for stages one and two of the study.

```
┌─────────────────────────────────────────────────────────────┐
│                                                               │
│              1.  Engagement with the service                  │
│   The researcher attended several meetings to meet the        │
│   professionals in the service and introduce the project.     │
│   Professionals were informed of the inclusion criteria for   │
│   service-users and carers and provided with instructions     │
│   for how to introduce the study.                             │
│                                                               │
│                          ▼                                    │
│                                                               │
│              2.  Introducing the study                        │
│   Clinicians were asked to give the service-user/carer        │
│   information sheet (Appendix 5) to service-users and carers  │
│   who met the inclusion criteria when they attended the       │
│   service for appointments. At this stage, people who were    │
│   willing to find out more about the project consented to     │
│   have their contact details passed on to the researcher.     │
│   Clinicians sent the researcher the contact details of       │
│   potential participants, with the time and date they were    │
│   seen to ensure a 24-hour gap between provision of the       │
│   information sheet and contact from the researcher.          │
│                                                               │
│                          ▼                                    │
│                                                               │
│              3.  Arranging participation                      │
│   The researcher telephoned potential participants to         │
│   determine their availability for participation in focus     │
│   groups/cognitive interviews. Participants had the           │
│   opportunity to voice any concerns or ask questions about    │
│   the study.                                                  │
│                                                               │
│                          ▼                                    │
│                                                               │
│         4.  Obtaining informed consent and participating      │
│   The researcher arranged to meet with service-users and      │
│   carers to conduct research activities. At the meeting,      │
│   participants had an opportunity to answer further           │
│   questions, after which, written informed consent was        │
│   obtained from each participant (Appendix 6).                │
│                                                               │
└─────────────────────────────────────────────────────────────┘
```

Figure 1. Procedure for recruitment of service-users and carers for stages 1 and 2.

After the focus groups, the recruitment strategy was revised to ensure that the views of service-users/carers were adequately captured in stage 2. An Assistant Psychologist telephoned service-users and carers who had previously attended a post-diagnosis group. They were given a brief outline of the study and asked whether they would like more information. If they agreed,

information sheets were posted to them. After this, the process continued as detailed in stages 3-4 in figure 1.

The Health of the Nations Outcome Scale (HoNOS) clustering tool (Wing et al., 1998) is a measure used by NHS mental health services to categorise the level of a service-user's needs. HoNOS clusters were used to identify service-users who might be eligible to participate. People are assigned to HoNOS clusters 18 or 19 when there is evidence of cognitive impairment or dementia (low-moderate need). In practice, this generally applies to people in the early stages of dementia. The inclusion criteria for service-users were as follows:

1. Diagnosis of dementia.

2. Assignment to HoNOS cluster 18 or 19.

3. Fluent in speaking and understanding of English.

For carers, the inclusion criteria were as follows:

1. Unpaid family member or friend currently caring for a service-user with dementia who has attended the service.

2. Fluent in speaking and understanding of English.

2.3.3.2.   Stage 3 (trial of the PREM)

The target respondents for the PREM were service-users with moderate-advanced dementia. The team caseload was reviewed to identify service-users in HoNOS clusters 20 and 21 (cognitive impairment or dementia

complicated – high need/physical or engagement) were identified. The field supervisor compiled a list of these individuals, and this was circulated to the professionals in the team. Professionals were asked to trial the PREM during routine appointments with service-users who met the following inclusion criteria:

1. Diagnosis of dementia.

2. Assignment to HoNOS cluster 20 or 21.

3. Able to understand English.

2.3.3.3.   Exclusion criteria

Service-users who were deemed not to have the capacity to consent were not included in the project if there was no-one available to act as a consultee on their behalf.

2.4. **Procedure**

2.4.1. Stage 1: Focus groups
The first stage in developing the PREM involved two focus groups. Focus groups are recommended as a starting point when developing measures (Frost, Reeve, Liepa, Stauffer, & Hays, 2007). They allow the researcher to adopt an exploratory approach, obtaining qualitative information about attitudes to particular topics from a relevant sample (Giesen, Meertens, Vis-Visschers, & Beukenhorst, 2012). This methodology has been used widely as a method of gaining a consensus on topics to inform items for a pilot measure

(e.g. Bobrovitz et al., 2012; Bosworth et al., 2015; Pusic et al., 2009; Taylor et al., 2015). Focus groups can help to increase content validity (which is defined as "the extent to which a specific set of items reflects a content domain"; DeVellis, 2012, p. 59) by asking participants for their views about important aspects of the construct of interest (Bobrovitz et al., 2012); in this case, the care of people living with moderate-advanced dementia.

2.4.1.1. Procedure

Krueger (1994) recommends that groups are kept as homogeneous as possible to promote open discussion between participants. For this reason, focus groups for service-user/carers and professionals were conducted separately. The focus groups were held in a meeting room at the research site. They were facilitated by the researcher. A list of topics was devised for each focus group, with pre-planned probes under each topic (Morgan, 1996; Appendix 7) to ensure that relevant areas were covered in depth (Ritchie, Lewis, Nicholls, & Ormston, 2013). The groups commenced with an introduction to explain the purpose and format of the group. The focus groups covered similar topics, although the introduction and probes were adapted for the service-user/carer focus group, in line with guidance about running focus groups with older people (Barrett & Kirk, 2000).

Exploration of each topic started with open questions to encourage participants to contribute individual views. First, the aspects of care that are

important to people living with dementia were discussed. Next, the

PROM/PREM that is currently used in the service was distributed (Appendix 8;

used with permission from Whelan et al., 2010) to prompt discussion about

the content of the new PREM. Participants were asked to consider how the

PREM could capture the unique aspects of care that are important to people

living with moderate-advanced dementia. Finally, an 'easy-read' PREM from

services for people with learning disabilities (Appendix 9; used with

permission from Raczka, Theodore, & Williams, 2014) was distributed to the

participants to order to facilitate discussion of ideas about the format of the

new PREM. The focus groups were audio-recorded.

2.4.1.2. Sample

Morgan (1996) suggests a target of six to ten people per focus group to

enable a balance between sustaining a discussion between too few people

and focusing a discussion between too many. The group for healthcare

professionals was attended by two Psychiatrists, two Occupational Therapists,

a Support Worker, a Clinical Psychologist, a Trainee Counselling Psychologist

and a Community Mental Health Nurse (N=8; five female, three male).

Two carers and one service-user (N=3) attended the service-user/carer focus

group. Unfortunately, the attendance was lower than expected as two

participants cancelled at short notice due to illness. As the group had been

postponed once already due to unsuccessful recruitment, it was decided to

proceed with the group, revising the recruitment strategy to ensure that

service-user/carer views were adequately captured in the cognitive interviews.

2.4.1.3. Analysis

The audio-recordings of the focus groups were reviewed and the ideas from

both groups were collated and reviewed by the research team (the researcher

and the academic and field supervisors, both of whom are Clinical

Psychologists), and cross-referenced with the literature regarding production

of accessible measures and important aspects of care (see Results section

3.1.3 for further details). Following these discussions, an initial draft PREM

was produced (Appendix 10).

2.4.2. Stage 2: Cognitive interviews

Cognitive interview pretesting has been employed widely as a method of

pretesting PREMs before they are trialled in the field (Bobrovitz et al., 2015;

Girling et al., 2015; Hopwood, Lloyd, Tallett, Chow, & Warner, 2011; Sawicki

et al., 2015; Taylor et al., 2015). Cognitive interviewing involves participants

completing a measure and concurrently providing feedback about the process

of answering the questions to identify any sources of response error (Willis,

2005). By asking respondents to reveal the cognitive processes that underlie

their responses, researchers can identify any unintentional errors or biases

pertaining to understanding of the questions, how respondents retrieve their

answers from memory, how they make a decision about how to answer or the

process of generating a response using the options provided (Tourangeau,

1984). This can help to ensure that a measure accurately captures the information that it aims to capture, increasing its validity (Willis, 2005). It is essential that new measures are subject to reliability and validity checks to ensure that they are psychometrically robust. However, these checks tend to be conducted after the construction of questions has been finalised and large amounts of data collection have taken place (Willis, 2005). Cognitive interviewing is often conducted at an early stage in scale development, before large-scale data collection (Willis, 2005).

2.4.2.1. Procedure

The interviews involved the PREM being administered and answered by the respondent, followed by the interviewer probing for other specific information relevant to the question or answer (Willis, 2005). Concurrent probing is recommended as it allows questioning about information when it is fresh in a respondent's mind (Ericsson & Simon, 1980), supporting peoples' memory of how they originally reacted to the question when it was asked (Willis, 2005). It was felt that this approach would be particularly supportive of service-users with early dementia who had memory impairments.

An interviewer-administered technique was used, simulating the conditions of how the PREM would be delivered in a real world setting. The interview schedule (Appendix 11) was constructed in accordance with guidance from the literature. Willis (2005) recommends identifying potential problems with

items in advance of the cognitive interviews so that probes can be planned in advance to target these areas. The planned probes were discussed with the research team to ensure that they adequately targeted the potential difficulties with the PREM. Examples of planned probe questions[1] included:

- *What went through your mind when you heard that question?*
- *Can you repeat this question in your own words?*

Participants were offered at least two alternatives (e.g. *Do you think this question was easy or difficult to answer?*) to avoid leading their responses. The cognitive interview methodology in this project was somewhat atypical, as, for reasons outlined in section 2.3.1, the participants were not individuals from the target group who would eventually be completing the PREM. The interviews therefore sought to gain a consensus on whether the PREM might be problematic for people in the target group, based on personal or professional experiences of dementia. Some of the probes were designed to access respondents' views about this, for example:

- *How easy or difficult would it be for someone with moderate-advanced dementia to answer this question?*
- *How easy or difficult would it be for someone with moderate-advanced dementia to remember whether someone had listened to them?*

---

[1] *NB: the wording of some probes was taken directly from Willis (2005).*

Throughout the interviews, reactive probes (probes that are "triggered by something the subject has said or done that might signal a problem, rather than a search for problems by the interviewer"; Willis, 2005, p. 89) were also used to capture unanticipated sources of response error during the interviews. For example, the following probes were prepared in case the participants indicated that it might be difficult for someone with moderate-advanced dementia to answer a question:

- *What might help someone with moderate-advanced dementia to answer this question?*
- *Would it be helpful or unhelpful to include a visual prompt?*

Although cognitive interviews are not traditionally used to address content validity, it was felt that it would be beneficial to obtain further clarification that the PREM was capturing areas of importance, particularly in light of the small sample size in the service-user/carer focus group. To target this, participants were asked whether the items on the PREM addressed all of the important aspects of care for people living with moderate-advanced dementia.

Before the interviews commenced, participants who had not been involved in stage 1 reviewed the information sheets and completed consent forms. Prior to the start of the interview, participants were provided with instructions

(adapted from Willis, 2005, p. 142), which asked them to imagine they had just finished an appointment with a healthcare professional and were completing the PREM to provide feedback about their experience. Participants were given assistance to ensure that they understood what would be required of them, and had an opportunity to ask further questions before the interview commenced. The interviews were audio recorded.

2.4.2.2. Sample

Willis (2005) suggests that multiple iterative rounds of cognitive interviewing are used to inform adaptations to a measure. However, due to the time-limited nature of the project, only one round of testing was carried out, with the researcher acting as the interviewer. In line with recommendations ("8-12 interviews are usually sufficient within a round"; Willis, 2005, p150), a planned sample of four professionals and four service-users or carers was set for the cognitive interviews. After one interview had been conducted jointly with a service-user and a carer, it became clear that joint service-user/carer interviews were extremely effective in supporting service-users to participate as carers could clarify instructions and assist with communication difficulties for service-users. The final sample was comprised of three service-user/carer couples (N=6) and four professionals (total sample N=10), participating in seven interviews in total. Of the professionals who participated, three were occupational therapists (two female, one male) and one was a clinical psychologist (male). Demographic information was not collected for service-users and carers (see section 2.6.1 for a further discussion of this).

2.4.2.3.   Analysis

After the cognitive interviews, the researcher reviewed the audio recordings and collated the responses on a spreadsheet (a more detailed description of the analysis is outlined in the results chapter; see section 3.2). The findings were reviewed with the research team, and the implications for necessary adaptations to the PREM were discussed. A second draft was produced following the cognitive interviews. This draft was referred to as 'Draft PREM Version 2 – trial with service-users' (Appendix 12).

2.4.3. Stage 3: Pilot of the draft PREM

Preliminary pilot testing of a measure is important before a major scale development project is launched (Clark & Watson, 1995). Pilot studies are recommended to confirm that there are no obvious errors and scales have adequate psychometric properties before they are trialled more widely (Johanson & Brooks, 2010).

2.4.3.1.   Procedure

2.4.3.1.1.   Training session for professionals

The researcher conducted a training session for the professionals; this was attended by nine people. The researcher delivered a PowerPoint presentation to provide background about the project and introduce the PREM. Professionals were instructed about how to obtain consent and administer the PREM.

Each professional was given a pack (Appendix 13) containing all the necessary materials to obtain consent and administer the PREM. The pack provided a brief background to the project and detailed written guidance for seeking consent and subsequently administering the PREM. The pack provided all the necessary information to guide professionals who were not able to attend the training session. At the end of the training session, there was an opportunity for professionals to ask questions. The researcher provided contact details for professionals to get in touch with any questions, and arranged to attend the service for 'drop-in clinics' where professionals could discuss any difficulties in obtaining consent or administering the PREM.

2.4.3.1.2. Obtaining consent

Professionals were instructed to assess whether service-users who met the inclusion criteria had capacity to consent to completing the PREM. In line with guidance in the Mental Capacity Act (2005), professionals assessed whether service-users could adequately understand, retain and weigh up the information relevant to the decision about whether to trial the PREM, and communicate their decision. Service-users were always assumed to have capacity until formal assessment suggested otherwise.

If the service-user was deemed to have capacity, the professional provided them with an information sheet. There were two different information sheets

available, a standard version (Appendix 14) and an easy read version (Appendix 15). Professionals were instructed to use their judgement to decide which version to use. Once the service-user had read the information sheet, they were asked to sign a consent form (Appendix 16) confirming that they had provided consent to trial the PREM.

The procedure for gaining consent from service-users deemed not to have capacity adhered to the guidance available (Department of Health, 2008). If the service-user did not have capacity to consent, professionals identified a personal consultee (a family member, unpaid carer or friend) who was asked to provide an opinion on the service-user's preferences about participating in the trial. Professionals explained the nature of the consultee role, supporting this with an information sheet (Appendix 17). Once a consultee agreed to provide an opinion, they were asked to complete a declaration form (Appendix 18). A supportive assent process is recommended when conducting research with people who cannot consent for themselves (Allan, 2001), and professionals were instructed to check in regularly with the service-user to ensure that they did not object to trialling the PREM. If the service-user did not have capacity, professionals supported them to go through the information sheets so that they could understand the purpose of the research if possible. In practice, consultees were used for four service-users who were judged to be unable to provide consent.

2.4.3.2.   Sample

Johanson and Brooks (2010) recommend that a preliminary pilot of a scale should try to aim to capture responses from 30 representative participants from the population of interest. Professionals were asked to administer the PREM to up to three service-users who met the inclusion criteria for stage 3 (see section 2.3.3.2 for details). It was hoped that this should enable the PREM to be trialled with at least 30 people (as the team was comprised of seventeen professionals). Details of the numbers of professionals who took part in the trial and subsequent interviews are displayed in figure 2.
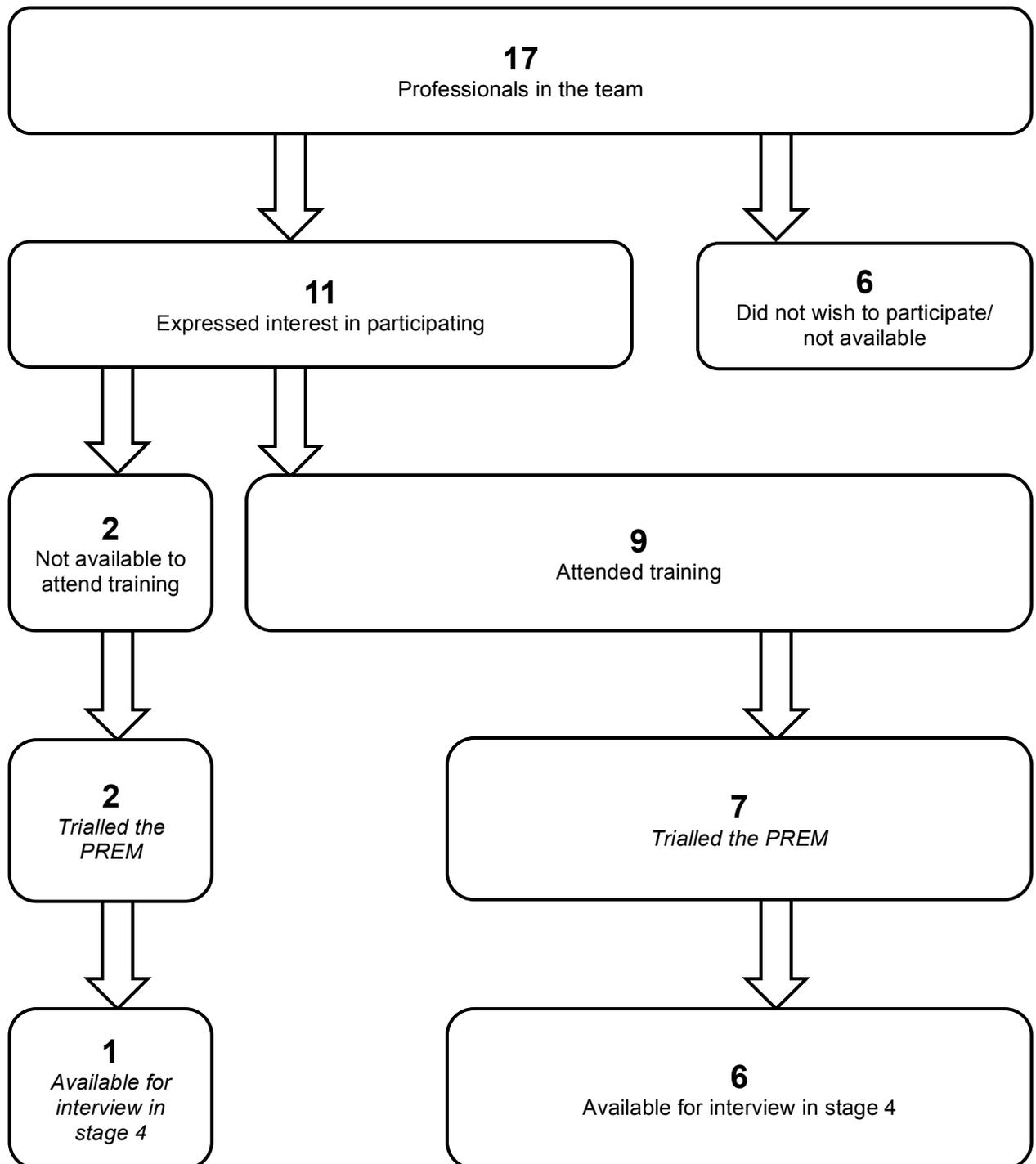
Figure 2. Professionals who took part in the trial of the PREM.

Professionals were asked to notify the researcher once they had trialled the PREM to arrange their participation in stage 4.

2.4.4. Stage 4: semi-structured interviews with professionals

The final stage of the project involved individual interviews with professionals. Interviews were audio-recorded, transcribed and analysed using thematic analysis (TA). TA is a qualitative method of analysis that has been used widely for analysing qualitative data (Clarke & Braun, 2014). It is described as "a method for identifying, analysing and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 6). TA can be used to identify patterns in data, but it can also be used to organise data in an interpretive way to address a research question (Clarke & Braun, 2014). TA differs from other methods of qualitative analysis in that it is not aligned to a specific theoretical orientation. This enables it to be used flexibly from a range of epistemological positions (Braun & Clarke, 2006).

The choice of methodology was carefully considered to ensure that the research questions could be addressed. Given that the aim of the interviews was to gather information about the experiences of professionals to inform further development of the PREM, it was necessary to adopt an epistemological stance of critical realism, in which "reality is assumed to exist but to be only imperfectly apprehendable" (Guba & Lincoln, 1994, p. 110). The reports from the professionals were assumed, for the purposes of this enquiry, to be broadly representative of reality. The 'critical' aspect acknowledges the likelihood of a number of complex factors influencing the professionals' responses. However, a detailed exploration of these factors was not the aim

of the research. By adopting this framework, the interviews could be used to gather information about successes, challenges and ways of driving improvements in care as reported by professionals, thus addressing the research questions.

Adopting a critical realist stance excluded the possibility of using certain qualitative approaches, such as Interpretative Phenomenological Analysis (IPA; Smith, Flowers, & Osborn, 1997). If IPA is used to analyse qualitative data, analysts must assume that it is not possible to directly access peoples' genuine experiences by asking them. Instead, IPA places emphasis on an individual's interpretation of their own experiences and aims to "capture the quality and texture of individual experience" (Willig, 2013, p. 87). It was important to acknowledge the influence of how the professionals construed their experiences, yet obtaining a detailed understanding of this was not the aim of the interviews. For this reason, TA was favoured over IPA as it enables the analysis to retain a focus on the material whilst acknowledging the limits of reality (Braun & Clarke, 2006). Grounded theory (Glaser & Strauss, 1967) is another approach that is widely employed to gain understanding of qualitative data. Grounded theory seeks to provide an exploratory framework through which the data can be understood (Willig, 2013). The study did not aim to develop new theories about the process of professionals of administering the PREM to people with dementia. For this reason, it was felt that grounded theory was not suitable as a method of analysis.

2.4.4.1. Procedure

An interview schedule was constructed with reference to the aims of the semi-structured interviews and the guidance available. Britten (1995) advises that interviews should start with questions that the respondent can answer more easily before moving on to any more difficult or sensitive topics. Patton (2002) suggests that qualitative interview questions should be open-ended, neutral, sensitive and clear. Gill, Stewart, Treasure, and Chadwick (2008) highlight the importance of constructing questions that yield as much information as possible about the topic of interest in order to address the aims and objectives of the research. Probe questions can help to ensure that the topics are explored sufficiently by eliciting more detail, verifying meanings or clarifying the boundaries of a response (Patton, 2002). The final interview schedule (Appendix 19) was comprised of five open-ended questions, with a number of pre-prepared follow-up probe questions.

The interviews were conducted by the researcher. Each interview lasted between 20 and 30 minutes.

2.4.4.2. Sample

There is an absence of accepted guidance about sample size for qualitative enquiries using thematic analysis, and justification of sample size is often dictated by the resources available and the depth of analysis required (Fugard & Potts, 2015). For research involving a purposive sample, where

"participants are selected according to predetermined criteria relevant to a particular research objective" (Guest, Bunce, & Johnson, 2006, p. 61), six to eight interviews with a homogenous sample can be sufficient as long as the sample is carefully selected in line with the aims of the research (Kuzel, 1992). As the sample consisted only of professionals working in the older peoples' community service who had trialled the PREM, it was considered to be homogenous with reference to the aims of the research. By the end of data collection, nine professionals had attempted to trial the PREM with service-users. Of these, seven were available to take part in an interview (five female, two male). Details of the sample are displayed in table 3.

The professionals who took part in the interviews provided an indication of the severity of dementia of the service-users who trialled the PREM. Of the 14 service-users described in the interviews, six were described as having "moderate" dementia. One service-user was described to be in the "moderate-advanced" stages of dementia, and the other seven were thought to be in the advanced stage of dementia.

Table 3

Trial of the PREM by professionals

Discipline	Number of service-users PREM was trialled with	Available for interview
Occupational Therapist	4	Yes
Occupational Therapist	2	Yes
Occupational Therapist	1	Yes
Occupational Therapist	1	Yes
Community Psychiatric Nurse	2	Yes
Community Psychiatric Nurse	1	Yes
Community Psychiatric Nurse	1	No
Psychiatry Registrar	3	Yes
Consultant Psychiatrist	1	No

2.4.4.3.   Analysis

Braun and Clarke (2006) detail a six-stage approach for researchers using thematic analysis in qualitative psychology research. These stages are detailed in Table 4, alongside an explanation of how they were adhered to in the research. NVivo for Mac was used to organise the analysis.

Table 4

Stages of thematic analysis (Braun & Clarke, 2006)

Stage	Activity in this project
1. Familiarising yourself with the data and identifying items of potential interest	The researcher conducted and transcribed the interviews, then read and re-read the transcripts, making notes to highlight comments that were particularly salient or interesting.
2. Generating initial codes	The transcripts were reviewed once again, and the researcher assigned initial codes to data that were relevant in the context of the research question. An example of a coded section of data can be seen in Appendix 20.
3. Searching for themes	Once a list of codes had been generated, the full list was reviewed and codes were combined or removed where necessary. The remaining codes were reviewed and grouped into initial themes (initial themes are displayed in Appendix 21)
4. Reviewing potential themes	The themes were reviewed at the level of the coded data extracts to ensure that the extracts fitted within the theme they had been assigned to. This resulted in modification of the themes, combining some and removing others that were not relevant to the research question. The full transcripts were reviewed once more to ensure that the themes captured all areas of importance in the data.
5. Defining and naming themes	The themes were reviewed and names were generated for themes and sub-themes which were felt to describe the content adequately.
6. Producing the report	The themes were written up into an analytic narrative, detailing their relevance to the aims of the research and grounding each theme in extracts from the data. This can be seen in the results section. Examples of additional extracts to evidence themes can be seen in Appendix 22.

2.5. Service-user/Carer Involvement

The project was developed with the values of service-user and carer involvement in mind, and seeking the perspectives of service-users and carers was embedded throughout the development of the PREM. The perspectives of service-users and carers were sought in stages 1 and 2 to guide the development of the PREM, and their views were weighted equally to those of professionals. Service-users and carers were eager to contribute to the project, and many of the participants expressed a view that the research was addressing an important area for people living with dementia and their families. In the trial of the PREM in stage 4, service-users' responses and reactions to the PREM were the main outcome of interest. The professionals' experiences of how service-users responded to the PREM were used to guide the conclusions drawn from the trial and make recommendations about further development.

2.6. Research Quality

Recommendations relating to quality in qualitative research were adhered to throughout the study, referring to guidelines by Elliott, Fischer, and Rennie (1999). This included consideration of the following areas:

2.6.1. Situating the sample

It is recommended that authors provide an adequate description of the research participants to enable readers to understand the limits of generalisability of the findings (Elliott, Fischer, & Rennie, 1999). This was

partially limited by the terms of the ethical approval, which specified that participation in the research should be minimally intrusive for service-users/carers. To address this, the ethics application stated that no personal information would be collected about participants except for their names and contact details. For this reason, demographic information about service-users/carers was not recorded, and is therefore not described in the write-up of the project. The sample is described in as much detail as possible to try to ensure that the context of the results is clear.

2.6.2. Grounding in examples

Data extracts are provided throughout to provide concrete examples of themes and ideas used at each stage. Examples of initial codes and the process of developing themes are appended (Appendix 20 and 21) to illustrate how the analysis was undertaken.

2.6.3. Providing credibility checks

A colleague (Trainee Clinical Psychologist) who was also in the process of conducting TA of qualitative data reviewed an extract of the data from the semi-structured interviews to act as an additional analytical 'auditor' (Elliott, Fischer, & Rennie, 1999, p. 222). Throughout the analysis, extracts of coding and examples of themes were shared with supervisors, who provided verification about the interpretation of data. Data extracts are provided throughout the results section to enable readers to review the credibility of the analytic process and act as further 'auditors' of the analysis.

2.6.4. Coherence

The results are presented in a narrative structure to enable readers to comprehend how the data were understood. The description of the data is organised into broad categories or themes, with sub-headings or sub-themes which highlight the nuances of the data.

2.6.5. Accomplishing general versus specific research tasks

The sample and methodology were selected to attain an initial understanding of the topic, and this is made explicit (e.g. the trial of the PREM aimed to gain an initial understanding of the process to inform further development, rather than seeking to draw definite conclusions about the best ways of collecting feedback from the target population). Aspects of the methodology that resulted in limitations to the generalisability of the findings are described openly.

2.6.6. Resonating with readers

The researcher strived to conduct the analysis in a way that captured the subjective experiences of the participants, and the analysis was reviewed with supervisors to try to ensure that biases were minimised in the interpretation of data. The write-up was reviewed by the field supervisor (a clinical psychologist with extensive experience in working with people living with dementia) to ensure that the wording was sensitive to the experiences of people living with dementia and avoided terms that were dehumanising or minimising of peoples' experiences.

2.6.7. Owning one's perspective

The theoretical orientations underpinning the research have been described overtly in statements about epistemological stance (see section 2.4.4: Semi-structured interviews with professionals). The impact of the researcher's background, values and assumptions was considered throughout the process of the research (see section 2.7 Reflection on Own Contribution and section 4.7 Own reflections on research process).

2.7. Reflection On Own Contribution

I am a 28-year-old white British Trainee Clinical Psychologist. My interest in the topic stemmed from personal and professional experiences of dementia. Caring for a grandparent with vascular dementia drew my attention to the challenges of accessing peoples' experiences when communication abilities are compromised. These experiences led me to feel passionate about peoples' rights to receive good quality care in the later stages of dementia. My interest was further developed by a six-month placement in an older peoples' service as part of my Clinical Psychology training. It was important to be aware of my own beliefs about what is and is not possible both in terms of using PREMs in services and the communication abilities of people with dementia. I tried to keep in mind the heterogeneity of the client group and the varying pressures on services that could introduce challenges that I personally had not experienced. I strived to acknowledge the influence of my own views and experiences and remain open-minded to new stories when conducting the project. I have reflected further on personal-professional

beliefs and the potential impact of these on the research in the discussion

(see section 4.7).

3.   Results

The results from each stage of the project are described below. Revisions were made to the PREM after stages 1 and 2; these are described throughout each section. Findings and themes are detailed as a narrative account of the data with respect to the research question (Braun & Clarke, 2006). Quotations are provided throughout to ground the results in examples and enable appraisal of the fit between the data and the interpretation of the results (Elliott, Fischer, & Rennie, 1999). For clarity, parts of some of the quotations have been omitted to remove non-relevant data. This is denoted by '…'.

3.1.   Stage 1: Focus Groups

The findings from the focus groups were grouped into participants' (Eight health professionals, two carers and one service-user) views about the content and the format of the new PREM (Appendix 23). The main findings are discussed below.

3.1.1. Content
3.1.1.1.   *Adapting items from the existing measures*

Professionals in particular identified how many of the items on the existing PROM/PREM would not apply to people living with moderate-advanced dementia.

I think some of the questions, like 'have you been given a care plan?', 'have you got a number to contact in a crisis?', I mean no-one's gonna be giving them that…this is more for someone else to check whether we're doing what we're supposed to be doing. Health Professional 1 (HP1)

Some participants commented on how the wording of some of the items might be challenging for people living with moderate-advanced dementia.

It's just too complex, some of the questions aren't they? 'Has the care or treatment you've received helped you to achieve your personal goals as set out in your care plan?', they've already forgotten, before you get to the end of it. HP1

Professionals described doubts about the appropriateness of some of the items on the accessible PREM for retention on the new measure. For example, examining the item 'was I nice to you?' prompted discussion about how although conveying a caring and compassionate stance is important, service-users may not always agree with decisions that professionals make in their best interest, and therefore may not think that the professional was nice to them.

If you're having a difficult discussion with somebody about something… HP1

Like if we're telling them that they've got to stop driving HP2

Tough love! We wouldn't be nice… HP3

This raised a challenge in striving to capture whether service-users feel that professionals have attended to the important aspects of their experience, despite sometimes making decisions that they disagree with.

3.1.1.2. Capturing what is important to people living with moderate-advanced dementia

All participants seemed to agree that good quality care from the perspective of service-users is defined by the extent to which a professional attends to the individual needs of the person.

> *They will remember if you've supported them to do something…it's about the individual person and what they find most helpful, you might go out and get a pint of milk for somebody and they think that's the best thing…*HP8

This suggested that seeking out and responding to the wishes of the individual characterises good quality care. When talking about negative experiences of care, the service-user and one of the carers shared their experiences of older people and those with dementia being excluded from interactions.

> *If there's someone with dementia…they won't ask the question to that person, they'll just talk over them. They don't take them as a person, they'll talk to the carer.* Carer 1 (C1)

When you become a pensioner, you are overlooked. Whether you've got dementia or not, people look through you, they treat you like a child… they don't want to involve you in conversations or things like that…you're excluded from a lot of things when you get older. Service-user (SU)

These views highlighted the potential for negative and disempowering interactions with people living with dementia. All participants seemed to agree that working collaboratively with service-users fosters interactions that are inclusive and supportive of personhood. This suggested that the PREM should capture the degree to which interactions included clients by eliciting and respecting their views. When asked what characterises good quality care, the service-user provided their views:

These things are getting difficult for me, but I do like to be having my own decisions, you know?...just tell me the truth. Tell me what is happening at the time and what is likely to happen…you need to have people [with advanced dementia] being treated with dignity and compassion. SU

These views were in agreement with ideas raised by the professionals, who proposed that being treated with dignity and respect and feeling heard and understood would be important areas to capture in the PREM.

3.1.2. Format

3.1.2.1.   Keeping it simple

Most of the participants were in agreement that even the simple format of the accessible PREM could be challenging for people in the advanced stages of dementia. They stressed the importance of keeping the questions concise and ensuring that the PREM was not too long. Participants spoke about considering sensory impairments that are common in older people, and ensuring that the design took this into account.

> *It's hard enough for me to read, I have problems reading small writing.* SU

The professionals suggested that the design should include text in large, clear font and different colours to help people to engage with the PREM. There were mixed views about the use of visual stimuli such as smiley faces, with the service-user, carers and some of the professionals favouring the use of smiley faces as a visual prompt, and other professionals expressing concern about the validity of these as universally recognised symbols. When reviewing the accessible PREM, some of the professionals felt that the combination of several words, five response options, supplementary pictures and smiley faces could be too much information for people to process.

> *The picture, I know it's there to supplement the question, but it makes it quite busy.* HP1

The participants were generally in favour of reducing the number of response options available and simplifying the appearance of any stimuli. They stressed

the importance of tailoring a measure to peoples' abilities, including considering how people are able to respond.

Even simple things like can they hold a pen, can they write their name. Sometimes at that stage they're not really writing much, so…does it have to be with a pen? HP3

Professionals gave ideas about how the idiosyncratic communication abilities of each client could be supported by presenting information in different modalities.

One option could be to use the pictures if people don't understand…you use a picture to kind of supplement really, 'cause I think…some people respond to pictures more than they would to conversation. HP3

In addition, some of the participants suggested that it would be valuable to record qualitative observations to capture nonverbal feedback from service-users who found it more challenging to engage in verbal interactions.

They might express a particular mood or a state of being in response to how a session is going…that's information that you could use as a sense of how they are in that moment, how they're responding to the session. HP6

3.1.2.2. Minimising the impact of cognitive impairments

Participants discussed the impact of cognitive impairments on the ability to reflect on experiences of care after a delay, which could limit the feedback

service-users are able to provide unless information is collected either during a session or immediately afterwards.

If you're going to be asking them about the treatment they had yesterday, they're going to have no recollection of that…so the focus is…getting an immediate response based on something you've done there and then. HP6

To overcome this, professionals recommended eliciting feedback soon after interactions. One participant provided an idea as to how the PREM could be administered flexibly to accommodate for memory impairments that could make it difficult for people to reflect on earlier parts of the session.

Another option for how to administer it is actually embedding it within the discussion that you have, so rather than having it as a separate bit of the session...actually ask [the question] right after you've summarised a bit so that it's in their minds and they're aware of it. HP6

Most participants said that offering pre-determined choices was also preferred, as it was felt this would assist people with executive function difficulties by adding structure and removing the need for generation of responses.

3.1.2.3. Collecting genuine feedback

Some of the discussion centred on how sincere feedback could be obtained from service-users if feedback is elicited by the professionals who are delivering their care.

I suppose the other thing is also about who does it?… if the person that's done the assessment administers it to the person who's answering it, there might be some bias there. They might feel obligated to say yes because of the classic 'I might not get the treatment that I need'. HP3

This raises the possibility of a bias that could threaten the validity of the PREM. However, across both focus groups, it was felt that the PREM should be something that people should be supported to do, as asking service-users to complete it independently could be overwhelming for them. Participants weighed up the risk of introducing a bias by professionals collecting feedback against the possibility of carers administering the PREM and intentionally or otherwise recording their own views of the person's experience.

So obviously the carer can help but they will kind of like bring their own stuff into it so that will be their experience of the person. So that's a big challenge. HP8

I think carers…shouldn't impose their will on anyone. SU

Reviewing these ideas, it was decided that the initial PREM should be designed as a tool that professionals complete within sessions, acknowledging that this method could result in a reluctance to provide honest feedback. This was taken into consideration when designing the cognitive interviews to ensure that it was explored and addressed as far as possible.

3.1.3. Producing a draft measure for cognitive interviews

The findings were gathered and discussed with the research team. Before

making decisions about items in the PREM, the findings from the focus group

were cross-referenced with ideas from the literature regarding important

aspects of patient experience (Gerteis et al., 1993) and important aspects of

care for people living with dementia (HIN, 2014; see table 2 in section 1.5.2

for a summary). This assisted decision-making about constructs to capture,

and helped to verify the content validity, particularly in light of the small

sample size in the service-user/carer focus group. Five primary items were

generated, and alternative wording was agreed where possible to inform

planned probes in the cognitive interviews and gauge which wording had the

highest level of clarity. Table 5 summarises each item and the constructs it

sought to access, alongside relevant domains from the patient experience

literature.

Table 5

Items on the initial draft PREM (Version 1 – cognitive interviews)

Item	Underlying construct	Primary wording	Alternative wording	Associated Picker principle/HIN domains
1	Supporting service-user to express their needs and responding to those needs	Did I listen to you?	Did I work with you/listen to your views?	Respect for patient-centred values, preferences and expressed needs/ Involvement
2	Valuing service-users' opinions and experiences, being collaborative not prescriptive	Did I treat you with respect?	Did I include you?	Respect for patient-centred values, preferences and expressed needs/Support to maintain some independence
3	Treating service-user as a person rather than seeing the dementia first	Was I interested in you as a person?	Did I try to get to know you?	Respect for patient-centred values, preferences and expressed needs /Dignity and empathy
4	Being caring and compassionate	Did you think I cared about you?	(no alternative wording produced)	Emotional support/Ongoing support
5	Providing all the information service-users want	Did I answer all of your questions?	Did I give you all the information you needed?	Communication and education/ Learning about dementia, using services

The findings from the focus groups regarding the design of the PREM were cross-referenced with literature about producing accessible materials for older people and people living with dementia (Dementia Engagement and Empowerment Project, 2013; Morrell, Shifren, & Park, 1999; National Institute on Aging, 2016; US Department of Health and Human Services, 2012). Further details of recommendations from these resources are displayed in Appendix 24.

Two different response scales were produced for the next stage of the project. These scales required participants to point to provide their answer, thus eliminating the need for writing. A full version of the draft PREM, including both response scales, (version 1 – cognitive interviews), is displayed in Appendix 10.

3.2. **Stage 2: Cognitive Interviews**

Some authors have used coding systems for the qualitative assessment of items to analyse the feedback obtained from cognitive interviews (see Willis, Schechter, & Whitaker, 1999). However, Willis (2005) suggests that it 'may be unnecessary to go to this level of detail in order to diagnose problems and make question modifications' (p. 167). Instead, it is sufficient to review each interview, recording qualitative comments about the problems raised with

each item, and aggregating these once all the interviews have been completed (Willis, 2005). In line with these recommendations, notes were made from the audio recordings of interviews (an example showing how these notes were organised is displayed in Appendix 25). Following this, ideas about possible areas for modification were extracted and collated in tables (Appendix 26). Further discussion with the research team assisted decision-making about revisions, particularly where contradictory opinions were expressed by participants. Revisions of different aspects of the PREM are discussed below.

3.2.1. Introduction to the PREM

Although all participants (Four professionals, three service-users and three carers) seemed to interpret the instructions as intended, some participants raised concerns that people living with advanced dementia might not understand the introductory page. Some of the professionals felt that it would be important to use only short sentences without any conjunctions (HP2: *"using sentences without any joining words, like tell me about your experiences"*). Two of the professionals did not approve of using the word 'feedback' (HP1*: "given the age group, is the word feedback something that is familiar for those people?"*, HP2: *"'feedback' is quite a technical word"*). Participants expressed a view that the words "I want" could be perceived as aggressive (HP1: *"'I want', or 'I would like?'"*). The wording was revised to respond to these suggestions. Some of the professionals said it would be important to provide a more comprehensive introduction to prime the service-

user about what to expect and explain the rationale for using the PREM. More detailed instructions were incorporated into the subsequent version of the PREM, ensuring that minimal information was presented on each page.

3.2.2. Response scales

All participants indicated that the response scale would be easy for them to use, and in practice they demonstrated that they could use the scale as intended, although one of the service-users required a more extensive explanation of the scale. All participants were in agreement that the scale with accompanying 'yes' and 'no' text was preferable to the scale with only a tick and a cross. Some of the participants speculated about whether it would be difficult for someone with advanced dementia to understand the scale (C3: *"I think some people might find that a bit difficult but I can't think of a way to make it better, I think you might still lose a few people on it"*). Professionals said that it would be important to test peoples' understanding of the scale before presenting the items to ensure that they were able to use it; therefore a practice scale was incorporated into the PREM for professionals to test service-users' understanding.

Views on the use of colour varied; one participant felt that using red/green might lead people to think red was 'wrong' and green was 'right', influencing peoples' responses (HP4: *"Indirectly suggests that no is wrong, it's better to keep it neutral"*). Given that this view was only expressed by one person, and the responses in the focus groups and the literature suggested that colour

could be helpful in supporting people to communicate, the coloured scale was retained at this stage.

3.2.3. Did I listen to you?

All participants demonstrated an understanding of the question that was in line with its intended meaning (e.g. C3: *"Sometimes when you tell a doctor something, they don't always answer with the answer you were expecting, so you don't know if they've listened to what you've said"*). However, participants suggested that people with advanced dementia could misunderstand the question.

> *…someone with advanced dementia would probably find that confusing, they'd make harder work of it than it is.* C1

> *I think probably [people with] moderate dementia [would understand], possibly people with more advanced dementia…may not even understand the question.* HP2

Participants suggested that reminding people of key points in the discussion (HP2: *"So today we've talked about X, Y and Z"*) could help by providing context. It was felt that it would be important to keep the discussion in the here and now, so the wording of this item and subsequent items was revised to reflect this ('*Have I listened to you today*?'). It was hoped that specifying a time period would provide context, supporting people to answer the question. For further discussion of revisions to support service-users with memory impairments, see the 'general comments' section below.

3.2.4. Did I treat you with respect?

For this item, participants acknowledged the wide range of meanings that could be attributed to the concept of 'respect' (HP1: *"It's a hard one because people have different perceptions of what respect means to them"*). When alternative ideas for wording the question were offered, some participants felt that these did not capture the concept of respect (HP1: *"It's slightly different, respect is more than including someone"*). However, participants indicated that service-users would have their own ways of knowing whether they felt respected (HP2: *"I suppose if they have a general feeling of OK-ness then they would consider they were treated with respect"*). The professionals provided some ideas about how the nature of their work could affect peoples' views:

> *Because of the nature of the questions we ask, for example if you're asking an older lady about personal care…she might find that offensive but it's part of our role and something we need to know about how they're coping day to day.* HP1

It was agreed that if service-users felt that they had not been respected as a result of an interaction with a professional, it would be important to capture this information, regardless of what had led them to feel this way. Given that the concept of respect had been raised as an important aspect of care both in the focus groups and in the literature, a re-worded version of the item was retained ('*Have I been respectful today*?').

3.2.5. Was I interested in you as a person?

Participants demonstrated an understanding of this item as intended (e.g. SU3: *"He [doctor] treats every person the same, so it's a no"*), but the majority preferred the alternative wording of the question (SU1: *"The word getting in the way was 'interested', because it's a very long word"*). People were in agreement that the alternative wording was more colloquial and succinct. It was agreed that the present tense version of the alternative wording should be adopted (*'Have I tried to get to know you today?')*.

3.2.6. Did you think I cared about you?

Participants generally felt that this item captured an important concept about professionals conveying a caring attitude, yet some participants felt that the word 'care' might have associations with personal (physical) care (HP2: *"People might immediately think of personal care, so whether there might be some confusion that they haven't done that but just sat here and talked"*). Other concerns were raised that people could experience the question as confrontational (HP1: *"It could sound confrontational, they might say 'why are you asking me this?'"*). Participants gave suggestions for alternative wording of this item, and after discussion with the research team, it was agreed that the wording should be revised to, '*Have you felt comfortable talking to me today?*'.

3.2.7. Did I answer your questions?

Professionals speculated that people with advanced dementia might not associate questions they had to the content of the session:

They might find it quite hard because they may not associate all your questions to stuff that's gone on in the room…asking questions that aren't related to the session, by nature of where their mind is. HP2

A re-worded version of the question was retained, as the findings from the focus groups and literature review suggested that an important indicator of good quality care involved service-users being provided with the information they wanted, regardless of whether or not this related to the content of the session. As with the previous items, participants suggested that providing context would be important to assist people with more advanced dementia to answer (HP4: *'Ground it in "in this interview"…in our meeting today, did I answer all of your questions?'*), and the item was re-worded as '*Have I answered your questions today?*).

3.2.8. Content of the PREM

All of the participants indicated that the five items covered the aspects of care that would be important to people living with dementia. Although some participants made suggestions about additional items, such as whether the session had ended with a clear plan going forward, it was felt that adding further items to the PREM would not be beneficial given that the important aspects of care were said to be captured by the existing items. Furthermore, the importance of brevity in the design of the PREM had been strongly emphasised throughout the focus groups and cognitive interviews.

3.2.9. General comments

When going through the items, a number of concerns were voiced about the impact of memory impairments:

> *She doesn't remember quite often something from ten minutes ago, so if the interview is half an hour long you won't get a full answer…C2*

> *I forget some things very quickly and it's very hard, she might say I told you 15 minutes ago but I don't have the attention span.* SU1

To respond to these concerns, the PREM was designed so that it could be used flexibly throughout the session, in line with a suggestion from one of the professionals at the focus groups. If professionals suspected that memory impairments could affect a service-user's recollection of the session, they were instructed to use the PREM partway through the session (e.g. at a break in the conversation or after the completion of an assessment tool) rather than waiting until the end of the session to collect feedback.

Participants identified a number of potential threats to the validity of service-users' responses, for example if they did not understand but wished to answer anyway due to social desirability bias or a wish to end the feedback process:

> *For some people they might be answering quite quickly to hurry things along or to please you.* HP4

I don't think she could [answer honestly], because I think she'd be afraid if you told the doctor no then they wouldn't give you treatment. C2

This was mentioned frequently, raising the concern that professionals could introduce a bias by eliciting feedback about their own performance. However, it was felt that the professionals were best placed to trial the PREM given their clinical experience, ability to attend a training session and regular professional contact with individuals in the target group. In order to address this concern, professionals were instructed to reassure service-users that providing genuine feedback would not result in any adverse outcomes for them. Professionals were instructed to ask people to elaborate on their responses to elicit more detailed feedback and check whether the 'scores' people provided were consistent with any extra qualitative feedback. They were also encouraged to check in with the person's understanding frequently, repeating questions to support communication and reduce the likelihood of acquiescence.

A number of participants suggested that it would be beneficial to include visual prompts to support peoples' understanding (e.g. HP2: *"My immediate thought would be having some ears on here, it could be sensory overload but if it was a simple diagram I think it would be alright"*). Remaining mindful of the concern that too many stimuli could be distracting, an optional visual prompt was provided for each item. These prompts were laminated cards with line drawings of symbols for use if service-users struggled with the verbal presentation of the questions.

The cognitive interviews also informed decisions about how participants'

responses should be recorded. Some participants said that it would be

important to record non-verbal information (HP3: 'Capture the qualitative

aspects as well as the yes/no'). For each item, there was a scale to record

responses and a space for qualitative comments and observations, with a

space at the end for any general comments or observations. A second draft

PREM including the visual prompts and the response sheet (version 2 – trial

with service-users) can be seen in Appendix 12. The results of the cognitive

interviews also informed the production of written guidance for professionals

about administering the PREM (Appendix 13).

3.3. **Stage 4: Trialling the PREM - Interviews with Professionals**

Four main themes, each with component subthemes (Table 6), were produced

from seven professionals' accounts of trialling the PREM with a total of 16

service-users. The themes were generated by analysing the interview

transcripts to extract aspects of professionals' reports that were salient and

interesting in the context of the research. The account of each theme is

interspersed with quotations, which were selected as they were felt to best

"capture the essence" of the theme being described (Braun & Clarke, 2006, p.

23).

Table 6

List of themes

Theme	Sub-themes	Number of participants contributing to the theme
1: Finding the right tool for the job	No room for another tool?	4
	How does it feel?	6
	Is direct feedback genuine?	5
2: Communicating with the person	Responding to the person, not the manual	7
	Not assuming it's right to use a PREM	6
	Getting to know people to find out what works	4
3: How dementia can get in the way	Symptoms can get in the way	7
	Beyond asking	4
4: What worked well?	Successes in using the PREM	5
	What worked for professionals	4
	Putting a PREM into practice	5

3.3.1. Theme 1: Finding the right tool for the job

Participants described a number of difficulties associated with using 'tools' like

the PREM to get feedback about peoples' experiences. This theme captures

the practical limitations in capturing feedback using a tool, and the feelings

evoked in different people when using it. It also describes concerns about the

authenticity of feedback.

3.3.1.1. No room for another tool?

Participants outlined the pressures professionals face in services, and how this can make it difficult to use tools. Reports indicated that professionals may view the PREM as additional 'paperwork' that adds to their workload.

> *I can't remember the last time I took one of the PROMs or PREMs out that we're supposed to … you're so busy doing all the other pieces of paperwork that have to be done.* HP2

Some participants detailed how they would prioritise clinical duties over using a PREM in a session.

> *By the time you've actually gone through, sort of worked with somebody, gone to their needs, addressed various different things with that person and perhaps with their carer…there isn't always the time I guess to then start doing this.* HP5

By striving to address peoples' needs, professionals are adhering to an important aspect of good quality care. However, these efforts will not be recorded if professionals do not have time to utilise the mechanisms available to monitor care quality. This highlights one of the challenges of introducing new tools into services.

3.3.1.2. How does it feel?

Participants spoke about their own reactions to the PREM. Some participants had noticed that they felt some anxiety about trialling a new tool. They may

have been conscious that using the tool improperly could affect the service-user's confidence in their abilities as a professional.

… you would think that well it's dead simple, so there's nothing to worry about, but that's not true you actually still need to be prepared, and have your paperwork in the right order so you look competent and know what you're doing. HP5

Participants reported that when service-users had struggled to use the PREM, it was upsetting for both the service-user and the professional.

I could see then that yeah this man, this is upsetting him, this is something he's not, you know, feeling comfortable with. I felt uncomfortable with it as well at that point. HP7

Some participants also speculated that using a tool that was not pitched at the right level could be irritating for service-users.

I think it could annoy them…they could feel they're being patronized.
HP5

Some of the participants shared their own emotional reactions to the feedback they were receiving from service-users, for example, feeling "rejected" (HP6) upon hearing of a service-user's dissatisfaction with their care. The potential for the PREM triggering negative emotions highlights the importance of careful planning when implementing such tools. Participants also spoke about how although a good rapport can facilitate the administration of tools, the absence of a good rapport could lead to reluctance to administer feedback tools.

I don't think I'd feel comfortable using it, if it was somebody as I say who you don't have such a good relationship with, or somebody who gets a bit stroppy and irritable. HP5

When explaining how they had selected service-users for the trial, participants indicated a tendency to choose service-users they felt they had a good rapport with.

… I chose somebody who I've worked well with, not because I thought I'd get positive feedback but because I know that she would probably be quite happy to do the questionnaire with me. HP5

This demonstrates that professionals may prefer to use feedback tools when they anticipate the process to be unproblematic and to potentially result in good feedback. Conversely, professionals may not use the tools with service-users who respond less favourably to the professionals providing care or to outcome measures in general.

3.3.1.3. Is direct feedback genuine?

Participants reported that certain people would not feel comfortable using any tools to provide feedback, particularly if they had less favourable views of the professional.

He doesn't actually like completing questionnaires because he feels that he wants to be pleasant to people. HP2

Some participants said that using a feedback tool directly with a service-user could be awkward. One participant gave an account of a situation in which

she used the PREM with someone who was not mobile, requiring her to kneel next to the service-user to present the PREM.

> *I think you're putting them in a really awkward situation, sitting close with them, asking them those questions, where it's you that they're assessing…* HP5

When the professional is supporting the service-user to respond to the PREM, the prominence of the power differential between the service-user and the professional is increased, as service-users are reminded that they are being asked to evaluate someone who is offering them a service. They may feel uneasy about giving negative feedback that may threaten the therapeutic relationship and result in the withdrawal of this service.

Participants detailed ways in which they believed the therapeutic relationship could hinder the process of obtaining genuine feedback.

> *… [the people who trialled the PREM were] people that I'd known for a very long time who like me and probably want to please me, and wouldn't want to upset me, by saying something negative.* HP3

This highlights the potential for a social desirability bias influencing the feedback people provide. Given these difficulties, participants frequently raised the idea of carers trialling the PREM instead of professionals.

> *I suppose if there's a carer involved, it's getting the carer to work with that person, because like usually I think you'll get the better, more honest response if you anonymise the questionnaire for*

people to reply back. So, if we can actually…train the carers how to

use it. HP2

Participants said that if feedback was anonymised, people might be more willing to voice their genuine views about how they had experienced care. Professionals did identify some challenges of setting this up, including the time pressures on carers.

… [carers] often just don't have time to do that sort of thing, I mean

we send out PROMs, PREMs, surveys get sent out, and there's a

very poor response rate. HP3

Participants also raised concerns that carers could impose their own views on feedback or influence the feedback that people provide.

…thinking about carers…having said that, carers…might influence

the patients. HP2

These ideas have implications for striving to collect genuine feedback that is minimally influenced by biases.

3.3.2. Theme 2: Communicating with the person

In their accounts of trialling the PREM, professionals detailed the variety of different experiences of communicating with different service-users. Through this, it became clear that a fundamental part of working well with people living with dementia is in looking beyond the diagnosis and examining the nuances of communication with each person individually. This theme captures this in the context of trialling the PREM, considering the importance of responding to

individual preferences, needs and abilities, and how a flexible approach is paramount if feedback is to be elicited from this group.

3.3.2.1. *Responding to the person, not the manual*

Professionals were provided with guidance about how to use the PREM, yet in practice they reported that for some people, adhering strictly to the guidance would have been detrimental to the feedback process.

> *…the scale with the colours…it would have complicated issues for him.* HP6

Participants reported successes from tailoring the way they used the PREM with different people, such as the gentleman discussed above, who responded better when the visual stimuli were removed. Participants also detailed how, in practice, the PREM could not always be administered in a standardised way.

> *…she was talking throughout it so there was conversation going on, it wasn't completely standardised, she would be asking me when she could go for lunch, while we were doing it, if I knew where so and so had gone and those sorts of things.* HP3

These reports suggest that a PREM needs to be responsive to what works for the individual rather than striving for a purely standardised process at the expense of getting feedback. One participant gave an example of how this could be done:

I just talk to them about…what's happened in their day, things like that. What they perhaps had for breakfast, um, their likes and dislikes, and then maybe I've slipped in a question you know once I've kind of, I suppose made them feel a bit easier. HP7

These ideas suggest that people should be instructed to use the PREM flexibly rather than indiscriminately administering it in ways that may not be effective for some people. The participants were generally in agreement that the PREM should be something that can be tailored to the individual, and gave ideas for how it could be used slightly differently with different people.

You could try using parts of this…having pictures within it for some people to see whether or not that would make a difference. HP3

Some reports gave rise to the idea that a stepped approach would be helpful for people with more advanced dementia who could not engage with the current version of the PREM. This could be done by providing different versions of the PREM.

I probably could've used a different tool to this…If we'd had something observational…you could tick off when someone's looking at you, whether they're calm, whether they're smiling. HP3

3.3.2.2.   Not assuming it's right to use a PREM

Participants' reports suggested that the PREM was not suitable for certain people who ostensibly met the research criteria, particularly if their cognition was relatively intact.

… a couple of times she said 'ooh this is silly', she wasn't angry or upset about it but she would probably have been able to use a more complex tool… she did make the odd comment that suggested that it was for children, for toddlers, that sort of thing. HP3

This instance demonstrates the importance of professionals exercising judgement to determine whether a measure is appropriate for use with someone, even if they appear to meet the criteria for its use. One participant described their experience of doing this:

I think by the time you've spent 20 minutes, half an hour whatever length of time you've spent for them, you might get a feel for, is this appropriate for them. HP4

Considering the suitability of the PREM for the person also requires taking account of more transient factors such as peoples' current emotional and physical states. One participant shared their views of how they make decisions about whether to try to communicate with service-users:

…if they don't wanna talk to you then accepting, you know…I'm not gonna gain anything and certainly it's not gonna be of any benefit to them me being there if I'm causing them to feel more anxiety or distress…you know if they've got a physical health difficulty going on, I think all of that should be taken into consideration as well. HP7

Professionals also outlined how they took account of other factors such as the environment, considering how this might affect the service-user and their ability to engage and communicate to the best of their abilities.

> *…there was maybe like a nurse and staff would be entering the room and leaving the room…for me it was a case of shall I proceed with it here, shall I take him somewhere else where we would be sitting one to one but for me it felt like he was quite settled, I didn't want to disturb him.* HP7

3.3.2.3.   Getting to know people to find out what works

Participants described how knowing service-users helped them to anticipate the communication techniques that would be more effective.

> *…I know him quite well, and I know that he's able to respond to short questions with short answers.* HP1

Prior knowledge can help professionals to determine whether someone will be able to engage with a tool like the PREM. Some participants gave examples of how getting to know service-users can foster good engagement, which could also assist in the feedback process.

> *I started to speak with him about his interests, you know his music, his likes and he was responding to me and I knew then that he was understanding what I was asking.* HP7

When professionals detailed their experiences of trialling the PREM, a diverse range of accounts emerged about how the PREM could be used in different ways to elicit feedback from different people. For example:

> *So then I realized that the visual cues with those, was sufficient for, so it sort of reinforced the information and it seemed to work. Reading to him, and then the visual cue, that helped him.* HP6

For other service-users, the visual prompts were not necessary to aid understanding, but regular prompting supported them to use the scale.

> *I didn't need to use the visual prompts, because they can actually read this…but making sure that he remembered it and where to go along the scale, and reminding him what it means along the scale.* HP2

These accounts illustrate the effectiveness of learning what works for each person and tailoring the administration of the PREM according to this.

3.3.3. Theme 3: How dementia can get in the way

Participants explained how during the course of the trial, they had encountered situations where dementia symptoms stood in the way of using the PREM to collect feedback. This theme aims to capture how the cognitive and non-cognitive symptoms of dementia can get in the way of successful use of the PREM as a feedback mechanism. This includes the specific challenges encountered when trialling the PREM with people with advanced dementia.

3.3.3.1. Symptoms can get in the way

A number of participants spoke about how cognitive and non-cognitive dementia symptoms can make it more difficult to engage people in verbal interactions. Not establishing a sufficient level of engagement can be an obstacle to using tools like the PREM.

> *One did not want to be approached at all, I mean she just walked away and she's not used to being interviewed and that's a usual part of her dementia…*HP6

The experiences of participants suggested that if service-users were agitated or distressed, they would not be able to engage with the PREM.

> *…he'd deteriorated an awful lot… he was too agitated to even look at these individual cue cards or anything.* HP3

When considering why people had not been able to use the PREM, some participants described how non-cognitive symptoms were the primary obstacle to obtaining any feedback.

> *…both of those were people that had got quite challenging behaviour and were agitated.* HP3

The participants also talked about ways in which cognitive impairments stood in the way of using the PREM. This was particularly problematic when professionals used the PREM in care homes, as it was more difficult to find a private space. One participant gave an example of how a service-user struggled to take part in the feedback process due to distractibility and impairments in attention.

…there was another client out on the other side that was distracting her, kind of doing this [rude gestures] to her, so I then closed the curtains thinking that would be OK but she'd already been a bit wound up by then as well. HP1

In some instances, the response from service-users led professionals to believe that service-users were not comprehending the PREM.

When I was… asking him have I listened to you today for one example, and pointing at the 'yes' 'no' response and the colour coded, where would you place yes/no pointing, umm, I don't think he understood, you know, I could tell he didn't understand because he just stared at it. HP7

For some participants, it was unclear whether the barrier lay in failing to understand the question, or whether impairments in attention could have resulted in the service-user becoming distracted from the aims of the interaction.

…instead of commenting on his interaction with me, the service provider, he goes off [on] tangents. HP6

The impact of cognitive impairments was particularly evident in the use of the response scale, with the majority of participants reporting unsuccessful experiences.

…this scale didn't really mean anything to her it didn't seem… she didn't get the idea of the scale at all. HP5

…but they couldn't use the [scale]...even when I prompted them a

few times, they weren't able to point and they looked quite confused

by it. HP1

Participants commonly reported that service-users did not appear to understand that they could provide a response other than 'yes' or 'no'.

…maybe if it should be a 'no', 'sometimes', 'yes' possibly, or maybe

there needs to be a mid-point on there…they're either looking 'no'

or 'yes', and although you're explaining to them, this is a scale, you

can point anywhere along here…I don't think my lady got it. HP5

3.3.3.2. Beyond asking

Participants who trialled the PREM with service-users in the advanced stages of dementia reported that the PREM could not be used successfully, despite efforts to make it accessible.

So, she obviously didn't have any speech, she didn't really

understand basic commands, so probably she was too impaired,

even for this. HP3

In a few cases, people with advanced dementia appeared to understand or engage initially, but subsequent responses indicated that this impression of understanding was incorrect, or short-lived.

The first lady appeared to understand when I was asking her if I

could administer it with her so we sat down and started to do it, but

she then became very very distressed, agitated, making grunting

noises, waving her arms round so I stopped. HP4

Some participants believed that service-users' responses were not reliable, even when they appeared to comply with the instructions.

So I think with the likes of him, even though he said no he didn't

feel I'd listened to him, I felt he was just because I'd said is it yes or

is it no, I felt he was just copying where I'd put my finger. HP1

Professionals' doubts about the communication abilities of service-users may lead them to modify their approaches, particularly when verbal communication is significantly impaired. In some cases, professionals described limiting their interactions with the service-user and communicating only with carers.

Getting any information out of her was hard… I held off virtually all

my questions for her, I had to ask the son. HP4

This can mean that carers, rather than service-users, are seen as the recipients of interventions. This could, in the eyes of professionals, eliminate the need to collect feedback from service-users. When speculating about people in the advanced stages of dementia and their capacity to communicate their feelings about interactions, some participants expressed a view that people with advanced dementia cannot initiate purposeful communication at all.

You really can't get any meaningful communication with them at

all…you don't know whether they're hot, cold, hungry, thirsty, to try

and get feedback from those people…on anything other than

picking up whether they're becoming less agitated or more agitated when you're with them. HP3

A prominent narrative from the accounts of participants emerged, suggesting that when people are no longer able to communicate meaningfully through verbal interactions, they cannot communicate at all. When this was the case, participants indicated that they would not attempt to collect feedback from people as they believe there is no merit in doing so.

People like that who I've met who you ask them even what their name is, will give you an answer that's completely muffled and disjointed and nothing to do with their name, I don't, I think that they would probably be beyond asking, understanding and something like that. HP5

Although the outcome of the trial suggested that the PREM could not be used to directly elicit verbal feedback from some people with advanced dementia, professionals reported instances where they were able to better understand the experiences of people with advanced dementia through the process of trialling the PREM.

I think, looking back at both of them…the feedback I was getting, I was getting meaningful feedback, I could see they were distressed, they weren't enjoying the process. HP3

Such instances describe more indirect inferences that may not be regarded as 'feedback' in the traditional sense, particularly in the context of outcome measures. However, the participants' reports suggested that even when the

PREM was not used as intended, the process resulted in professionals

gaining more insight about the experiences of service-users that could be

used to improve their care.

> *I felt he wanted to get his needs across and not the*
> *questionnaire…not my care necessarily… but…I got a sense of,*
> *this is his felt need at the time.* HP6

3.3.4. Theme 4: What worked well?

The majority of the professionals indicated that they had been able to use the

PREM to elicit feedback from service-users. This theme encapsulates these

success stories, detailing the nature of the interactions where people were

able to use the PREM to provide feedback and describing the aspects of

trialling the PREM that professionals viewed favourably. It also captures how

professionals believed the feedback could be used to drive improvements in

care.

3.3.4.1. Successes in using the PREM

Successful experiences with the PREM seemed to be characterised by a

good understanding of the intention of the PREM and what was required of

people completing it.

> *…it only took a couple of minutes because he understood*
> *straightaway what we were doing and why we were doing it.* HP2

Various participants reported that despite cognitive impairments, people were able to understand the concept of the PREM and use it as intended to provide feedback.

> *I didn't have to go over the question two or three times, I think she kind of got it, appeared to understand what I was asking her and the pointing thing was working, so she could remember to point.* HP4

At times, the level of understanding exhibited by the service-user took the professionals by surprise, demonstrating a level of ability that professionals were not aware of.

> *…I said, I'm just going to say the question again so you understand, have I tried to get to know you today, she said no. I said OK, can you think of any reason, she said, you already know me…I was quite surprised when she said that.* HP5

Even when people were not able to use aspects of the PREM, such as the scale, participants felt that people had still been able to use the PREM to pass on feedback about their views and experiences.

> *Because I felt that they were understanding the question that I was asking them, but they just weren't understanding that they had to point on that scale.* HP1

> *…then when, you feel comfortable talking to me he said 'yes', then he said 'I'm fine'. So that's a form of, without marking the, in the*

scale, he tells you its fine, so he gives you some idea of explaining

the scale in his own words. HP6

One participant spoke about their experience of how the PREM had helped to compensate for the specific impairments of one service-user.

The fact that he didn't have to find the words, he's very conscious of

the fact that he's now got some word-finding difficulties, so I think

for him that was what worked. HP3

Although people expressed a view that the potential for generalisation of the findings could be limited by the size of the trial and the heterogeneity of the client group, many of the participants were hopeful about the use of a similar tool in the future.

…I think it's the one experience, I can only go on the one time I've

used it, I think it worked well for the person I saw that day, and I

think it would work generally if I was to see other people in that

situation. HP2

I'm happy to use it… I think it has, it would be helpful in the future.
HP4

3.3.4.2.   What worked for professionals

Professionals provided ideas for aspects of the PREM that should be retained in future versions.

…I like it the way you provide us with this booklet because it's very clear, and it's very short, concise, to the point, so it's much easier for him to understand and see what it's about. HP2

Participants spoke about how although some of the research processes such as gaining consent to trial the PREM were time consuming, the use of the actual PREM was straightforward and it was not difficult to incorporate it into a session.

…it didn't add anything in terms of time, how long I had to spend with somebody. HP1

Some participants felt that the PREM enabled them to conclude a session in a more positive way, compared to the somewhat abrupt way that sessions could end.

…reflecting on what we'd just talked about… I think that was a nicer way to end than me just saying "I'm going now bye". HP4

Participants spoke about how the process of capturing qualitative information using the PREM could actually help the service-user to feel heard, thus improving the person's experience.

…the good part is that there's additional comments on the form…which actually captures, in a way, a narrative form of how did, so the patient feels, if I were the patient I would feel they listened to my feelings so it's not just like collecting some data. HP6

3.3.4.3. Putting a PREM into practice

Participants spoke about how they felt that feedback from the PREM could be used to drive changes that could be used to improve the experiences of people with dementia, for example by identifying where difficulties exist at the service level.

> *…one thing is really looking beyond [my practice] …what are the reasons that might be impeding my practice, is it because of training issues, is it resources, is it workload, so, with all different things, it may be resources, or something that's outside of my control as well.* HP2

Using feedback obtained from the PREM, the team as a whole could reflect on the changes that need to take place to improve experiences at an individual level.

> *…the team will discuss well actually why is that…could it be…you haven't got the time you need to spend with the person, you know is everybody under so much pressure that we're all rushing in, rushing out, and maybe you'd identify that that actually a person is not feeling listened to because you're not allowing them enough time.* HP5

Participants spoke about how they could use feedback from service-users to inform their work with service-users and tailor interventions to their individual needs.

…one could include this feedback in the recovery goal of the patient… as a clinician, it helps me to plan, work with the patient… to identify what the patient needs. HP6

Participants outlined how they might go about changing their practice to respond to negative feedback from service-users.

…if somebody is saying "no" or is more to a negative end of that, you could be asking "what could I have done to make you feel that you'd been listened to". HP3

Other participants reflected that by using the PREM, the service could communicate a commitment to a dementia-friendly stance that is responsive to the needs of service-users.

… at times I don't think that we are terribly dementia friendly in general. I think that sometimes we're asking lots and lots of questions, and it's not sometimes very pictorial…. I think it has a wider implication not just on feedback but also other ways we get information. HP4

3.4. Further development of the PREM

The results gave rise to suggestions about further development of the PREM. Some of the recommendations were in relation to specific aspects of the PREM; these are detailed in Appendix 27. Other more general recommendations about capturing feedback from people in the moderate-advanced stages of dementia also emerged from the findings. Through the

interviews, it became clear that using a single 'tool' to collect feedback from people living with moderate-advanced dementia may not adequately meet the needs of the entire client group. The findings can be used to inform the flexible approaches that services should adopt when attempting to get feedback from service-users with moderate-advanced dementia. This can help to avoid excluding people with more marked impairments. The clinical implications of the findings and ideas for how they could be taken forward are discussed in section 4.3.

4.   Discussion

This study explored the process of developing and conducting a small-scale pilot of a PREM for people living with moderate-advanced dementia. A qualitative methodology was used, refining the PREM through each stage of an iterative process. This culminated in the final stage in interviews with seven professionals who had trialled the PREM with sixteen service-users. Data were collected and analysed using thematic analysis, aiming to answer the following questions:

1. What are the successes in using the PREM to collect feedback from people living with moderate-advanced dementia?
2. What are the challenges in using the PREM to collect feedback from people living with moderate-advanced dementia?
3. How could feedback be used to drive improvements in care?

This chapter will initially summarise the findings of the current study in relation to the research questions, and then in greater depth consider the key themes generated in the interviews with professionals in relation to existing literature. The discussion will largely focus on the themes generated in the interviews with professionals, as this was the final outcome of the project. However, findings and implications associated with earlier stages of the research will be

discussed where necessary. Finally, implications for clinical practice and future research will be considered, as well as plans for dissemination and strengths and weaknesses of the research.

4.1. **Overview of Main Findings**

Professionals noticed a number of different successes and challenges when trialling the PREM with people living with moderate-advanced dementia. Successes were characterised by person-centred communication approaches. Participants described how they elicited feedback by tailoring the administration of the PREM to peoples' needs and abilities. They found that by using a flexible approach, they were able to access the experiences of service-users more effectively. They emphasised the importance of getting to know service-users to facilitate these processes. Participants described how some service-users were able to provide feedback in spite of cognitive impairments that could have presented an obstacle to them doing so. The accessible format of the PREM reportedly helped some people to communicate their experiences. When the PREM was well-matched to peoples' abilities, participants generally found it straightforward to use and reported that it could be used to elicit feedback.

Professionals also reported some challenges that could present obstacles to collecting feedback using the PREM. Alongside practical challenges such as having the time to complete the PREM, professionals sometimes felt that

service-users were not necessarily providing genuine feedback. Some professionals noticed negative responses to using the PREM in themselves and service-users; they said this could affect how able they felt to use it. Using the PREM in a standardised way would have presented a challenge for many of the service-users involved in the trial, and professionals said that it was not suitable for some of the people they attempted to trial it with. They described some instances where people were too high-functioning for the accessible format of the PREM, and other times when peoples' impairments stood in the way of them engaging in the feedback process. Participants communicated a view that the PREM was not suitable for use with people in the advanced stages of dementia, with some professionals suggesting that it would not be possible to collect any feedback from this group.

Participants gave some insights into how the PREM could be used to drive improvements in care. They felt that if the PREM could be used to collect feedback, this could help to identify how service pressures could be affecting their practice and affecting the experience of the service-user. They also suggested feedback could help them to adapt the ways they interacted with service-users to improve their experiences.

4.2. Key Findings

Existing literature and psychological theory will now be considered in relation

to the research findings, namely the four main themes generated from the

accounts of the professionals who trialled the PREM:

The right tool for the job

Communicating with the person

How dementia can get in the way

What worked well?

4.2.1. The right tool for the job

Participants reported that there were a number of things that could present

obstacles to using a feedback tool in services. They described feeling that

there may not be time to use a PREM on top of their existing clinical duties.

This finding is in line with existing research examining clinicians' views about

using outcome measures, which have found that clinicians can feel

"oppressed by paperwork demands" (Garland, Kruse, & Aarons, 2003, p. 403),

and clinicians may not use standardised tools in their clinical practice unless

they are compulsory (Batty et al., 2013; Garland, Kruse, & Aarons, 2003;

Gilbody, House, & Sheldon, 2002; Lueger et al., 2001).

Slade, Thornicroft, and Glover (1999) highlight how although the traditional iterative approach to developing feedback tools in conjunction with relevant stakeholders is effective in improving their psychometric properties, this approach often does not address the feasibility of using the tool within clinical practice. They suggest that by ensuring that brevity, acceptability, simplicity, availability, relevance and value are taken into account when designing a tool, its feasibility can be enhanced. The methodology in this study aimed to assess the feasibility of using a tool, and the reports from professionals indicated that although some of the consent processes associated with the research were time-consuming, it was feasible to use the PREM within a session due to its brevity and relatively straightforward method of administration. In the further development of feedback processes, it would be important to consider other factors affecting feasibility to ensure that professionals feel able to integrate the routine use of a PREM into their practice.

In the current study, professionals reported that they would generally prioritise clinical tasks over the use of the PREM as they were more concerned with addressing clinical needs. It may be that professionals did not view the PREM as part of the process of addressing peoples' needs. Garland, Kruse, and Aarons (2003) found that professionals viewed outcome measures as separate from the clinical judgement they have historically relied upon for capturing feedback from their clients. They suggested that ideological barriers rooted in the views held by clinicians could be more difficult to address than

practical challenges in implementing tools (Garland, Kruse, & Aarons, 2003).

Davies and Cleary (2005) present a number of potential barriers that can

challenge the implementation of tools at the organisational level (e.g.

competing priorities detracting from a focus on patient-centred care), at the

data level (e.g. lack of specificity) and at the level of the individual

professional (e.g. defensiveness and resistance to change on the part of

clinicians; Davies & Cleary, 2005). These factors may further explain the

resistance some participants expressed about using the PREM.

Abrahamson (1996) proposed that for clinicians to be willing to use a measure,

they must be involved in the process of developing the measure at every

stage. By collecting feedback from professionals throughout the research, the

current study met this standard. The information that was gathered about

professionals' views of tools can be used to consider how to thoughtfully

introduce feedback processes into services. This will be imperative given that

the views of professionals can facilitate or impede the use of feedback tools

(Garland, Kruse, & Aarons, 2003).

Professionals described the feelings that were evoked when using the PREM,

and how these could present a challenge to its use. They experienced

discomfort when service-users struggled to understand the PREM, and

anxiety about not administering it competently. Their reports seemed to be

rooted in concerns that using the PREM could have a negative impact on the

therapeutic relationship. These concerns fit with concepts from existing research about the use of outcome measures more generally. Youn, Kraus, and Castonguay (2012) describe how professionals may have concerns that feedback about their practice could be collected and used in a punitive way or that formalised measures could be detrimental to the therapeutic alliance. This may help to explain the apparent selection bias some of the professionals described when trialling the PREM, tending to choose service-users they had a good relationship with.

Boswell, Kraus, Miller, and Lambert (2015) suggest that challenges may arise in using measures if professionals have concerns about how the data will be used. In a review of the literature regarding professionals' experiences of using PROMs, Boyce, Browne, and Greenhalgh (2014) found that measures were viewed more positively when they were viewed as tools to assist care management of individual clients rather than ways of generating performance data about clinicians. This suggests that the ways in which tools are construed in services can influence the feelings evoked in association with them. Clarity about the purpose of a PREM and how feedback will be used could help to allay some of the concerns expressed by the professionals.

Throughout all stages of the project, participants expressed concerns about whether it was possible to acquire genuine feedback when directly asking service-users about their experiences. These concerns present a challenge in

the use of patient-reported measures, as the interpretation and use of feedback obtained using such tools is based on the assumption that people are reporting their experiences accurately (Lohr & Zebrack, 2009). In the current study, professionals felt that service-users would be less likely to report the negative aspects of their experiences of care. This is in agreement with findings from previous research, which indicate consistently high satisfaction ratings from surveys about healthcare (Edwards & Staniszewska, 2000; Sitzia & Wood, 1997; Williams, Coyle, & Healy, 1998; Willis et al., 2015).

Bauld, Chesterman, and Judge (2000) found that older people were even more likely to express higher levels of satisfaction than younger people, possibly due to concerns about support being withdrawn if they gave negative feedback, or an unwillingness to criticise individual professionals for fear of undermining their relationship with them. Although these findings refer to older people and not people living with dementia specifically, they suggest that the concerns raised by professionals may be justified and that service-users' feedback could have been positively skewed as a result of some of the above biases. Professionals' selection of service-users for the trial on the basis that they would most likely provide positive feedback may have further biased the responses.

Professionals provided their own views about the underlying causes of biases in feedback. Some participants speculated that service-users might avoid

giving negative feedback as they would not want to upset clinicians. In line with this, Geron (1998) describes how a systematic bias can exist whereby people provide socially desirable responses that they believe the interviewer would like to hear. Acquiescent responses ("a tendency to agree with statements regardless of their content"; Ware Jr, 1978, p. 328) and extreme response bias, where a person tends towards the positive or negative extreme response options (Willis et al., 2015) may also skew peoples' responses. Meisenberg and Williams (2008) found increased tendencies towards acquiescence and extreme responding in older people, and speculated about whether this was associated with a reluctance to challenge traditional values and social conventions (Meisenberg & Williams, 2008). Once again, the research pertains to older people and not people living with dementia specifically. However, it suggests that there may be truth in professionals' concerns about social desirability or other biases.

Bowling (2005) suggests that although face-to-face interviews can reduce the cognitive burden on respondents, this format is more likely to be associated with excessively positive or socially desirable responses due to the presence of an interviewer. This raises the question of whether the benefits of an interviewer supporting people with cognitive impairments are negated by the biases that may be introduced by the presence of the interviewer. This challenge was raised by some of the participants in the current study, and warrants further attention in the development of feedback processes.

Professionals suggested that asking service-users to submit anonymous feedback could reduce the impact of biases. However, participants also indicated that service-users would require some assistance to complete a PREM, so it may not be feasible for service-users to submit anonymous feedback independently. It has been suggested that biases can be reduced by collecting more in-depth feedback rather than using a single score, employing both positively and negatively worded items (Willis et al., 2015) or providing more response options to widen the distribution of scores (Geron, 1998). Measuring dissatisfaction is said to produce more reliable reflections of service-users' experiences (Sitzia & Wood, 1997; Williams, Coyle, & Healy, 1998). These suggestions could contribute to improving the validity of a tool, yet biases may still affect ratings.

Lohr and Zebrack (2009) encourage a critical approach that takes context into account. They suggest that because the process of using a PREM involves a social interaction, the "truth" that is conveyed in the exchange is a product of the different social, conversational and emotional influences that are present during the interaction. Consequently, any feedback provided using such methods is likely to be skewed in some way. They recommend considering multiple perspectives by triangulating information from different sources in order to try to gain an understanding of the service-user's experiences which can inform their care (Lohr & Zebrack, 2009). In the current study, participants spoke about how they would direct questions to carers, although this tended to be in situations where they were unable to communicate with the service-

user directly. It may be that incorporating feedback from both sources would result in a more reliable picture of service-users' experiences.

Most of the participants suggested that carers could assist service-users to reduce the influence of social desirability biases. However, they acknowledged that asking carers to assist service-users to complete the PREM could result in carers incorporating their own views into the feedback. This could risk furthering the malignant social psychology described by Kitwood (1993) by disempowering the person with dementia or invalidating their subjective experiences. If the role of the carer is not clearly demarcated, carers could provide responses on behalf of service-users rather than assisting them to communicate. Previous research has found that carers are not always accurate when speculating about the wishes of people living with dementia (Horton-Deutsch, Twigg, & Evans, 2007), questioning the reliability of carers as proxy responders (Boyer, Novella, Morrone, Jolly, & Blanchard, 2004; Novella et al., 2006; Yip, Wilber, Myrtle, & Grazman, 2001). This evidence led the current study to focus on striving to access the subjective views of service-users.

Participants acknowledged the value of using carers as a resource to support communication and reduce response biases, yet the risks of involving carers in the feedback process should be considered. Considering the findings from this study in the context of what is known from previous research, it may be

that some degree of bias will always be present when using supportive

communication methods to gather feedback. However, the risk of incurring

some biased responses should be weighed up against the risk of excluding

people living with dementia from participating in feedback processes entirely,

contributing to further marginalisation of the group. In line with

recommendations from research regarding other tools (e.g. the FFT; Sizmur,

Graham, & Walsh, 2015), the most sensible course of action may be to

interpret responses with caution and avoid using PREMs to compare

performances between different services if it is suspected that biases are

significantly influencing the data.

4.2.2. Communication with the person

Successful experiences of using the PREM seemed to be typified by flexibility

in administration. This is in agreement with the results of previous research

relating to gathering feedback from this group (Aggarwal et al., 2003). Strict

adherence to the instructions would have presented an obstacle to

communication in some cases, yet adopting a flexible approach could be

incompatible with established methods of collecting feedback. Edwards and

Staniszewska (2000) describe how the principal methods of collecting

feedback in services are "quantitative and to some extent reductionist,

working with implicit assumptions that we know what we want to measure and

are able to measure it" (p. 418). The use of standardised feedback tools are

widespread, as they are relatively straightforward and cost-effective to put into

practice, and services may have confidence in their use (Edwards &

Staniszewska, 2000). However, most of the available standardised measures have not been validated or adapted for people who struggle to understand them due to cognitive impairments (Kroll et al., 2012).

Participants described how it was difficult to remain standardised in their administration of the PREM. When discussing the administration of PROMs, Dawson, Doll, Fitzpatrick, Jenkinson, and Carr (2010) state that the wording of a validated tool should not be changed as small alterations can affect the psychometric properties of the tool. However, the heterogeneity across people living with moderate-advanced dementia presents a challenge to the use of a feedback tool with a strictly standardised administration process. Participants' reported successes in collecting feedback using flexible approaches suggest that this is an area for careful consideration in further development of the PREM. See 'implications for clinical practice and future research' (section 4.3) for further discussion of this.

Professionals' reports of trialling the PREM suggested that successful experiences of obtaining feedback involved drawing on knowledge about the person and how they communicate to assist the process of gathering their subjective experiences. Kitwood (1993) explains the manifestation of dementia as an interaction between personality, biography, physical health, neurological impairment and social psychology. By incorporating knowledge of peoples' personality and preferences in combination with considerations

about the environment and physical health, professionals were able to adapt their communication to administer the PREM successfully. Edvardsson, Winblad, and Sandman (2008) suggest that "successful interventions require the establishment and maintenance of a meaningful relationship, and this is of the utmost importance in person-centred care" (p.363). In the context of trialling the PREM, professionals' reports suggest that the therapeutic relationship was a useful resource in adapting communication and accessing the subjective experiences of service-users. However, the therapeutic relationship could also complicate the collection of feedback by introducing a bias (as discussed earlier in section 4.2.1).

Participants described ways in which they adapted communication to enable them to successfully trial the PREM with service-users. Røsvik, Brooker, Mjorud, and Kirkevold (2013) highlight that it is not the task but the way in which the task is carried out that is person-centred. Brooker (2004) describes a four-part composite definition of PCC using the VIPS framework: (a) Valuing people with dementia and those who care for them (V); (b) Treating people as Individuals (I); (c) Looking at the world from the Perspective of the person with dementia (P); (d) A positive Social environment (S). Professionals' successes in trialling the PREM can be understood within this framework. By striving to find ways of communicating with service-users, professionals were demonstrating a value base which supports people with dementia and does not devalue them due to age or cognitive impairments (Brooker, 2004). By adapting their administration of the PREM according to how service-users

responded, they were able to tailor communication to support each individual to communicate.

Professionals said that they considered the environment, peoples' emotional states and physical health to help them view the world from the perspective of people with dementia and anticipate how these factors could influence communication. By raising conversation topics of known interest to service-users, professionals were able to assist people to remain calm and focused and thus promote a positive social environment. These experiences suggest that adhering to the principles of PCC helped to reduce excess disabilities that could otherwise have presented an obstacle in the 'task' of using the PREM.

4.2.3. Dementia symptoms

Professionals reported that they were not able to use the PREM with people who were agitated or distressed, and spoke of how "challenging behaviour" had prevented some people from engaging with the PREM, particularly when people were in the more advanced stages of dementia. Engaging with the structured process of the PREM may be challenging for certain people at times. However, the idea of behaviour as an obstacle to communication has been challenged. Cohen-Mansfield (2001) argues that behaviour that is seen as challenging reflects an attempt to communicate a need that is not currently being met. James (2011) encourages professionals to view 'behaviours that challenge' not as obstacles but as methods to communicate beliefs or needs. The meaning of these behaviours can be considered within the context of an

individual's premorbid personality, cognitive/neurological deficits, perceptual/physical impairments and drug-related issues, all of which may contribute to the way that they express their needs (James, 2011).

Although professionals in the current study said that 'behaviours that challenge' sometimes stood in the way of using the PREM, they acknowledged that they were often still able to glean information about how someone was feeling or how they were experiencing their current situation by looking at nonverbal indicators; for example, whether or not they were distressed or unhappy. This suggests that even when 'behaviours that challenge' made it difficult to get feedback, professionals were still able to learn about the person's experiences if behaviour was conceptualised as an attempt to communicate.

Participants identified how cognitive impairments stood in the way of using the PREM as intended. At times, it was difficult to know whether service-users understood the purpose and process of the PREM. This finding is not surprising, considering the global cognitive impairments associated with moderate-advanced dementia (Clare, 2007). Difficulties were particularly evident in the use of the scale, with service-users struggling to understand how to use it or tending to avoid providing responses other than 'yes' or 'no'. It may be that impairments in attention (Kolanowski et al., 2012) and comprehension (Weirather, 2010) stood in the way of people engaging with

the scale, or the relatively open-ended format of the scale did not provide

enough structure for people, leading to an increase in the extreme response

biases that are said to be more prevalent in older people (Meisenberg &

Williams, 2008). Overall, the experiences of the professionals in trialling the

PREM suggested that in some cases, the PREM itself was not a suitable tool

for obtaining feedback. This was particularly true in the cases of service-users

with whom verbal communication was not possible. This leads to

consideration of the approaches that can be used to capture experiences from

these people.

Professionals indicated that a stepped approach to communication could be

used, using observational tools with people who cannot engage in verbal

communication to record information about their mood and implied wellbeing.

These ideas are in line with existing approaches that have been used to

understand the subjective experiences of people in the more advanced stages

of dementia, such as Dementia Care Mapping (DCM; Brooker, 2005). DCM

attempts to take the standpoint of the service-user (Kitwood, 1993) using an

observational approach. The method involves recording behavioural cues to

code what has happened to service-users in a care environment. DCM has

been used as a tool for practice development and research (Brooker, 2005),

demonstrating the utility of an observational approach.

Observational approaches have been criticised for failing to take into account the subjective views of service-users when considering their care needs (Murphy, Gray, & Cox, 2007). Murphy, Tester, Hubbard, Downs, and MacDonald (2005) reported success in the use of an adapted version of 'Talking Mats', an established visual framework, with people living withed dementia. They found that the supportive communication framework assisted people who had very limited verbal abilities to be able to express their views (Murphy et al., 2005). It may be that although using the PREM is not possible with some people, their views can still be accessed using creative methods that deviate from the traditional 'survey' approach. A difficulty may lie in considering how to incorporate this feedback within the quantitative framework favoured by services.

Many of the professionals expressed a belief that there was little utility in seeking the views of some service-users. Professionals reported that clients who were in the advanced stages of dementia would not be capable of communicating reliable feedback, and described how they would instead direct questions to carers. Despite demonstrating clear positive regard for service-users, the narratives expressed by professionals could unwittingly propagate the malignant social psychology described by Kitwood (1993). PCC is characterised by acknowledging a change or concealment in personhood rather than a loss (Edvardsson, Winblad, & Sandman, 2008), yet if professionals assume that people with advanced dementia are 'beyond asking', they may disempower service-users by neglecting to seek their views.

In these circumstances, service-users are viewed purely in terms of their symptoms, which can contribute to the diminishment of their personhood (Kitwood, 1997).

Using a social constructionist framework, Sabat and Harre (1992) propose that if a person with dementia is positioned as inadequate or confused, they will have their behaviour interpreted in a way that serves to confirm this explanation. People who are in regular contact with service-users are responsible for construing their symptoms and abilities, and if professionals express a view that people cannot communicate, this may constrain further attempts to ask service-users for their opinions, presenting a barrier to the consistent administration of feedback processes in services. Notwithstanding the undeniable challenges inherent in communicating with people in the advanced stages of dementia, it is important to consider how the dominant discourses in the dementia care system could lead to higher levels of excess disability. If professionals hold and express a view that personhood persists into the advanced stages of dementia, this helps to cultivate a culture of continuing to seek peoples' subjective experiences, even when they appear to find it difficult to communicate them.

4.2.4. Success stories
Despite reports of challenges using the PREM, most of the professionals described successes in using it to get feedback. They described how, despite cognitive impairments, most people were able to understand the purpose of

the PREM. Some of the service-users were able to use it as intended, and for some people, the accessible format compensated for specific impairments. This provides further support for the notion that people are able to provide feedback, if they are given the support to do so (Allan, 2001; Goldsmith, 1996). The fact that the PREM administration took place immediately after the session is likely to have helped people to minimise the impact of memory impairments (Moore & Hollett, 2003). Even when people struggled to use the PREM, they were still able to provide feedback in idiosyncratic ways.

Professionals described the strategies they used to assist people to give feedback. These were in line with 'enabling' dementia communication strategies, as presented by Adams and Gardiner (2005). They posit that communication within caring relationships can be 'enabling', where people "help people living with dementia to express their thoughts, feelings and wishes or represent the person with dementia as someone who is able to make decisions about their own care" (Adams & Gardiner, 2005, p. 190). In contrast, 'disabling' communication prevents people from expressing themselves and represents them as unable to make their own decisions. Professionals provided various examples of using enabling communication strategies, such as choosing to administer the PREM in a client's room to remove unwanted stimuli and minimise distractions, and valuing and respecting contributions by encouraging people to elaborate on their responses. These processes may have contributed to successful experiences of using the PREM.

Some professionals reported being surprised by the levels of insight and ability demonstrated by service-users. The process of using the PREM may have supported service-users to express greater levels of awareness ("the ability to hold a reasonable or realistic perception or appraisal of/and or respond accordingly to, a given aspect of one's environment, situation, functioning or performance"; Clare, 2010b, p. 20). Clare (2010b) describes how the nature of interpersonal interactions can impede or assist people to express their awareness. There is evidence to suggest that people often have a considerable degree of awareness, even in the advanced stages of dementia (Clare, Rowlands, Bruce, Surr, & Downs, 2008b). However, if people express any confusion or reduced orientation to reality, professionals may regard them as unaware and treat them as such (Clare et al., 2008b), limiting further interactions with them and reducing the likelihood of further expressions of awareness. Clare (2010b) recommends that professionals should acknowledge the reciprocal influence of interactions, and rather than assuming that someone does not have insight into their situation, they should strive to support the person to express their awareness. In the current study, using the PREM enabled professionals to learn about service-users' levels of awareness. A greater understanding of service-users' awareness may help professionals to better respond to individual needs.

Some participants reported that they appreciated the PREM as a more positive way of ending a session, thus improving their experience of the care

interaction. Marshall, Haywood, and Fitzpatrick (2006) reviewed the literature regarding the impact of using PROMs, and found that a significant minority of studies showed benefits of asking service-users to complete measures about particular aspects of their mental health such as depression. They acknowledged the relational nature of the process of consulting people about their symptoms or experiences. It may be that through using PROMs, the quality of the communication between professionals and clients is enhanced (Marshall, Haywood, & Fitzpatrick, 2006). Unsworth, Cowie, and Green (2012) found that both professionals and service-users found routine outcome measures helpful at times, and that outcome measures validated positive experiences of service-users.

Professionals in the current study described how they believed that capturing non-verbal, qualitative feedback could help service-users to feel more 'listened to'. These intermediate effects have not been a focus of research so far, and thus it is not possible to draw conclusions about the mechanisms by which they operate (Marshall, Haywood, & Fitzpatrick, 2006). Although conclusions must remain tentative in light of the small scale of the research, the current study provides preliminary evidence that using a PREM could positively influence the interactions between people living with dementia and professionals. Further exploration of this could help to explore the nature of this phenomenon in more depth.

Professionals described ways in which the feedback could drive improvements in care. They spoke about how feedback could help them to think about how to adapt their methods in response to how service-users experienced their care. They also felt the PREM could be used to identify the impact of service-wide issues such as resource shortages on the experiences of care for the individual. These ideas are in agreement with proposed applications of patient-reported measures described in the literature (Greenhalgh, 2009). Unfortunately, despite the assumed benefits associated with using patient-reported measures, the associated positive impact on care quality is more theoretical than empirical (Garland, Kruse, & Aarons, 2003). A review into the impact of using patient-reported measures suggested that there is little methodologically robust research to evidence the value of PROMs and PREMs as devices for improving care (Valderas et al., 2008). Although there is some evidence to suggest that service-user feedback can help to improve care (e.g. Reinders et al., 2011), this is only likely to take place if sufficient resources and infrastructure are available to use feedback about experiences of care (de Silva, 2013). This suggests that implementation of the ideas described by professionals about using feedback would require careful consideration in a service context. This will help to ensure that PREMs are used in a meaningful way and not imposed carelessly as perfunctory gestures to demonstrate that services are responding to policy recommendations.

4.3. Implications for Clinical Practice and Future Research

The findings of this project suggest that participants had some success in using the PREM to gather feedback, which indicates that there may be some scope for its further development for wider use. Suggestions that emerged about specific improvements to the PREM are summarised in Appendix 27; these can be used to refine the PREM for further trials. Despite the successes, participants also described how the PREM did not meet the needs of every service-user, and in some cases the tool was not an appropriate way of gathering feedback. Overall, this implies that although the PREM could be used to gather feedback about some peoples' experiences of care, adopting it as a single method of collecting feedback is likely to exclude some people in the target group. The findings therefore give rise to recommendations about how services can strive to meet the needs of the entire client group. Further research could elucidate the specific characteristics of an approach that enables the collection of feedback from all individuals with moderate-advanced dementia. Implications for clinical practice and ideas for future research will now be discussed.

4.3.1. Developing an approach rather than an individual tool

As a single tool is unlikely to be suitable for everyone in the target population, professionals should use their clinical judgement to determine how to approach the collection of feedback, remaining open-minded in their employment of strategies. Operationalising a flexible approach in services presents a challenge, as the metrics that are used to reflect care quality are

traditionally relatively uniform to enable comparison between services. Future research could further elucidate the properties of a feedback approach that enables a degree of flexibility, yet retains some uniform properties that would allow feedback data to be compared more widely between individuals and services. This could be done by defining flexibility as a construct and measuring how it is employed; for example, by quantifying and recording the extent to which people deviate from the standardised instructions when using feedback tools with people living with moderate-advanced dementia.

Adopting a stepped approach to the collection of feedback may be necessary, given the differences in the level of impairment across the client group. A stepped approach could incorporate the PREM produced through this project to collect feedback from people in the moderate stages of dementia who are able to participate in simple verbal exchanges. A further simplified version of the PREM could be provided for people with more marked cognitive impairments (e.g. a version using only single words or visual stimuli). An observational tool could then be offered for people in the more advanced stages of dementia who are unable to participate in any structured verbal interactions, perhaps undertaking more structured qualitative observations of changes in emotional expression or behaviour. If an observational tool was to be adopted, extensive investigation should ensure that it strives to capture the subjective experiences of the service-user with as much accuracy as possible.

Further research could adopt a similar methodology to the current study, using iterative processes to refine different versions of tools that form a broad approach to the collection of feedback. Qualitative methodologies would be important in establishing the conditions under which each tool should be used. Small-scale pilots with service-users could help to establish the specific characteristics of the target population for each tool to inform guidance for professionals who go on to administer the tool to service-users in the future.

4.3.2. A person-centred approach to collecting feedback

When eliciting feedback from people living with moderate-advanced dementia, professionals should exercise the principles of PCC, using their knowledge of the individual to tailor their communication according to peoples' strengths, interests and preferences. In line with established recommendations (Kitwood, 1993), professionals should consider static factors such as personality and history in conjunction with more dynamic factors such as physical health and the environment to tailor their communication and support people to provide feedback.

4.3.3. Trialling feedback processes on a larger scale

If further research was able to provide clarity about the use of a flexible or stepped approach, a larger-scale trial of the approach could be conducted to examine the psychometric properties of feedback tools and enable them to be distributed more widely for use in services. Before this happens, it would be essential to establish the mechanisms by which the use of experience

measures could contribute to improvements in care. Future research could gain a consensus on this by consulting experts using a Delphi methodology. Empirical investigations could then measure whether the introduction of experience measures contributes to improvements in care for people living with dementia.

4.3.4. Minimising biases through the method of administration

Given the social desirability biases that are likely to be introduced by professionals administering experience measures, it may be beneficial to consider other methods of administration. Ideas may include:

- Training carers to assist service-users to use the PREM, providing visual prompts such as photos and names of professionals to support service-users where necessary;

- Adopting a user-focused monitoring approach, in which other service-users (e.g. people in the early stages of dementia) administer tools to people in the moderate-advanced stages of dementia;

- Arranging for another member of the team to visit the service-user to administer the PREM.

The above suggestions would enable feedback to be anonymised if necessary, which could help to reduce social desirability biases. However, each approach would raise ethical considerations and require the allocation of resources, which could present further challenges.

4.3.5. Views of professionals and service-users about the PREM

The introduction of any feedback process needs to be carefully planned to ensure that there is stakeholder engagement with its use. Professionals should be offered support to understand the value of eliciting feedback about care, and to discuss ways of incorporating feedback mechanisms into their existing workload. Future research could use a qualitative approach (e.g. Grounded Theory) to further explore professionals' attitudes about gathering PREM data to understand where obstacles could lie at the level of the workforce. This research could help to elucidate the aspects of PREMs that professionals view favourably, as strengthening these could encourage professionals' involvement in the development and implementation of feedback processes.

Given the potential for negative emotional responses to the collection of feedback, professionals should be provided with opportunities to reflect on the difficulties in collecting feedback about their care, and to work through any concerns; for example, about the impact the process may have on the therapeutic relationship. Although the findings provide some insight into professionals' views about collecting feedback, details of service-users' views about PREMs remain elusive. Future research could employ qualitative methods to gain a greater understanding of what it is like for people living with dementia to give feedback about their experiences of care. This could help to advance understanding of the sources of bias in gathering feedback, and identify ways of reducing the impact of these.

4.3.6. Addressing beliefs about people with advanced dementia

There is a danger of the prevailing assumptions about dementia influencing practices in dementia care, leading professionals to limit their communication with service-users. To address historical beliefs about people with advanced dementia and their capabilities, there may be a role for clinical psychologists in providing training and consultation to offer an alternative view in line with the values asserted by Kitwood. It will be important to ensure that dismissive attitudes towards people with advanced dementia are challenged, and that professionals are encouraged to adopt a stance that acknowledges the personhood of people with advanced dementia. Professionals should strive to include people with advanced dementia and encourage them to express their views where possible. Services may need to reconsider conventional definitions of 'feedback' to ensure that the experiences of people with advanced dementia remain as important as those of any other service-user.

4.4. Dissemination

Dissemination of the results is essential to ensure that the findings can influence the processes of gathering feedback from service-users in a meaningful way. To this end, the findings from the project will be presented to the professionals at the research site. Suggestions for next steps will be presented to enable the service to act on some of the recommendations. The findings will also be shared with the co-ordinators of the dementia programme in an academic health science network, and the PREM will be shared at a

patient and public involvement meeting in another NHS trust. Further

collaboration with these programmes is planned in order to establish the best

methods of disseminating the findings to relevant academic, clinical and

service-user groups. Opportunities to share the findings with other special

interest groups (e.g. the Faculty for Psychology of Older People) will be

explored with supervisors in due course. An abridged version of the thesis

will be prepared for submission to suitable journals for publication.

4.5.   Strengths of the Project

Dementia is an area that has, until recently, been relatively under-represented

in clinical research (Alzheimer's Society, 2014). This is particularly true of

research that actively involves people living with dementia, with a historical

trend to overlook their perspectives (McKeown, Clarke, Ingleton, & Repper,

2010). This project demonstrates an effort not only to involve people living

with moderate-advanced dementia (including incorporating processes to

include people who did not have the capacity to consent), but to support the

development of initiatives that facilitate the collection of their views on a long-

term basis.

The project sought to encourage the collection of feedback about experiences

of care from people living with moderate-advanced dementia in services by

offering a tool to support the process. To the knowledge of the author, this is

something that has not been done previously, and therefore the project

addresses both a gap in the literature and a shortfall in service provision for this client group.

The project adds to the knowledge base about communication in people living with moderate-advanced dementia, offering evidence that with adequate support and person-centred approaches, people are often able to communicate their subjective experiences of the care process. The project offers an example of how PCC can enhance the delivery of a patient-reported measure, adding to the literature about the applications of PCC.

The project used a qualitative approach to explore the possibility of tailoring a tool. By referring to the available guidance (Elliott, Fischer, & Rennie, 1999), the project aimed to adhere to the recommended standards for quality in qualitative research. Through collecting the views of relevant stakeholders and adopting an iterative approach, the project sought to produce a user-defined tool that reflected the needs of the target client group. Although the conclusions suggest that a single tool may not be appropriate for all individuals in the target population, new knowledge was generated about how to approach the collection of feedback from individuals who may previously have been excluded from engaging in feedback processes.

4.6. Limitations of the Project

The most salient limitation of the project was its small scale. The sample size was relatively small across all stages, most notably in the service-user/carer focus group and the trial of the PREM. The findings have been interpreted in light of the small sample size, which means that conclusions must remain tentative at this stage.

The methods employed in the first two stages of the project (focus groups and cognitive interviews) were thought to be unsuitable for people in the moderate-advanced stages of dementia, and thus they were not recruited to take part. Although the PREM was trialled with people living with moderate-advanced dementia in stage 3, the findings were interpreted through the lens of the professionals' experiences, instead of asking service-users directly for their views about the PREM. Decisions about the sample and methodology were made by carefully weighing up the risks and benefits of including people in the target group versus producing a good quality PREM. It was ultimately decided that it was important to be guided by previous research regarding established processes in the early stages of scale development. However, by not capturing the views of the target group directly, the representativeness of the sample and applicability of the findings is somewhat limited.

Another factor that may have affected the representativeness of the sample was the use of HoNOS clusters as inclusion criteria. Professionals reported

concerns about trialling the PREM with people who were relatively able cognitively, and how they were aware that they may have been patronising recipients by implying that they could only understand simplified materials. Reports of confusion and uncertainty in allocation to clusters (Bekas & Michev, 2013) raises the concern that clusters may not have been a reliable method of 'staging' dementia. Using a staging instrument such as the Clinical Dementia Rating (Morris, 1997) could have helped to better ensure that the PREM was trialled with people who fit the criteria with regards to their cognition and communication.

The fact that the PREM was trialled as part of a research project introduced procedures that made the process more complicated. Professionals reported that although the PREM itself was relatively straightforward to trial, the consent procedures were time-consuming and introduced obstacles that led them to trial the PREM with fewer people. The lengthy consent procedures could have dissuaded some of the professionals from pursuing the research processes, particularly if they had to contact a consultee. Indeed, it was reported that a few service-users were excluded because a consultee was not readily available to comment on their wishes. This may have contributed to the small sample size in the pilot of the PREM.

When making the ethics application, it was agreed that collection of information about participants would be restricted to minimise the degree of intrusiveness for service-users and carers and encourage them to participate. However, collecting information about age, ethnicity and gender from service-users and carers would have helped to situate the sample and allowed for more clarity about the limits of generalisation. In practice, participants were extremely helpful and showed no reluctance to share their experiences, which suggests that they may not have objected to further information being collected. In hindsight, this could have been considered when making the ethics application as there would have been a justified argument for collecting demographic information.

4.7. **Own Reflections on Research Process**

This project was the first time I had conducted qualitative research. I appreciated the opportunity to embark on an in-depth exploration of peoples' experiences of an area that I am interested in. At times, I found the subjective nature of the interpretation of data somewhat unsettling, leading me to question the robustness of the analysis. My supervisors provided support in verifying the analysis of the data, and I was able to reflect on how my contributions may have influenced the interpretation of the data without devaluing the findings.

The project involved a number of stages. I noticed that I was sometimes concerned that the methodology may have compromised detail in order to complete each stage within the allotted timeframe. I tried to remain flexible and prioritise the collection of good quality data where possible, for example, by delaying one of the focus groups due to a small sample size. However, the process taught me that conducting research often involves unprecedented obstacles that may stand in the way of adhering to the plans as they were initially proposed. This knowledge will be useful in considering how to balance pragmatism with methodological robustness when I am involved in research in the future.

Despite the overwhelming support and positive feedback from professionals about the project, I was surprised to discover that there is still a degree of hopelessness within dementia services about cultural change in the dementia care system. A number of professionals expressed some reluctance to engage with the project, and seemed to refute the view that striving to gather the experiences of people with advanced dementia was valuable or even possible. This demonstrated to me the challenge that is presented to any individual or group wishing to effect change within the system. A great deal of commitment is required to drive reforms and challenge hopelessness about novel possibilities within dementia services.

I acknowledge that I conducted this project with experience of multiple different roles within the dementia system. My personal experiences of caring for a family member with dementia helped me to recognise the difficulties faced by service-users and their carers, and to remain enthusiastic and determined in the face of obstacles in the research process. These experiences may also have driven my inclination to challenge the view that people living with dementia are 'beyond asking', having observed first-hand the benefits of engaging people with advanced dementia. My experiences as a clinician enabled me to empathise with the pressures in services as described by professionals. Finally, as a researcher, I was inspired by previous and ongoing efforts by researchers in the field, and was proud to be part of a movement that is prompting significant changes in the ways that people living with dementia are viewed and treated. I also recognised that I was eager for the PREM to succeed, given my previous personal and professional experiences with dementia and my investment in the project as part of my Clinical Psychology training. By acknowledging the biases these views could introduce, I tried to ensure that I was as attentive to the challenges in using the PREM as I was to the successes. Through doing this, I aimed to present a balanced account of the findings.

4.8. Conclusion

This project consisted of the design and trial of a PREM for people living with moderate-advanced dementia. The findings provide some preliminary evidence that a PREM could be used to elicit feedback from this group. Given

the small scale of the pilot, further investigation is required to test methods of

collecting feedback on a larger scale and make definitive conclusions. This

may involve presenting the PREM as one option in a multi-faceted stepped

approach to accessing feedback from people living with moderate-advanced

dementia. At this stage, the project provides promising initial evidence that it

is possible to gather feedback about experiences of care from a group of

individuals who have historically been excluded from participating in feedback

processes.

5.   References

Abrahamson, L. S. (1996). *Effective implementation of an outcome measurement system: A case study of Psychsentinel.* Unpublished master's thesis. University of Connecticut.

Adams, T., & Gardiner, P. (2005). Communication and interaction within dementia care triads: Developing a theory for relationship-centred care. *Dementia, 4*(2), 185-205. doi: 10.1177/1471301205051092

Aggarwal, N., Vass, A., Minardi, H., Ward, R., Garfield, C., & Cybyk, B. (2003). People with dementia and their relatives: Personal experiences of Alzheimer's and of the provision of care. *Journal of psychiatric and mental health nursing, 10*(2), 187-197. doi: 10.1046/j.1365-2850.2003.00550.x

Ahronheim, J. C., Morrison, R. S., Baskin, S. A., Morris, J., & Meier, D. E. (1996). Treatment of the dying in the acute care hospital: Advanced dementia and metastatic cancer. *Archives of Internal Medicine, 156*(18), 2094-2100.

Albert, S. M., & Logsdon, R. G. (2000). *Assessing Quality of Life in Alzheimer's Disease*. NY: Springer.

Alborz, A., McNally, R., & Glendinning, C. (2005). Access to health care for people with learning disabilities in the UK: Mapping the issues and reviewing the evidence. *Journal of Health Services Research and Policy, 10*(3), 173-182. doi: 10.1258/1355819054338997

All-Party Parliamentary Group on Dementia. (2014). Building on the National
Dementia Strategy: Change, progress and priorities. (A.-P. P. G. o.
Dementia, Trans.) (pp. 9): All-Party Parliamentary Group on Dementia.

Allan, K. (2001). Communication and Consultation: Exploring Ways for Staff to
Involve People With Dementia in Developing Services. Bristol: The
Policy Press.

Alzheimer's Society. (2014). Dementia Research. from
https://www.alzheimers.org.uk/site/scripts/documents_info.php?docum
entID=429

Andersen, C. K., Wittrup-Jensen, K. U., Lolk, A., Andersen, K., & Kragh-
Sørensen, P. (2004). Ability to perform activities of daily living is the
main factor affecting quality of life in patients with dementia. *Health and
quality of life outcomes, 2*(1), 52. doi: 10.1186/1477-7525-2-52

Arons, A. M., Krabbe, P. F., Schölzel-Dorenbos, C. J., van der Wilt, G. J., &
Rikkert, M. G. O. (2013). Quality of life in dementia: A study on proxy
bias. *BMC Medical Research Methodology, 13*(1), 1-8. doi:
10.1186/1471-2288-13-110

Astell, A. J., & Ellis, M. P. (2006). The social function of imitation in severe
dementia. *Infant and Child Development, 15*(3), 311-319. doi:
10.1002/icd.455

Baddely, A., Logie, R., Bressi, S., Della Sala, S., & Spinnler, H. (1986).
Dementia and working memory. *The Quarterly Journal of Experimental
Psychology Section A: Human Experimental Psychology, 38*(4), 603-
618.

Ballard, C., Fossey, J., Chithramohan, R., Howard, R., Burns, A., Thompson, P., . . . Fairbairn, A. (2001). Quality of care in private sector and NHS facilities for people with dementia: cross sectional survey. *British Medical Journal, 323*(7310), 426-427.

Banerjee, S. (2010). Living well with dementia: Development of the national dementia strategy for England. *International Journal of Geriatric Psychiatry, 25*(9), 917-922. doi: 10.1002/gps.2598

Barrett, J., & Kirk, S. (2000). Running focus groups with elderly and disabled elderly participants. *Applied ergonomics, 31*(6), 621-629.

Basch, E., Snyder, C., McNiff, K., Brown, R., Maddux, S., Smith, M. L., . . . Wood, W. (2014). Patient-reported outcome performance measures in oncology. *Journal of Oncology Practice, 10*(3), 209-211. doi: 10.1200/JOP.2014.001423

Batty, M. J., Moldavsky, M., Foroushani, P. S., Pass, S., Marriott, M., Sayal, K., & Hollis, C. (2013). Implementing routine outcome measures in child and adolescent mental health services: From present to future practice. *Child and Adolescent Mental Health, 18*(2), 82-87. doi: 10.1111/j.1475-3588.2012.00658.x

Bauld, L., Chesterman, J., & Judge, K. (2000). Measuring satisfaction with social care amongst older service users: issues from the literature. *Health & social care in the community, 8*(5), 316-324.

Beattie, A., Daker‐White, G., Gilliard, J., & Means, R. (2004). 'How can they tell?' A qualitative study of the views of younger people about

their dementia and dementia care services. *Health & social care in the community, 12*(4), 359-368.

Bekas, S., & Michev, O. (2013). Payment by results: Validating care cluster allocation in the real world. *The Psychiatrist Online, 37*(11), 349-355.

Bjertnaes, O. (2014). Patient-reported experiences with hospitals: Comparison of proxy and patient scores using propensity-score matching. *International Journal for Quality in Health Care, 26*(1), 34-40. doi: 10.1093/intqhc/mzt088

Bobrovitz, N., Santana, M. J., Ball, C. G., Kortbeek, J., & Stelfox, H. T. (2012). The development and testing of a survey to measure patient and family experiences with injury care. *Journal of Trauma and Acute Care Surgery, 73*(5), 1332-1339. doi: 10.1097/TA.0b013e31825c4d57

Bobrovitz, N., Santana, M. J., Kline, T., Kortbeek, J., & Stelfox, H. T. (2015). The use of cognitive interviews to revise the Quality of Trauma Care Patient-Reported Experience Measure (QTAC-PREM). *Quality of Life Research, 24*(8), 1911-1919. doi: 10.1007/s11136-015-0919-5

Bond, J., Stave, C., Sganga, A., Vincenzino, O., O'connell, B., & Stanley, R. (2005). Inequalities in dementia care across Europe: Key findings of the Facing Dementia Survey. *International Journal of Clinical Practice, 59*(s146), 8-14. doi: 10.1111/j.1368-504X.2005.00480.x

Bosworth, A., Cox, M., O'Brien, A., Jones, P., Sargeant, I., Elliott, A., & Bukhari, M. (2015). Development and Validation of a Patient Reported Experience Measure (PREM) for Patients with Rheumatoid Arthritis (RA) and other Rheumatic Conditions. *Current rheumatology reviews, 11*, 1-7. doi: 10.2174/1573397111666150522093712

Bowling, A. (2005). Mode of questionnaire administration can have serious effects on data quality. *Journal of public health, 27*(3), 281-291. doi: 10.1093/pubmed/fdi031

Boyce, M. B., Browne, J. P., & Greenhalgh, J. (2014). The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: A systematic review of qualitative research. *BMJ quality & safety, 23*(6), 508-518. Retrieved from doi:10.1136/bmjqs-2013-002524

Boyer, F., Novella, J. L., Morrone, I., Jolly, D., & Blanchard, F. (2004). Agreement between dementia patient report and proxy reports using the Nottingham Health Profile. *International Journal of Geriatric Psychiatry, 19*(11), 1026-1034.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi: 10.1191/1478088706qp063oa

Britten, N. (1995). Qualitative interviews in medical research. *British Medical Journal, 311*(6999), 251-253.

Brooker, D. (2004). What is person-centred care in dementia? *Reviews in Clinical Gerontology, 13*(3), 215-222. doi: 10.1017/S095925980400108X

Brooker, D. (2005). Dementia Care Mapping: A Review of the Research Literature. *The Gerontologist, 45*(1), 11-18. doi: 10.1093/geront/45.suppl_1.11

Care Quality Commission. (2014). Cracks in the Pathway: People's experiences of dementia care as they move between care homes and hospitals.: Care Quality Commission.

Carpenter, M. A. (2004). The role of the physician for the elderly in the assessment, diagnosis and treatment of patients with dementia. In S. Curran & J. Wattis (Eds.), *Practical Management of Dementia: A Multi-Professional Approach*. Oxford: Radcliffe Medical Press.

Central London Community Healthcare. (2012). CLCH Quality Report: Community Learning Disability Services: Specialist Services: CLCH.

Charlesworth, G. (2008). Living at home. In M. Downs & B. Bowers (Eds.), *Excellence in dementia care: research into practice* (pp. 286-300). UK: McGraw-Hill Education.

Chenoweth, L., King, M. T., Jeon, Y.-H., Brodaty, H., Stein-Parbury, J., Norman, R., . . . Luscombe, G. (2009). Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *The Lancet Neurology, 8*(4), 317-325. doi: 10.1016/S1474-4422(09)70045-6

Clare, L. (2007). *Neuropsychological rehabilitation and people with dementia*. Hove: Psychology Press.

Clare, L. (2010a). Awareness in early-stage Alzheimer's disease: A review of methods and evidence. *British Journal of Clinical Psychology, 43*, 177-196. doi: 10.1348/014466504323088042

Clare, L. (2010b). Awareness in people with severe dementia: Review and integration. *Ageing and Mental Health, 14*(1), 20-32. doi: 10.1080/13607860903421029

Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008a). The experience of living with dementia in residential care: An interpretative phenomenological analysis. *The Gerontologist, 48*(6), 711-720. doi: 10.1093/geront/48.6.711

Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008b). 'I don't do like I used to do': A grounded theory approach to conceptualising awareness in people with moderate to severe dementia living in long-term care. *Social Science and Medicine, 66*(11), 2366-2377. doi: 10.1016/j.socscimed.2008.01.045

Clark, L. A., & Watson, D. (1995). Constructing validity: Basic issues in objective scale development. *Psychological Assessment, 7*(3), 309-319.

Clarke, V., & Braun, V. (2014). Thematic Analysis. In A. C. Michalos (Ed.), *Encyclopaedia of Quality of Life and Well-Being Reserch* (pp. 6626-6628). Dordrecht, Netherlands: Springer.

Cohen-Mansfield, J. (2000). Heterogeneity in dementia: Challenges and opportunities. *Alzheimer Disease & Associated Disorders, 14*(2), 60-63.

Cohen-Mansfield, J. (2001). Nonpharmacologic interventions for inappropriate behaviors in dementia: A review, summary, and critique. *The American Journal of Geriatric Psychiatry, 9*(4), 361-381.

Cohen, D. (1991). The subjective experience of Alzheimer's disease: The anatomy of an illness as perceived by patients and families. *The*

American Journal of Alzheimer's Care and Related Disorders and Research, 6, 6-11.

Davies, E., & Cleary, P. D. (2005). Hearing the patient's voice? Factors affecting the use of patient survey data in quality improvement. *Quality and safety in health care, 14*(6), 428-432. doi: 10.1136/qshc.2004.012955

Dawson, J., Doll, H., Fitzpatrick, R., Jenkinson, C., & Carr, A. J. (2010). The routine use of patient reported outcome measures in healthcare settings. *Bmj, 340*, c186. doi: 10.1136/bmj.c186

de Silva, D. (2013). Measuring patient experience: Evidence scan: The Health Foundation.

de Vries, K. (2003). Palliative care for people with dementia. In T. Adams & J. Manthorpe (Eds.), *Dementia Care* (pp. 114-135). London: Arnold Publishers.

Dementia Engagement and Empowerment Project. (2013). Writing Dementia-Friendly Information. In D. E. a. E. Project (Ed.): Dementia Engagement and Empowerment Project.

Department of Health. (1997). The new NHS: Modern. Dependable.

Department of Health. (2005). Mental Capacity Act. London: HMSO.

Department of Health. (2008). Guidance on nominating a consultee for research involving adults who lack capacity to consent. London: Department of Health.

Department of Health. (2009). Living well with dementia. London: Older People and Dementia Branch.

Department of Health. (2010a). Living Well With Dementia: A National

    Dementia Strategy. Leeds: Department of Health.

Department of Health. (2010b). Nothing ventured, nothing gained: risk

    guidance for dementia. London: Deparment of Health, Older People

    and Dementia Branch.

Department of Health. (2013). Dementia: A state of the nation report on

    dementia care and support in England. London: Deparment of Health.

Department of Health. (2014). The Mandate: A mandate from the Government

    to NHS England: April 2015 to March 2016. London: Department of

    Health.

DeVellis, R. F. (2012). *Scale Development: Theory and Applications*.

    Thousand Oaks, CA: SAGE Publications.

Dewing, J. (2008). Personhood and dementia: Revisiting Tom Kitwood's

    ideas. *International Journal of Older People Nursing, 3*(1), 3-13. doi:

    10.1111/j.1748-3743.2007.00103.x.

Doyle, C., Lennox, L., & Bell, D. (2013). A systematic review of evidence on

    the links between patient experience and clinical safety and

    effectiveness. *BMJ Open*, 3:e001570. doi: 10.1136/bmjopen-2012-

001570

Dubois, B., Feldman, H. H., Jacova, C., DeKosky, S. T., Barberger-Gateau,

    P., Cummings, J., . . . Jicha, G. (2007). Research criteria for the

    diagnosis of Alzheimer's disease: revising the NINCDS–ADRDA

    criteria. *The Lancet Neurology, 6*(8), 734-746. doi: 10.1016/S1474-

    4422(07)70178-3

Edvardsson, D., Fetherstonhaugh, D., & Nay, R. (2010). Promoting a

continuation of self and normality: person‐centred care as described

by people with dementia, their family members and aged care staff.

Journal of clinical nursing, 19(17‐18), 2611-2618. doi: 10.1111/j.1365-

2702.2009.03143.x.

Edvardsson, D., Winblad, B., & Sandman, P.-O. (2008). Person-centred care

of people with severe Alzheimer's disease: current status and ways

forward. *The Lancet Neurology, 7*(4), 362-367. doi: 10.1016/S1474-

4422(08)70063-2.

Edwards, C., & Staniszewska, S. (2000). Accessing the user's perspective.

Health & social care in the community, 8(6), 417-424. doi:

10.1046/j.1365-2524.2000.00267.x

Ekman, S. L., Norberg, A., Viitanen, M., & Winblad, B. (1991). Care of

demented patients with severe communication problems. *Scandinavian

Journal of Caring Sciences, 5*(3), 163-170.

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for

publication of qualitative research studies in psychology and related

fields. *British Journal of Clinical Psychology, 38*, 215-229.

Enache, D., Winblad, B., & Aarsland, D. (2011). Depression in dementia:

epidemiology, mechanisms, and treatment. *Current opinion in

psychiatry, 24*(6), 461-472. doi: 10.1097/YCO.0b013e32834bb9d4.

Ericsson, K. A., & Simon, H. A. (1980). Verbal reports as data. *Psychological

review, 87*(3), 215.

Ettema, T. P., Dröes, R.-M., de Lange, J., Ooms, M. E., Mellenbergh, G. J., & Ribbe, M. W. (2005). The concept of quality of life in dementia in the different stages of the disease. *International Psychogeriatrics, 17*(3), 353-370. doi: 10.1017/S1041610205002073

Frost, M. H., Reeve, B. B., Liepa, A. M., Stauffer, J. W., & Hays, R. D. (2007). What Is Sufficient Evidence for the Reliability and Validity of Patient-Reported Outcome Measures? *Value in Health, 10*, S94-S105. doi: 10.1111/j.1524-4733.2007.00272.x

Fugard, A. J. B., & Potts, H. W. W. (2015). Supporting thinking on sample sizes for thematic analyses: A quantitative tool. *International Journal of Social Research Methodology, 18*(6), 669-684. doi: 10.1080/13645579.2015.1005453

Garcia, S. F., Hahn, E. A., Magasi, S., Lai, J.-S., Semik, P., Hammel, J., & Heinemann, A. W. (2015). Development of self-report measures of social attitudes that act as environmental barriers and facilitators for people with disabilities. *Archives of physical medicine and rehabilitation, 96*(4), 596-603. doi: 10.1016/j.apmr.2014.06.019

Garland, A. F., Kruse, M., & Aarons, G. A. (2003). Clinicians and outcome measurement: What's the use? *The journal of behavioral health services & research, 30*(4), 393-405.

Geron, S. M. (1998). Assessing the satisfaction of older adults with long-term care services: Measurement and design challenges for social work. *Research on Social Work Practice, 8*(1), 103-119.

Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T. L. (Eds.). (1993). *Through the patient's eyes: Understanding and promoting patient-centered care*. San Francisco: Jossey-Bass.

Giesen, G., Meertens, V., Vis-Visschers, R., & Beukenhorst, D. (2012). Questionnaire Development. In Statistical Methods (201210). The Hague: Statistics Netherlands. Retrieved from https://www.cbs.nl/nr/rdonlyres/99b7482f-e09e-4d86-90a1-666dc42745bd/0/2012questionairedevelopmentart.pdf.

Gilbody, S. M., House, A. O., & Sheldon, T. A. (2002). Psychiatrists in the UK do not use outcomes measures. *The British journal of psychiatry, 180*(2), 101-103.

Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Methods of data collection in qualitative research: Interviews and focus groups. *British Dental Journal, 204*, 291-295. doi: 10.1038/bdj.2008.192

Girling, I., Day, E., Fazakerley, K., Gray, T., Hindmarsh, P., Musgrove, N., . . . Christie, D. (2015). What young people want from their diabetes team: developing a patient reported experience measure (PREM) for young people with type 1 diabetes. *Practical Diabetes, 32*(4), 142-147a. doi: 10.1002/pdi.1941

Glaser, B., & Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine.

Godwin, B., & Waters, H. (2009). 'In solitary confinement': Planning end-of-life well-being with people with advanced dementia, their family and professional carers. *Mortality, 14*(3), 265-284. doi: 10.1080/13576270903056840

Goldsmith, M. (1996). *Hearing the Voice of People with Dementia: Opportunities and Obstacles*. London: Jessica Kingsley Publishers.

Goodrich, J., & Cornwell, J. (2008). Seeing the Person in the Patient: The Point of Care review paper. London: The Kings Fund.

Greenhalgh, J. (2009). The applications of PROs in clinical practice: what are they, do they work, and why? *Quality of Life Research, 18*(1), 115-123. doi: 10.1007/s11136-008-9430-6

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (Vol. 2, pp. 105). Thousand Oaks, CA: Sage.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field methods, 18*(1), 59-82. doi: 10.1177/1525822X05279903

Hancock, G. A., Woods, B., Challis, D., & Orrell, M. (2006). The needs of older people with dementia in residential care. *International Journal of Geriatric Psychiatry, 21*(1), 43-49. doi: 10.1002/gps.1421

Henwood, A., & Ellis, M. (2015). Giving a voice to people with advanced dementia. *The Psychologist, 28*(12), 976-979.

HIN. (2014). What is important to people with dementia: Statements to help assess healthcare quality based on empirical research. In S. L. Health Innovation Network (Ed.). London: Health Innovation Network.

Hoe, J., Hancock, G., Livingston, G., & Orrell, M. (2006). Quality of life of people with dementia in residential care homes. *British Journal of Psychiatry, 188*, 460-464. doi: 10.1192/bjp.bp.104.007658

Holst, G., & Hallberg, I. R. (2003). Exploring the meaning of everyday life, for those suffering from dementia. *American Journal of Alzheimer's Disease and Other Dementias, 18*(6), 359-365. doi: 10.1177/153331750301800605

Hopwood, B., Lloyd, K., Tallett, A., Chow, C., & Warner, J. (2011). Developing an allergy specific patient reported experience measure (PREM). *Archives of Disease in Childhood, 96*(Suppl 1), A48-A48. doi: 10.1136/adc.2011.212563.107

Horton-Deutsch, S., Twigg, P., & Evans, R. (2007). Health care decision-making of persons with dementia. *Dementia, 6*(1), 105-120. doi: 10.1177/1471301207075643

House of Commons Health Committee. (2004). Palliative Care: Fourth Report of Session 2003-04. In H. o. C. London (Ed.), (Vol. 1). London: House of Commons London: The Stationery Office Limited.

Hubbard, G., Cook, A., Tester, S., & Downs, M. (2002). Beyond words: Older people with dementia using and interpreting nonverbal behaviour. *Journal of Ageing Studies, 16*(2), 155-167. doi: 10.1016/S0890-4065(02)00041-5

Hughes, C. P., Berg, L., Danziger, W. L., Coben, L. A., & Martin, R. L. (1982). A new clinical scale for the staging of dementia. *The British journal of psychiatry, 140*(6), 566-572.

Jahagirdar, D., Kroll, T., Ritchie, K., & Wyke, S. (2012). Using patient reported outcome measures in health services: A qualitative study on including people with low literacy skills and learning disabilities. *BMC Health Serv Res, 12*, 431. doi: 10.1186/1472-6963-12-431

James, I. A. (2011). *Understanding behaviour in dementia that challenges: a guide to assessment and treatment*: Jessica Kingsley Publishers.

Johanson, G., & Brooks, G. (2010). Initial scale development: Sample size for pilot studies. *Educational and Psychological Measurement, 70*(3), 394-400. doi: 10.1177/0013164409355692

Kitwood, T. (1993). Person and process in dementia. *International Journal of Geriatric Psychiatry, 8*(7), 541-545.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.

Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: personhood and well-being. *Ageing and society, 12*(3), 269-287.

Kolanowski, A. M., Fick, D. M., Yevchak, A. M., Hill, N. L., Mulhall, P. M., & McDowell, J. A. (2012). Pay Attention!: The Critical Importance of Assessing Attention in Older Adults with Dementia. *Journal of gerontological nursing, 38*(11), 23-27. doi: 10.3928/00989134-20121003-05

Kroll, T., Wyke, S., Jahagirdar, D., & Ritchie, K. (2012). If patient-reported outcome measures are considered key health-care quality indicators, who is excluded from participation? *Health Expectations, 17*(5), 605-607. doi: 10.1111/j.1369-7625.2012.00772.x

Krueger, R. A. (1994). *Focus groups: A Practical Guide for Applied Research*. Thousand Oaks, CA: Sage Publications.

Kuzel, A. J. (1992). Sampling in qualitative inquiry. In B. F. Crabtree & W. L. Miller (Eds.), *Doing qualitative research: Research methods for primary care* (3rd ed., pp. 31-44). Thousand Oaks, CA: Sage Publications.

Lindow, V., & Morris, J. (1995). *Service User Involvement: Synthesis of Findings and Experiences in the Field of Community Care*. York: York Publishing Services.

Lohr, K. N., & Zebrack, B. J. (2009). Using patient-reported outcomes in clinical practice: challenges and opportunities. *Quality of Life Research, 18*(1), 99-107. doi: 10.1200/JCO.2013.53.4271

Lueger, R. J., Howard, K. I., Martinovich, Z., Lutz, W., Anderson, E. E., & Grissom, G. (2001). Assessing treatment progress of individual patients using expected treatment response models. *Journal of consulting and clinical psychology, 69*(2), 150.

Mander, C., & Rigby, C. (2014). Obtaining patient feedback for doctors revalidation using accessible resources: A service evaluation to investigate the development and implementation of accessible multi-source feedback resources for doctors' revalidation within Solent NHS Trust. *Accessible MSF Project, Solent NHS Trust.* 2014, from http://www.solent.nhs.uk/_store/documents/accessible_patient_feedback_report.pdf

Marshall, S., Haywood, K., & Fitzpatrick, R. (2006). Impact of patient-reported outcome measures on routine practice: a structured review. *Journal of Evaluation in Clinical Practice, 12*(5), 559-568. doi: 10.1111/j.1365-2753.2006.00650.x

Mayhew, P. A., Action, G. J., Yauk, S., & Hopkins, B. A. (2001). Communication from individuals with advanced DAT: Can it provide clues to their sense of self-awareness and wellbeing? *Geriatric Nursing, 22*(2), 106-110.

McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of clinical nursing, 19*(13‐14), 1935-1943. doi: 10.1111/j.1365-2702.2009.03136.x.

McVeigh, C., & Passmore, P. (2006). Vascular dementia: prevention and treatment. *Clinical Interventions in Ageing, 1*(3), 229-235.

Meisenberg, G., & Williams, A. (2008). Are acquiescent and extreme response styles related to low intelligence and education? *Personality and Individual Differences, 44*(7), 1539-1550. doi: 10.1016/j.paid.2008.01.010

Mental Health Research Network. (2013). Good Practice Guidance for Involving People with Experience of Mental Health Problems in Research. London: National Institute for Health Research.

Mitchell, S. L., Kiely, D. K., & Hamel, M. B. (2004). Dying with advanced dementia in the nursing home. *Archives of Internal Medicine, 164*(3), 321-326. doi: 10.1001/archinte.164.3.321

Monmouth Partners. (2014). A Guide to Patient Reported Measures - Theory, Landscape and Uses. London: Monmouth Partners.

Moore, T. F., & Hollett, J. (2003). Giving voice to persons living with dementia: The researcher's opportunities and challenges. *Nursing Science Quarterly, 16*(2), 163-167. doi: 10.1177/0894318403251793251793

Morgan, D. L. (1996). *Focus groups as qualitative research*. Thousand Oaks, CA: Sage publications.

Morrell, R. W., Shifren, K., & Park, D. (Eds.). (1999). *Processing of medical information in aging patients: Cognitive and human factors*

perspectives. Mahwah, NJ: Lawrence Erlbaum Associates, Inc., Publishers.

Morris, J. C. (1997). Clinical dementia rating: A reliable and valid diagnostic and staging measure for dementia of the Alzheimer type. *International Psychogeriatrics, 9*(S1), 173-176. doi: 10.1017/s1041610297004870

Morrison, R. S., & Siu, A. L. (2000). A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. *Journal of pain and symptom management, 19*(4), 240-248.

Morse, J. M. (2010). " Cherry picking": writing from thin data. *Qualitative Health Research, 20*(1), 3. doi: 10.1177/1049732309354285

Moyle, W. (2010). Is quality of life being compromised in people with dementia in long-term care? *International Journal of Older People Nursing, 5*(3), 245-252. doi: 10.1111/j.1748-3743.2010.00230.x

Murphy, J., Gray, C. M., & Cox, S. (2007). Communication and dementia: How talking mats can help people with dementia to express themselves: Joseph Rowntree Foundation.

Murphy, J., Tester, S., Hubbard, G., Downs, M., & MacDonald, C. (2005). Enabling frail older people with a communication difficulty to express their views: the use of Talking Mats™ as an interview tool. *Health & social care in the community, 13*(2), 95-107. doi: DOI: 10.1111/j.1365-2524.2005.00528.x

National Collaborating Centre for Mental Health [UK]. (2007). Dementia: A NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care. Leicester.

National Institute on Aging. (2016). Making Your Printed Health Materials Senior Friendly. Retrieved 31/1/2016, from https://www.nia.nih.gov/health/publication/making-your-printed-health-materials-senior-friendly

Nelson, T., Livingston, G., Knapp, M., Manela, M., Kitchen, G., & Katona, C. (2002). Slicing the health service cake: The Islington study. *Age and ageing, 31*(6), 445-450.

NHS England. (2014). The Friends and Family Test. Redditch: NHS England.

Novella, J. L., Boyer, F., Jochum, C., Jovenin, N., Morrone, I., Jolly, D., . . . Blanchard, F. (2006). Health status in patients with Alzheimer's disease: an investigation of inter-rater agreement. *Quality of Life Research, 15*(5), 811-819. doi: 10.1007/s11136-005-5434-7

Parkin, E., & Baker, C. (2015). *Dementia - Improving diagnosis, care and research and statistics on prevalence*. House of Commons Library Briefing Paper 07007.

Patton, M. Q. (2002). *Qualitative Research and Evaluation Methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Perry, R. J., & Hodges, J. R. (1999). Attention and executive deficits in Alzheimer's disease: A critical review. *Brain, 122*, 383-404.

Phinney, A. (2008). Toward understanding subjective experiences of dementia. In M. Downs & B. Bowers (Eds.), *Excellence in Dementia Care: Research into Practice* (First ed., pp. 36-51). UK: McGraw-Hill Education.

Potkins, D., Myint, P., Bannister, C., Tadros, G., Chithramohan, R., Swann, A., . . . Ballard, C. (2003). Language impairment in dementia: Impact

on symptoms and care needs in residential homes. *International Journal of Geriatric Psychiatry, 18*(11), 1002-1006.

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, M., . . . Salimkumar, D. (2014). *Dementia UK: Second Edition - Overview*. London: King's College, London.

Prorok, J. C., Horgan, S., & Seitz, D. P. (2013). Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies. *Canadian Medical Association Journal, 185*(14), E669-680. doi: 10.1503/cmaj.121795

Pusic, A. L., Klassen, A. F., Scott, A. M., Klok, J. A., Cordeiro, P. G., & Cano, S. J. (2009). Development of a new patient-reported outcome measure for breast surgery: the BREAST-Q. *Plastic and reconstructive surgery, 124*(2), 345-353. doi: 10.1097/PRS.0b013e3181aee807

Raczka, R., Theodore, K., & Williams, J. (2014). *Feedback survey (Accessible PREM)*. Questionnaire. London Borough of Hammersmith and Fulham. Central London Community Healthcare.

Raczka, R., Williams, J., & Theodore, K. (2014). Making the Family and Friends Test accessible for adults with intellectual disabilities. *The Bulletin, 12*(3), 12-18.

Reinders, M. E., Ryan, B. L., Blankenstein, A. H., van der Horst, H. E., Stewart, M. A., & van Marwijk, H. W. (2011). The effect of patient feedback on physicians' consultation skills: a systematic review. *Academic Medicine, 86*(11), 1426-1436. doi: 10.1097/ACM.0b013e3182312162

Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (2013). *Qualitative research practice: A guide for social science students and researchers*. Thousand Oaks, CA: Sage.

Røsvik, J., Brooker, D., Mjorud, M., & Kirkevold, Ø. (2013). What is person-centred care in dementia? Clinical reviews into practice: the development of the VIPS practice model. *Reviews in Clinical Gerontology, 23*(02), 155-163. doi: 10.1017/S0959259813000014

Royal College of Paediatrics and Child Health. (2011). The Development of a Patient Reported Experience Measure (PREM) survey for children 0-16 years in Urgent and Emergency Care. London.

Rutherford, T. (2012). *Population ageing: Statistics*. House of Commons Library Standard Note 03228.

Sabat, S. (2001). *The Experience of Alzheimer's Disease: Life Through a Tangled Veil.* Oxford: Blackwell.

Sabat, S. R., & Harre, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing and society, 12*(4), 443-446.

Sampson, E. L., Blanchard, M. R., Jones, L., Tookman, A., & King, M. (2009). Dementia in the acute hospital: prospective cohort study of prevalence and mortality. *The British journal of psychiatry, 195*(1), 61-66. doi: 10.1192/bjp.bp.108.055335

Sampson, E. L., Gould, V., Lee, D., & Blanchard, M. R. (2006). Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age and ageing, 35*(2), 187-189. doi: 10.1093/ageing/afj025

177

Sawicki, G. S., Garvey, K. C., Toomey, S. L., Williams, K. A., Chen, Y., Hargraves, J. L., . . . Finkelstein, J. A. (2015). Development and Validation of the Adolescent Assessment of Preparation for Transition: A Novel Patient Experience Measure. *Journal of Adolescent Health, 57*(3), 282-287. doi: 10.1016/j.jadohealth.2015.06.004.

Scally, G., & Donaldson, L. J. (1998). Clinical governance and the drive for quality improvement in the new NHS in England. *British Medical Journal, 317*(7150), 61. doi: 10.1136/bmj.317.7150.61

Sekerak, R. J., & Stewart, J. (2014). Caring for the Patient With End-Stage Dementia. *Annals of Long-Term Care: Clinical Care and Aging, 22*(12), 36-43.

Sitzia, J., & Wood, N. (1997). Patient satisfaction: A review of issues and concepts. *Social science & medicine, 45*(12), 1829-1843.

Sizmur, S., Graham, C., & Walsh, J. (2015). Influence of patients' age and sex and the mode of administration on results from the NHS Friends and Family Test of patient experience. *Journal of Health Service Research Policy, 20*(1), 5-10. doi: 10.1177/1355819614536887

Slade, M., Thornicroft, G., & Glover, G. (1999). The feasibility of routine outcome measures in mental health. *Social psychiatry and psychiatric epidemiology, 34*(5), 243-249.

Smith, J. A., Flowers, P., & Osborn, M. (1997). Interpretative phenomenological analysis and the psychology of health and illness. In L. Yardley (Ed.), *Material Discourses of Health and Illness* (pp. 68-91). London: Routledge.

Strauss, A., & Corbin, J. (1990). *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Newbury Park, CA: Sage.

Streiner, D. L., Norman, G. R., & Cairney, J. (2014). *Health measurement scales: a practical guide to their development and use*: Oxford university press.

Struble, L. A., Kavanagh, J., & Blazek, M. (2013). *Services for people with moderate dementia*. West Sussex: John Wiley & Sons.

Tappen, R. M., Williams-Burgess, C., Edelstein, J., Touhy, T., & Fishman, S. (1997). Communicating with individuals with Alzheimer's disease: examination of recommended strategies. *Archives of Psychiatric Nursing, 11*(5), 249-256.

Tappen, R. M., Williams, C., Fishman, S., & Touhy, T. (1999). Persistence of self in advanced Alzheimer's disease. *The Journal of Nursing Scholarship, 31*(2), 121-125.

Taylor, R. M., Fern, L. A., Solanki, A., Hooker, L., Carluccio, A., Pye, J., . . . Whelan, J. S. (2015). Development and validation of the BRIGHTLIGHT Survey, a patient-reported experience measure for young people with cancer. *Health and quality of life outcomes, 13*, 107. doi: 10.1186/s12955-015-0312-7

The National Institute for Health and Care Excellence. (2006). Dementia: supporting people with dementia and their carers in health and social care. NICE Guideline (CG42).

The National Institute for Health and Care Excellence. (2010). Dementia: support in health and social care. NICE Quality Standard (QS1).

The National Institute for Health and Care Excellence. (2011). Donepezil,

galantamine, rivastigmine and memantine for the treatment of

Alzheimer's disease. NICE Technology Appraisal Guidance (TA217).

Tourangeau, R. (1984). Cognitive science and survey methods: A cognitive

perspective. In T. Jabine, M. Straf, J. Tanur, & R. Tourageau (Eds.),

Cognitive aspects of survey design: Building a bridge between

disciplines (pp. 73-100). Washington, DC: National Academy Press.

Unsworth, G., Cowie, H., & Green, A. (2012). Therapists' and clients'

perceptions of routine outcome measurement in the NHS: A qualitative

study. *Counselling and Psychotherapy research, 12*(1), 71-80.

US Department of Health and Human Services. (2012). Thing to know if your

material is written for older adults. *Toolkit for Making Written Material*

Clear and Effective. Retrieved 31/1/2016, 2016, from

https://www.cms.gov/outreach-and-

education/outreach/writtenmaterialstoolkit/downloads/toolkitpart09.pdf

Valderas, J., Kotzeva, A., Espallargues, M., Guyatt, G., Ferrans, C., Halyard,

M., . . . Alonso, J. (2008). The impact of measuring patient-reported

outcomes in clinical practice: a systematic review of the literature.

Quality of Life Research, 17(2), 179-193. doi: 10.1007/s11136-007-

9295-0

van der Flier, W. M., & Scheltens, P. (2005). Epidemiology and risk factors of

dementia. *Journal of Neurology, Neurosurgery & Psychiatry, 76*(suppl

5), v2-7. doi: 10.1136/jnnp.2005.082867

Vasse, E., Vernooij-Dassen, M., Spijker, A., Rikkert, M. O., & Koopmans, R.

(2010). A systematic review of communication strategies for people

with dementia in residential and nursing homes. *International Psychogeriatrics, 22*(2), 189-200. doi: 10.1017/S1041610209990615

Ware Jr, J. E. (1978). Effects of acquiescent response set on patient satisfaction ratings. *Medical care, 16*(4), 327-336.

Weirather, R. R. (2010). Communication strategies to assist comprehension in dementia. *Hawaii Medical Journal, 69*(3), 72-74.

Whelan, P., Andrews, T., Patel, S., & Lewis, A. (2010). Taking the Cinderella specialty to the PROM: developing a patient-related outcome measure for an older adult mental health service. *Quality and Ageing in Older Adults, 11*(4), 51-55. doi: 10.5042/qiaoa.2010.0718

Williams, B., Coyle, J., & Healy, D. (1998). The meaning of patient satisfaction: An explanation of high reported levels. *Social science & medicine, 47*(9), 1351-1359.

Willig, C. (2013). *Introducing Qualitative Research in Psychology* (3rd ed.). England: Open University Press.

Willis, G. B. (2005). *Cognitive interviewing: A tool for improving questionnaire design*. California: Sage Publications.

Willis, G. B., Schechter, S., & Whitaker, K. (1999). *A comparison of cognitive interviewing, expert review and behavior coding: What do they tell us?* Paper presented at the Proceedings of the American Statistical Association, Alexandria, VA.

Willis, R., Evandrou, M., Pathak, P., & Khambhaita, P. (2015). Problems with measuring satisfaction with social care. *Health & social care in the community*, 1-9. doi: 10.1111/hsc.12231

Wing, J., Beevor, A., Curtis, R., Park, S., Hadden, S., & Burns, A. (1998).
Health of the Nation Outcome Scales (HoNOS). Research and
development. *The British journal of psychiatry, 172*(1), 11-18. doi:
10.1192/bjp.172.1.11

Yip, J. Y., Wilber, K., Myrtle, R., & Grazman, D. (2001). Comparison of older
adult subject and proxy responses on the SF-36 health-related quality
of life instrument. *Ageing & mental health, 5*(2), 136-142.

Youn, S. J., Kraus, D. R., & Castonguay, L. G. (2012). The treatment outcome
package: facilitating practice and clinically relevant research.
Psychotherapy, 49(2), 115-122. doi: 10.1037/a0027932

Zarit, S. H., & Zarit, J. M. (2008). Flexibility and change: the fundamentals for
families coping with dementia. In M. Downs & B. Bowers (Eds.),
Excellence in dementia care: research into practice (First ed., pp. 86-
102). UK: McGraw-Hill Education.

LIST OF APPENDICES

6.   Appendices

Appendix 1: Approval from NHS ethics committee, Royal Holloway

Departmental Ethics Committee and Trust Research & Development

Department.

NHS
Health Research Authority
London - Harrow Research Ethics Committee

Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

22 October 2015

Miss Hannah Sugarman
Trainee Clinical Psychologist
Camden & Islington NHS Foundation Trust
Doctorate in Clinical Psychology, Department of Psychology
Royal Holloway, University of London
Egham, Surrey
TW20 0EX

Dear Miss Sugarman

Study title:	Design and pilot of a patient-reported experience measure for people with moderate-advanced dementia
REC reference:	15/LO/1369
IRAS project ID:	170826

Thank you for your letter of 15th October 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

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

Confirmation of ethical opinion

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

psychology.it.support@rhul.ac.uk

Ref: 2015/156R1 Ethics Form Approved Subject to Amendment

To

Cc

🛈 You forwarded this message

Application Details:	View the form click here Revise the form click here
Applicant Name:	**Hannah Sugarman**
Application title:	**Design and pilot of a PREM for people with moderate-advanced dementia**
Comments:	Approved subject to amendment.
	Please address the following reviewer's concern:
	Please could they make sure that paperwork, such as consent forms etc., clearly state that ethical approval has been obtained and by whom and with relevant ethics numbers.

Dear Hannah Sugarman

This NHS Permission is based on the REC favourable opinion given on **22 October 2015**.

I am pleased to confirm that the following study has now received R&D approval, and you may now start your research in **the trust(s) identified below**:

Study Title: Design and pilot of a patient-reported experience measure for people with moderate-advanced dementia **R&D reference:** 170826 **REC reference:** 15/LO/1369		
Name of the trust	Name of current PI/LC	Date of permission issue(d)
NHS Foundation Trust	Dr	25 November 2015
If any information on this document is altered after the date of issue, this document will be deemed INVALID		

Specific Conditions of Permission (if applicable)
Trust logos to be applied to participant information sheets and consent forms before study starts at
If any information on this document is altered after the date of issue, this document will be deemed INVALID

Appendix 2: Minor amendments to ethics application

Dear Miss Sugarman

Study title:	**Design and pilot of a patient-reported experience measure for people with moderate-advanced dementia**
REC reference:	**15/LO/1369**
Amendment number:	**2**
Amendment date:	**01 December 2015**
IRAS project ID:	**170826**

Thank you for your letter of 01 December 2015, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Dear Miss Sugarman

Study title:	**Design and pilot of a patient-reported experience measure for people with moderate-advanced dementia**
REC reference:	**15/LO/1369**
Amendment number:	**3**
Amendment date:	**18/02/16**
IRAS project ID:	**170826**

Thank you for your letter of 18 February 2016, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Appendix 3: Information sheet for professionals

NB: Trust logos and information identifying anyone other than the researcher have been removed from the Appendix.

Project title: Design and trial of a patient-reported experience measure for people with moderate-advanced dementia For administrative use only:

Centre number: Study number: Participant ID number: Version number: 3 Date: 20/11/2015

Participant information sheet for staff

You are invited to take part in a research study which is being conducted within your service. Whether or not you join the study is entirely up to you. If you decide not to take part, it will have no impact on your employment. Before you decide we would like you to understand why the research is being done and what it would involve for you. This information sheet provides an explanation of why the research is being conducted, what it will involve and how you can take part.

If, after reading the information sheet, you are interested in being involved, then you can let Dr X X know. If you have any questions after reading the information sheet, you can contact Hannah Sugarman by e-mail (Hannah.sugarman.2013@rhul.ac.uk) or phone (01784 414012)

Who is organising and funding the research?

This research is being conducted by Hannah Sugarman, Trainee Clinical Psychologist as the research component of a Doctorate in Clinical Psychology. Any funding will be provided by Royal Holloway, University of London. Hannah is supervised by Dr X X within the older adults' team, and by Dr Michael Evangeli at Royal Holloway, University of London.

What is the research?

The aim of this project is to develop a measure that can be used to get meaningful feedback about the experience of care from the perspective of patients with moderate-advanced dementia. To do this, we would like to ask staff to provide their input, as professionals with experience in working with people with moderate-advanced dementia.

Why is the research being done?

It is really important to deliver good quality person-centred care to people with moderate-advanced dementia. To do this, we need to be able to find out about the experiences of the care that they have received from their perspective, so that we know which areas we are doing well at and which areas could do with some improvements.

Unfortunately, the patient-reported experience measures (PREMs) we use to gather this information from other patients are not always suitable for people with moderate-advanced dementia. These people might have impairments which make it hard for them to use the pen and paper questionnaires we give to other people. We need to find more suitable methods of gathering feedback from these patients so that they are not excluded from the process of having input into their care.

This page describes what we plan to do in the study and how staff can be involved. There are a number of different stages to the study. You can be involved in as many or as few as you like – if you are involved in one stage, you do not need to be involved in another.

1

Project title: Design and trial of a patient-reported experience measure for people with moderate-advanced dementia For administrative use only:

Centre number: Study number: Participant ID number: Version number: 3 Date: 20/11/2015

Stages in the research

1. Focus groups (up to 1 hour)

We will be running a focus group for staff. In the group, staff will be asked to contribute their ideas about the design of a PREM for people with moderate-advanced dementia. Staff will be asked to think about what the PREM should cover and how it can be made accessible to this patient group. We will be running a separate focus group for service users and carers to provide their views. Using the ideas provided in the focus groups, we will produce a draft version of the measure.

2. Individual interviews (up to 30 minutes)

We will then be asking a few members of staff to be interviewed about the draft PREM. We will be asking them to think aloud about each item on the measure, what it means to them and if they can foresee any difficulties in using it with someone with moderate-advanced dementia. The feedback from these interviews will help us to adapt the PREM further to produce a version that can be trialled with patients.

3. Training in use of the PREM with patients (up to 45 minutes)

Staff will be asked to attend a training session in the use of the PREM. In this session, we will talk about who the PREM is suitable for, how to introduce the PREM to patients and how to administer the PREM. In the session, there will be opportunities to discuss any difficulties that might arise when the PREM is trialled with patients, including issues of decisions about informed consent.

4. Trialling the PREM with patients with moderate-advanced dementia

Staff will be asked to use the PREM with three patients they are working with who meet the inclusion criteria. They will be asked to use the PREM during a routine appointment with a patient to try to obtain feedback about their experience of care.

5. Interviews with staff about their experiences of the trial (up to 30 minutes)

At the final stage, we will conduct interviews with staff to find out about their experiences of using the PREM with patients. These interviews will be recorded, and the transcripts will be analysed to help us to identify obstacles in administering the PREM. This feedback will help us to refine the PREM even further and produce a final version which is ready for more formal testing to validate it for wider use.

Who will have access to information about me?

Until you agree that you would like to be involved in the research, no information about you will be passed on. If you would like to be involved, you can let Dr X X know, and your name, job title and e-mail address will be passed onto Hannah, who is conducting the project. You will not be required to provide any other personal or identifiable information as part of the study. If you have any questions

2

Project title:
Design and trial of a patient-reported experience measure for people with moderate-advanced dementia For
administrative use only:

Centre number: Study number: Participant ID number: Version number: 3   Date: 20/11/2015

3

before you want to agree to take part, please feel free to get in touch with Hannah directly using the e-mail address provided at the end of this information sheet.

Where will information be stored?

All information collected for the project will be stored securely. The focus groups and cognitive interviews will be recorded, and if you agree to be interviewed in the stage 5 of the project, the interviews will be audio-recorded. All recordings made will be stored on an encrypted USB drive which is not be accessible to anyone outside the research team. The interviews at the final stage will be transcribed and the audio recordings destroyed. The interview transcripts will also be stored securely on an encrypted, password-protected USB drive.

What are the advantages of taking part?

In agreeing to take part in this study, you will be contributing to the improvement of person-centred care for people with moderate-advanced dementia. By assisting the design and trial of a measure specifically for people with moderate-advanced dementia, we hope to empower people with dementia by encouraging them to be more involved in the delivery of their care. As a health care professional working with this client group, your insights and experiences are highly valued in a project of this kind.

What are the possible risks or disadvantages of taking part?

Participating in any stage of the project will require you to devote some of your time, which we understand might be difficult for you given the busy nature of your role. Asking you to trial the PREM during a routine appointment may also take some time, so it may be tricky to fit this in. We will support you to think about how to use the PREM and the best ways of fitting it into your appointments, without you having to rush or neglect important duties that you must also attend to during the appointment.

When the PREM is trialled in stage 4, you will be responsible for making decisions about whether someone has the capacity to provide informed consent to participate in the trial. As a health care professional working with people with dementia, you will already be trained and experienced in considering capacity, but we understand that this gives you something extra to consider in your work with clients.

The feedback that clients provide via the PREM should be treated as confidential. If, however, clients disclose any information which indicates that there may be poor care practices in place or risks of harm to them, you will be responsible for passing this information on using the local procedures in place for risk management. Although you will be familiar with these processes as part of your role as a health professional, seeking feedback about care experiences when trialling the PREM provides a specific opportunity for clients to disclose information about risk to you.

What will happen if I don't want to carry on with the study?

If you decide that you no longer want to take part in the study partway through, you have the option to withdraw. Deciding not to participate in the study or deciding to withdraw will not have any adverse impact on you – it is up to you to decide whether you would like to be involved.

Project title:
Design and trial of a patient-reported experience measure for people with moderate-advanced dementia For
administrative use only:

Centre number: Study number: Participant ID number: Version number: 3   Date: 20/11/2015

4

What will happen at the end of the research?

By the end of the research, we hope to have produced a measure that can be used with people with moderate-advanced dementia who are not able to use the existing measures that are currently in use in services. Throughout the different stages of the study, it is hoped that we will have improved the measure, so that by the end of the study, the measure is ready to be trialled on a larger scale to validate it for wider use with people with moderate-advanced dementia.

Who can I contact if I have any questions?

If you would like to know more, or have any questions about the research, you can contact Hannah Sugarman by e-mail (Hannah.sugarman.2013@rhul.ac.uk) or telephone (01784 414012) or Dr X.X (X .X @nhs.net).

Appendix 4: Consent form for professionals

Consent form for staff

Project title: **Design and trial of a patient-reported experience measure for people with moderate-advanced dementia**

Researcher: **Hannah Sugarman (Trainee Clinical Psychologist)**

ROYAL HOLLOWAY UNIVERSITY OF LONDON

Please initial box

➜ I confirm that I have read the information sheet dated __/__/____ (version number X) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

➜ I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any of my rights being affected.

➜ I understand that focus groups and interviews I contribute to as part of the study will be audio-recorded, and some of the recordings will be transcribed.

➜ I agree to the researchers' use of direct quotations to support the findings of the research when it is written up (any quotations will be anonymised)

➜ I agree to take part in the above study.

_____   _____   _____
Name of participant   Date   Signature

_____   _____   _____
Name of person taking consent   Date   Signature

Appendix 5: Information sheet for service-users and carers

Participant information sheet
for service users and carers

You are invited to take part in a research project.

Whether or not you decide we would like you to understand:

Before you decide whether or not you join the study is **completely up to you.**

- ◆ **What** the project is

- ◆ **Why** we are doing it

- ◆ **What** we will ask you to do if you decide to take part

The **next page** of the information sheet explains what the project is and why it is being done.

On **page 3**, there is information about what you would be asked to do if you wanted to be involved in the project.

On the **last pages** there are some frequently asked questions. If you have any other questions, feel free to ask a member of the older adults' team.

1

What is the project?

The idea of the project is to produce a new questionnaire for people with dementia. The new questionnaire is designed for people who struggle to use the existing questionnaires because their dementia is more advanced. To do this, we want to ask service users and carers for their opinions. This will help to make sure that the questionnaire is as good it can be.

The project is being organised by Hannah Sugarman, a Trainee Clinical Psychologist working with the older adults' team.

Why are we doing this project?

To run high quality services, we know it is really important to find out about what people who use them think. Usually we use questionnaires to do this. These questionnaires ask about how people have found the care they have received. They help us to decide which areas of the service need improvement.

Unfortunately, long pen and paper questionnaires are too hard for people to complete if they have more advanced dementia. This means that the current questionnaires are not given to them.

In other settings, questionnaires have been simplified to make them easier for people who struggle to fill in long questionnaires, by using pictures or making them shorter and easier to understand. We think it is really important that people with dementia get to give their feedback, at any stage of their condition. This will help us to make sure that we are tailoring care to make it as good as possible for everyone who receives it.

2

191

What would it involve for you?

In this project, we want to **create a new questionnaire** which can be used with people in the later stages of dementia.

To do this, we will use the questionnaires we have to give us ideas about what the new questionnaire should cover. We will also use simplified questionnaires that exist already to give us ideas about what the new questionnaire should look like.

The project involves **two different parts** for you. You could choose to be involved in one part or both parts – it is up to you.

Part One: Focus group

We will be holding a group for service users and carers.

At the group, we will be asking for your views about how we design the new questionnaire.

Your ideas will help us to decide how to change the questionnaires we have.

You will be asked to think about how we can make changes to make the questionnaire easier for people who have more advanced dementia.

Part Two: Interviews

After the focus group, we will produce a draft of the new questionnaire. Then we would like to interview people individually.

In the interviews we will ask people to look at the new questionnaire in detail. We will ask people to think about each question on the questionnaire and tell us what they think of it.

We want to find out whether people think that people with dementia will have any difficulties answering the questions. If they did, we want to think with you about how we could make the questions easier to answer.

3

What will happen next?

After the groups and the interviews, we will make more changes to the draft questionnaire. We will use peoples' feedback to change the questionnaire. Next, we will be asking the people who work in the team to try out the questionnaire. They will use it with people with moderate-advanced dementia to see how well it works. After they have done this, we will ask the staff for their feedback. The questionnaire will be edited one more time to make a final version.

At the very end of the project, we would really like get your feedback about the final version of the questionnaire. If you would like us to get in touch with you to ask you for your opinions at this stage, please let us know. We hope that the new questionnaire can be used by lots of different services to get feedback from people with dementia.

On the next pages, we have **listed some common questions** that come up when people take part in projects like this.

If you have another question that is not mentioned here, **please go ahead and ask.**

You can get in touch with us (the people organising the research) to ask questions if you want to. Our contact details are at the end of the information sheet. You can contact us by e-mail or phone, or we can give you a call.

4

Project title:
Design and trial of a patient-reported experience measure for people with moderate-advanced dementia
For administrative use only:
Centre number:
Version number: 3

Study number:
Date: 20/11/2015

Participant ID number:

Why have I been invited to take part?

You have been identified by your clinician as someone with the experience and knowledge to contribute to this research, either as a person living with early dementia or as a carer of a person with dementia.

The idea of the research is to produce a questionnaire for people whose dementia is moderate or advanced, but you have been asked to participate because you do not have moderate or advanced dementia. Your experience of *early* dementia enables you to provide valuable and useful opinions about what might be helpful for people with dementia.

Who will be given information about me?

No information about you will be passed on until you say that you are interested in being part of the project. If you would like to be involved, please let your doctor, nurse or therapist know. They can pass on your name and contact details to Hannah, who is organising the research. Hannah will then get in touch with you to arrange for you to come along to the focus groups and/or the interviews.

When we meet you, we will ask you for a few details about yourself. These will be simple things like your age and your ethnicity. If you have dementia, we will ask when you were diagnosed and which type of dementia you have. Other than this, we will not be asking for any other information about you.

What will happen to any information I provide?

Any information we collect will be kept securely on an electronic device. This device has a password so that no-one can access it except for the research team.

The focus group and the interviews will be tape-recorded. This will help us to remember what people have said. The tapes will also be kept securely on an electronic device. If you have any questions about this or any issues with your voice being recorded, please speak to the organisers.

5

Project title:
Design and trial of a patient-reported experience measure for people with moderate-advanced dementia
For administrative use only:
Centre number:
Version number: 3

Study number:
Date: 20/11/2015

Participant ID number:

All information you provide will be kept confidential. The only exception to this will be if anything you say makes us worry that there is a risk to you or to other people. We will let you know if this is the case.

We might want to use direct quotes from the tapes when we write our report at the end of the project. We won't use any names if we do this, so no-one will know who said what.

What are the advantages of taking part?

If you agree to be involved in the project, you will be giving a useful contribution to services for people with dementia. By providing your valuable input from your own experiences, you will be helping us to improve the services available for people with moderate to advanced dementia by helping them to give their feedback.

If you take part, you will be helping professionals working with people with dementia to improve how they communicate with patients about their care. This will help us to make sure that people with more advanced dementia get to give their feedback and have more say in their own care.

What are the disadvantages of taking part?

If you take part, you will need to commit some of your time. The focus group will take up to an hour and a half. If you agree to be interviewed, this will take up to half an hour. We understand that it is not always easy for people to give up their time. However, we would really appreciate it if you were able to give up some time to come and help us with this project.

If you take part, we will be asking you to give your opinions. For some people it might also be a bit upsetting to talk about their personal experiences of dementia. We are here to offer you support at any stage. If there is anything you are finding difficult to talk about, please come and speak to one of the organisers. If you decide you want to leave the project because it is upsetting then that will not be a problem. Just let one of the organisers know.

6

Slide 7:

Project title:
Design and trial of a patient-reported experience measure for people with moderate-advanced dementia
For administrative use only:
Centre number: Study number:
Version number: 3   Date: 20/11/2015
                                           Participant ID number:

What would happen if I wanted to leave the project partway through?

If you decide you don't want to be in the project any more, you can let us know. It is not a problem for you to leave the project at any stage. This will not affect your medical care or your rights. It is optional to participate and you only need to be involved if you want to be.

Who has organised this project?

This project is being organised by Hannah Sugarman, a Trainee Clinical Psychologist at Royal Holloway, University of London. Hannah is working with the professionals in the older peoples' team to organise and run this project. Dr X X, Consultant Clinical Psychologist in the older peoples' team, is supervising the project in the service, and Dr X X is supervising the project at Royal Holloway.

Who do I contact if I have any questions?

If you have any other questions that we have not covered, please feel free to get in touch with Hannah via e-mail (Hannah.sugarman.2013@rhul.ac.uk) or telephone (01784 414012)

7

Slide 8:

Project title:
Design and trial of a patient-reported experience measure for people with moderate-advanced dementia
For administrative use only:
Centre number: Study number:
Version number: 3   Date: 20/11/2015
                                           Participant ID number:

Hannah Sugarman
Trainee Clinical Psychologist, Royal Holloway, University of London
01784 414 012
Hannah.sugarman.2013@rhul.ac.uk

Dr X X
Consultant Clinical Psychologist, Older People X X Services, X

If you would be interested in being part of this research, please let your doctor, nurse or therapist know. They can arrange to put you in contact with Hannah so that she can get in touch with you.

8

Project title:
Design and trial of a patient-reported experience measure for people with moderate-advanced dementia
For administrative use only:
Centre number: Study number:
Version number: 3   Date: 20/11/2015
                                           Participant ID number:

What would happen if I wanted to leave the project partway through?

If you decide you don't want to be in the project any more, you can let us know. It is not a problem for you to leave the project at any stage. This will not affect your medical care or your rights. It is optional to participate and you only need to be involved if you want to be.

Who has organised this project?

This project is being organised by Hannah Sugarman, a Trainee Clinical Psychologist at Royal Holloway, University of London. Hannah is working with the professionals in the older peoples' team to organise and run this project. Dr X X, Consultant Clinical Psychologist in the older peoples' team, is supervising the project in the service, and Dr X X is supervising the project at Royal Holloway.

Who do I contact if I have any questions?

If you have any other questions that we have not covered, please feel free to get in touch with Hannah via e-mail (Hannah.sugarman.2013@rhul.ac.uk) or telephone (01784 414012)

7

Project title:
Design and trial of a patient-reported experience measure for people with moderate-advanced dementia
For administrative use only:
Centre number: Study number:
Version number: 3   Date: 20/11/2015
                                           Participant ID number:

Hannah Sugarman
Trainee Clinical Psychologist, Royal Holloway, University of London
01784 414 012
Hannah.sugarman.2013@rhul.ac.uk

Dr X X
Consultant Clinical Psychologist, Older People X X Services, X

If you would be interested in being part of this research, please let your doctor, nurse or therapist know. They can arrange to put you in contact with Hannah so that she can get in touch with you.

8

Appendix 6: Consent form for service-users and carers

Consent form for service users and carers

Project title: Design and trial of a patient-reported experience measure for people with moderate-advanced dementia
Researcher: Hannah Sugarman (Trainee Clinical Psychologist)

ROYAL HOLLOWAY UNIVERSITY OF LONDON

	Please put your initials below if you agree
I confirm that I have read the information sheet dated __/__/____ (version number X) for the project.	
I have had a chance to think about the information and ask questions. All of my questions have been answered.	
I understand that: ○ I do not have to take part. ○ I can leave the project at any time. ○ If I leave I do not have to give a reason. ○ If I leave the project, my care will not be affected.	
I understand that the groups and interviews will be audio-taped.	
I understand that the researchers may write up exactly what I said in quotes when they write the report for the project. These quotes will be anonymous – my name will not be used in the report.	
I understand that if I agree to take part, my name and contact phone number will be passed on to the research team.	
I agree to take part in the project.	

_____   _____   _____
Name of participant   Date   Signature

_____   _____   _____
Name of person taking consent   Date   Signature

Appendix 7: Topics for focus groups

Topics for focus group for professionals

Firstly, I'd like to thank you all for coming along today and devoting your time to this project, I really appreciate it and hope that we will be able to produce something that is really useful for the service as a result. You've all had a chance to read through the information sheet so I hope that you've all understood what the purpose of the project is. Today's focus group is a chance for me to hear your ideas about where to begin in designing a new PREM for people in clusters 20 and 21, who are in the more moderate-advanced stages of dementia and would likely not be able to complete the PREM that is used in the service at the moment. I will try not to keep you all too long, I'm aware that some people need to get away at 4pm, so please feel free to escape when you need to! What I'll ask is that so it's easier to understand when I listen back to the tape, we'll try to keep it so that only one person talks at once. I have a few different questions and areas to explore, so I'll try to keep us on track with the topics I'd like to ask you about so that you can all get away on time.

Starting with thinking quite generally about your experiences working with this client group, I'd like to hear about your experiences of the care of people with moderate-advanced dementia.

- What is important for services to think about when it comes to the care of people with moderate-advanced dementia?
    - Which ideas come to mind?
    - Differences compared to people in early stages?

Next, I'd like you to have a think about understanding how people with dementia experience their care.

- Think back to times when you have felt confident that you have understood how a person with dementia felt about their care.
    - How have you heard this feedback?
    - What aspects have people particularly fed back on?
    - Which aspects of care do you not hear as much feedback about?
- What do you think are some of the best ways to collect this information?
    - What are your experiences of the best ways to collect information that people do not readily volunteer?
    - Which ways have you found that have worked well?
    - Which ways which do not work well?

Next, I'd like us to think quite generally about the new, accessible measure that we want to design. I'd like us to think about how it will look, what it will cover and how it will be delivered.

- With your clients with moderate-advanced dementia in mind, what should we be thinking about when we are designing the measure?
    - Content (What should we be asking about? What do we need to make sure the measure covers? Is there anything we should prioritise over other aspects?)
    - Format (What should it look like? What should it not look like?)
    - Practical (How should it be delivered? How long should it take?)

The existing PREM used in the service will be distributed to professionals.

Next, I'd like us to consider the PREM that was developed in that is currently being used to collect information about experiences in your service. I'm sure you're all very familiar with it! I'd like us to use it to think about what we might want to change in the new measure, and what we might want to keep the same.

What have been your experiences when using this PREM to get feedback from people with moderate-advanced dementia?

Looking at the items in detail and the areas which the PREM asks about:

- Which items may not be relevant to people with moderate-advanced dementia? Which items would you exclude from the new PREM?
- Which ideas/themes from the existing PREM will be important to retain?
- Are there any aspects of care which are not covered that will be important to include in the new PREM?

The PREM used in services for people with learning disabilities will be introduced and distributed to professionals, and they will be given a few minutes to look at it.

Finally, I'd like us to think about a PREM used in a different service. This is an example of an accessible PREM which is in use in services for people with learning disabilities.

- Which aspects of this PREM could be used in a PREM for people with moderate to advanced dementia?
    - How easy do you think this measure is to understand?
    - How well does it cover important areas of care?
    - How well do you think something like this would encourage people with moderate-advanced dementia to volunteer useful information about their care?
    - Is there anything you don't like about it?

- Which aspects of this measure do you think we should take forward in the new PREM?
    - Which aspects of the content?
    - Which topics it covers?
    - Which response options?
- What might need to be different about an accessible measure for people with moderate-advanced dementia?
    - Is there anything that should definitely be different?
- Is there anything else you want to add?

Topics for focus group for service-users/carers

In the group today, I'd like to spend some time thinking about how we can get feedback from you. It's really important that the service understands what you think about your care. If they are asking about the things that are important to you, then they can make sure that they are addressing any issues. Services tend to use questionnaires to get this feedback from people. However, the questionnaires they have are not always suitable for everyone. Today, I would like to find out about what you think about some existing questionnaires. This will help me to think about how to change them to make them more suitable for you. I want to think about what the service should be asking you and how they should be asking it. If you have any questions, please ask any time.

- What is most important about the care provided for people with dementia?
    - Providing information?
    - Answering questions? Helping you to feel heard?
    - Helping you to feel safe/happy?
    - Being treated with respect?
    - Delivering bad news in a good way?
- Anything different that comes to mind for other people?
- How might what is important to you change as time goes on? What is different for people who have more advanced dementia compared to people who have recently been diagnosed with dementia?
- If you wanted to give your doctor/nurse/therapist some feedback about the care that you had received from them, how might you go about this?
    - How would you prefer to give feedback? Written/spoken?
    - Would you rather it be something you complete alone or is it better for a family member to help you?

The PREM used in the service will be distributed. The participants will be instructed to have a look at it and given a few minutes to do this. People with dementia will be supported to read through it by the facilitators.

- How might you use this questionnaire to give feedback to the team?

- What might make difficult for people with dementia to fill in this questionnaire?
- Is there anything missing from this questionnaire about the important parts of your care?
- How well does it ask about the parts of care that are important to the people with advanced dementia?
  - If we wanted to use it with people with more advanced dementia, which questions might we take out?
  - What might we keep in to make sure it was right for them?

The PREM used in services for people with learning disabilities will be introduced and distributed, and the participants will be instructed to have a look at it. People with dementia will be supported to read through it.

- What do you think about this?
  - What is good about this questionnaire? How could it be used to find out about people's experiences of care?
    - What do you think about the use of smiley faces?
    - Balance of pictures/words?
    - The use of colours?
    - The wording of the questions?
    - The questions – is it asking the right things?
  - What is not so good about this measure for getting feedback from people about their care?
- What might need to be different about a questionnaire for people with dementia?
  - Which questions has it left out that could be important?
  - What could be different about the style?
- Which parts of a questionnaire for people with dementia should be similar to this one?
- What might put someone off giving feedback about their care using something like this?
  - What can we do to help with this?
- Is there anything else you want to add?

Appendix 8: Older adult PROM/PREM from Whelan et al., 2010)

Thank you for taking the time to complete this questionnaire, in order to improve our services at _____ Trust _____ , we're and interested in hearing from the people who have used them.

This survey asks some questions about your experience with the following team:

Which Borough are you in?

Team

Your Experience of the Service

1. Have you been involved as much as you wanted to be in the decisions regarding your treatment / care?

☐ Yes, fully ☐ Yes, to some extent ☐ No, but I wanted to be

☐ No, but I did not want to be ☐ Don't know /can't remember

2. Have you been given sufficient advice and information about your condition and treatment / care options?

☐ Yes, fully ☐ Yes, to some extent ☐ Don't know / can't remember

---

3. Have you been given a copy of your care plan?

☐ Yes ☐ No ☐ Don't know /can't remember

4. Does the care and treatment you receive help you to achieve your personal goals as set out in your care plan?

☐ Yes, definitely ☐ Yes, to some extent ☐ No

☐ Don't know /can't remember ☐ Not applicable

5. Have you been treated with compassion, dignity and respect?

☐ Yes, always ☐ Yes, sometimes ☐ No

6. Did contact with this team help you access care for your physical health?

☐ Yes, fully ☐ Yes, to some extent ☐ No ☐ Not applicable, do not have any physical health problems

7. How well does your care co-ordinator or lead professional organise the care and services you need?

☐ Very well ☐ Quite well ☐ Not very well ☐ Not well at all

About You

1. Are you Male or Female? (If your gender is different to that assigned at birth, please select Transgender.)

☐ Male ☐ Female ☐ Transgender

2. To which age group do you belong?

☐ Under 18 ☐ 18-25 ☐ 26-35 ☐ 36-45 ☐ 46-55
☐ 56-65 ☐ Over 65

3. To which faith group do you belong?

☐ None /Atheist ☐ Agnostic ☐ Church of England ☐ Other

☐ Protestant ☐ Orthodox Christian ☐ Roman Catholic

☐ Other Christian ☐ Sikh ☐ Jewish ☐ Buddhist ☐ Hindu

☐ Muslim ☐ Jain ☐ Parsi /Zoroastrian ☐ Rastafarian

☐ Other Faith group   Do not wish to disclose

4. What is your sexual orientation?

☐ Heterosexual ☐ Gay ☐ Lesbian ☐ Bisexual

☐ Do not wish to disclose

5. What is your ethnicity?

☐ White British ☐White Irish ☐ White Gypsy / Irish

Traveller ☐White Other ☐ Mixed White & Black Caribbean

☐ Mixed White & Black African ☐ Mixed White & Asian

☐ Mixed Other

---

5. What is your ethnicity? (cont'd.)

☐ Asian or British Asian: Indian ☐ Asian or British Asian:

Pakistani ☐ Asian or British Asian: Bangladeshi ☐ Asian or

British Asian: Other ☐ Chinese ☐ Black or Black British

Carribean ☐ Black or Black British: African ☐ Black or Black

British: Other ☐ Arab ☐ Any Other Ethnic Group ☐ Do

not wish to disclose

6. Do you consider yourself to have a disability – this is a long-term condition lasting a year or more that has significant effect upon your day- to-day activities? Please select all that you feel apply.

☐ Physical /mobility ☐ Blind /partially-sighted ☐Deaf

/hard of hearing ☐Learning Disability ☐Speech / language

impairment ☐ Mental illness ☐Dyslexia ☐ Diagnosis of

Cancer /HIV+ /M.S. ☐Other progressive disability ☐Facial

disfigurement ☐ Other hidden disability ☐No disability

☐ Prefer not to answer

If you would like to complete this survey online please use the following link:

201

8. Do you have a telephone number for services, which you can call in a crisis?

☐ Yes ☐ No

9. If you have been in hospital recently did you feel safe?

☐ Yes, definitely ☐ Yes, to some extent ☐ No

☐ Not applicable, was not in hospital

10. Would you recommend this service to a friend or family member if they needed a similar service to you?

☐ Extremely likely to recommend ☐ Likely to recommend

☐ Neither likely or unlikely to recommend

☐ Unlikely to recommend ☐ Extremely unlikely to

recommend ☐ Don't know

11. If you have any additional comments, please feel free to write them into the box provided below.

202

Appendix 9: Accessible PREM for people with learning disabilities (used with permission from Raczka, Theodore & Williams, 2014)

Feedback survey

We want to find out what you think about our service
We want to know what you think about the things we do for you and how we could make things better.

We would like to ask you some questions
Such as whether you would tell a friend to come to the service if they needed to.
How quickly we saw you.

For each question, please tick the box
Under the picture that shows what you think

😊 Yes	😐 Sometimes	🙁 No
✓		

Your answers are private
We will not tell anyone else what your answers are.
Your answers will not change the care we give you.

Did you have help filling in this form?   Yes/No

To be filled in by the administrator:

What month is it?

Who did you see today? (Name and discipline)

_____

Developed by: Dr Roman Raczka, Dr Kate Theodore, Janice Williams

v5.

Were we nice to you? Did we listen to what you had to say?

Tick ONE box ✓

😊 Yes	😐 Sometimes	🙁 No

Did you understand what we told you?

Tick ONE box ✓

😊 Yes	😐 Sometimes	🙁 No

3

Questions about the service...

How was your meeting with us today?

	Very Good	Good	Ok	Bad	Very Bad

Did we ask you about what help you wanted?

	Yes	Sometimes	No

2

How quickly were you seen at the service today? Did you have to wait at all?

	Very quickly	Quickly	I didn't have to wait too long	I had to wait some time	I had to wait a very long time

Do you know someone with a learning disability? If they needed help, would you tell them to come and see us?

	Yes, of course	Maybe	Not sure	Probably not	No way	Don't know

4

Questions about you…

Are you…

Male   OR   Female

Tick ONE box

☐   ☐

How old are you? Write your age on the line

_____

Did you have an appointment?

☐ Yes

☐ No

What are the reasons for your answer? (you don't have to fill this in if you don't want to):

_____

_____

What could we do better? How could we improve the things we do for you? (you don't have to fill this in if you don't want to):

_____

_____

_____

_____

_____

5

205

What is your ethnic origin? Tick ONE box

Asian or Asian British

- [ ] Bangladeshi
- [ ] Indian
- [ ] Pakistani
- [ ] Any other Asian background

Mixed

- [ ] White and Black Caribbean
- [ ] White and Black African
- [ ] White and Asian
- [ ] Other Mixed Background

Other Ethnic Groups

- [ ] Chinese
- [ ] Anything else

Black or Black British

- [ ] African
- [ ] Caribbean
- [ ] Any other Black background

White

- [ ] British
- [ ] Irish
- [ ] Other White Background
- [ ] Not stated

What religion are you? Tick ONE box

- [ ] Don't believe in God
- [ ] Hindu
- [ ] Buddhist
- [ ] Sikh
- [ ] Anything else
- [ ] Christian
- [ ] Jewish
- [ ] Muslim
- [ ] I don't have a religion
- [ ] I don't want to say

Are you? Tick ONE box ✔

☐ Bisexual	☐ Gay man
☐ Heterosexual/ straight	☐ Lesbian/ gay woman
☐ Other	☐ I don't want to say

What sort of disability do you have? Tick as many boxes as you need to ✔

☐ Physical eg use a walking stick, crutches, wheelchair	☐ Sensory eg blind, deaf
☐ Mental health condition (long term)	☐ Other health condition (long term)
☐ Learning disability	☐ Other/Don't know

Appendix 10: Initial draft PREM (Version 1 – cognitive interviews)

Each sheet (A4 size) was presented to the participant individually. Two different response scales were presented as options in the cognitive interviews.

I want to get some feedback from you about our meeting today.

Did I listen to you?

Did I treat you with respect?

Was I interested in you as a person?

Did you think I cared about you?

Did I answer all of your questions?

👇 Please point somewhere along the line

[gradient line: red to green]

❌ ✅

👇 Please point somewhere along the line

NO   YES

[gradient line: red to green]

❌ ✅

Appendix 11: Cognitive interview schedule

Check familiarity, with project, refer them to information sheet again.

<u>Service-users/carers)</u>

At this stage of the project, I have produced a draft of a simple questionnaire. The questionnaire is designed to get feedback from people about their experiences of care. For some people, it is not as easy to give this feedback. This is sometimes true for people with more advanced dementia. I am asking you for your views about this because you do <u>not</u> have advanced dementia, but you do have experience of living with dementia.

For each question, I am interested in two things. First, I'd like to know what it's like to answer the questions, so I would like you to imagine that you have just finished an appointment with me (a health professional), and I am now presenting this to you at the end of our meeting.

Although I am asking you to answer the questions, I am not here to collect information about you. I am more interested in how you got to your answers, and what went through your mind when you heard the question.

As well as asking what it is like for you to answer the questions, I also want to know what you think about using this with people with more advanced dementia. This will help me to make changes to the questionnaire so that it is more suitable for these people. I will ask you questions about this as we go along.

If there is anything you are not sure about, please ask at any time.

<u>Professionals</u>

The aim of this stage is to test out the individual items on the measure that we have produced. First, I would like to find out about what you think it would be like for a service-user to answer the questions, then I would like to think more specifically about people with moderate-advanced dementia and what it would be like for them.

I will be administering it to you as though you were a service-user, and I would like you think about the process of answering the questions. I'll be asking you further questions to try to elicit your opinions about each item in detail. I will also be asking you about how you think the measure could be used with someone with in the moderate-advanced stages of dementia, based on your clinical experiences of working with these people. This will help me to think about how to adapt the measure to make it more suitable for use with this group. If there is anything you are not sure about, please ask at any time.

<u>Both</u>

I will now present the questionnaire to you. I would like you to imagine that you are completing it after an appointment or a meeting with a health professional.

<u>Interviews</u>

(Present the measure to them as though you are administering it to them, pausing to use probe questions after each item).

I want to get some feedback from you about our meeting today.

- *Before I get to the actual questions, tell me what this introduction is asking you.*
- *Is this introduction clear? Or confusing?*

Did I listen to you?

Did I treat you with respect?

Was I interested in you as a person?

Did you think I cared about you?

Did I answer all of your questions?

<u>General cognitive interviewing questions</u>

- *What do you think this question is asking about? / Can you repeat this question in your own words/Is this question clear?*
- *Can you tell me what time period the question was asking about?*
- *Can you tell me what you were thinking when I asked about this?*
- *How would you come up with an answer?*
- *Is it easy or difficult to decide what answer to give?*
  - o *What made it easy/difficult?*
  - o *Would a prompt help?*
- *Is there anything that would make this difficult to talk about in a survey, or could it be uncomfortable?*

<u>Questions about ease of using PREM with people with moderate-advanced dementia</u>

- *How easy or difficult would it be for someone with moderate-advanced dementia to answer this question?*
- *How well does this question apply to people with moderate-advanced dementia?*
- *How easy or difficult would it be to remember this, for someone with moderate-advanced dementia?*

- *What might help someone with moderate-advanced dementia to answer this question?*
  - *Would it be helpful or unhelpful to include a verbal prompt?*
  - *Would it be helpful or unhelpful to include a visual prompt?*
- *How well would a person with more advanced dementia be able to use this (pointing scale) to respond?*
  - *What might be good or bad about it?*

Examples of emergent/reactive (spontaneous) probes

To be used if uncertainty/inconsistency/misunderstanding ensues.

- *Are you saying that you do or don't consider X to be X?*
- *So, when I asked this, are you saying that you understood it to mean this? Or something else?*
- *You took a little while to answer that question. What were you thinking about?*
- *You seemed to be somewhat uncertain. If so, can you tell me why?*
- *Are there different things you think X might mean? If I wasn't able to clarify, what would you assume the question meant?*

General probes for more information

- *Tell me more on your opinions about that*
- *Can you explain what you mean by that?*
- *How much thought would you say you've given to this?*

Questions about the content and length of the measure

- *Do you think this covers the important aspects of care for people with moderate-advanced dementia?*
  - *Is there anything that needs to be added?*
  - *Are there questions that could be removed?*

Appendix 12: Draft PREM (Version 2 – trial with service-users)

All of the A4 sheets were compiled into a pack and comb bound. Each introductory page (shown in separate boxes below) was presented individually, and each question was presented alongside the response scale (the comb binding gave the option to present the question alone or the response scale alone if this eased administration for the service-user).
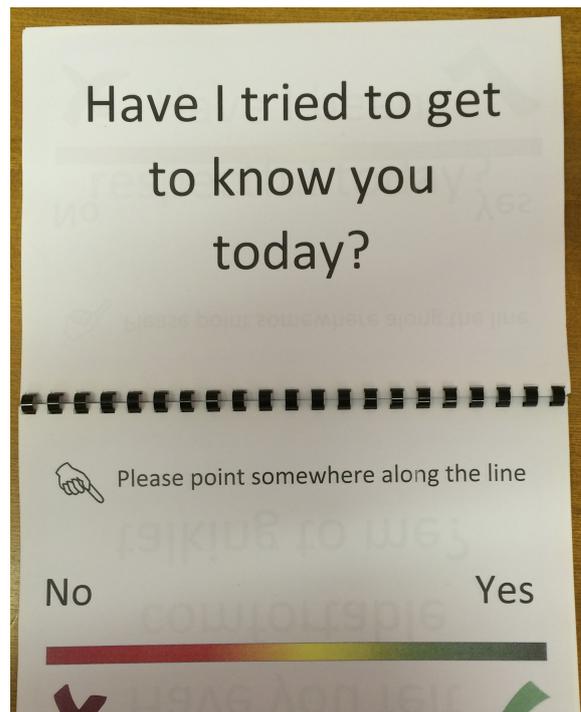
The instructions and subsequent questions were presented in the following order:

I would like to know how you found our talk today

This is so that I can improve my skills

I am going to ask you five questions

Response scale presented and practice question administered:

👉 Please point somewhere along the line

NO   YES

✗   ✓

Five questions presented individually on A4 size sheets as follows:

Have I listened to you today?

Have I been respectful today?

Have I tried to get to know you today?

Have you felt comfortable talking to me?

Have I answered your questions today?

Visual prompts

(These were provided separately on A6 size laminated cards)

Item	Prompt
Have I listened to you today?	
Have I been respectful today?	
Have I tried to get to know you today?	
Have you felt comfortable talking to me?	
Have I answered your questions?	
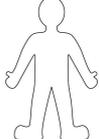
Name of service user: Name of staff member:
Date of administration:

Scoring sheet for PREM

Question 1
NO   **YES**
_____

Additional comments/observations:..
....
....

Question 2
NO   **YES**
_____

Additional comments/observations:..
....
....

Question 3

NO   **YES**
_____

Additional comments/observations:..
....
....

Question 4
NO   **YES**
_____

Additional comments/observations:..
....
....

Question 5
NO   **YES**
_____

Additional comments/observations:..
....
....

Project title: Design and trial of a patient-reported experience measure for
people living with moderate-advanced dementia

Guide for using the patient-reported experience measure

INTRODUCTION

What is the patient-reported experience measure?

The patient-reported experience measure (PREM) has been developed as part of a research project run by Hannah Sugarman, a Trainee Clinical Psychologist from Royal Holloway, University of London. It has been developed as a result of focus groups and individual interviews with professionals, service-users and carers in the Older Adults' Community teams.

Why is it being trialled?

People with moderate-advanced dementia are often excluded from using the existing measures in services which are designed to collect feedback from service-users. Lengthy pen-and-paper questionnaires tend not to be suitable for this group due to cognitive/communication impairments, and in the absence of any available measures that are more suitable, formal feedback from people with moderate-advanced dementia is generally not collected, with carer reports being relied upon instead. The aim of this project is to develop a simplified experience measure that aims to collect feedback about the experiences of care from the perspective of the person with dementia. This will help to include them more in the care process, allowing them to actively participate and contribute towards changes that improve their experience of the care process.

What is the process of trialling the measure?

After a training session, professionals will be asked to trial the PREM with people in clusters 20 and 21, according to the guidance provided in the training session and this pack.

What will happen after the PREM is trialled?

After professionals have trialled the PREM with up to 3 people who meet the inclusion criteria, they will be asked to attend an interview with Hannah. The aim of this interview will not be to collect the experiences of the service-users that were gathered by the professionals. Instead, the questions in the interview will focus on the process of trialling the PREM and what professionals experienced when doing so. The interviews will aim to discover what worked well and what was difficult, in order to inform further changes to the PREM.

When will the interviews take place?

The interviews can take place any time from the 10th February until the end of March. Professionals will be asked to contact Hannah (hsugarman@nhs.net) once they have tried the PREM with 3 people so that she can arrange a time and date to conduct an interview. The interviews will last no more than 30 minutes.

What should I do if I have questions or concerns?

Please feel free to contact Hannah at any time if there is anything you are unsure of. You are under no obligation to administer the PREM or take part in the interviews, participation is completely voluntary.

PREPARING TO ADMINISTER THE PREM

Identifying suitable respondents

The PREM can be administered to people in clusters 20 and 21 (people with moderate-advanced dementia). They must be able to speak a few words in English. The only other inclusion criteria relates to consent: if they are unable to consent for themselves, there must be a personal consultee available to advise on their wishes. See below for more information about consent.

The consent process for participation

Everyone who responds to the measure must either consent to doing so themselves, or have a personal consultee comment on their preferences. When considering if someone should complete the measure, use your clinical judgment to assess whether they have the capacity to consent for themselves. As you will know, this requires them to:

- Understand the information given to them about the project and the trialling of the PREM
- Retain that information long enough to decide whether they are willing to complete the PREM
- Weigh up the information provided to allow them to decide if they want to complete the PREM
- Communicate whether or not they would like to complete the PREM

The flow chart below shows how you should proceed once you have made a decision about capacity.
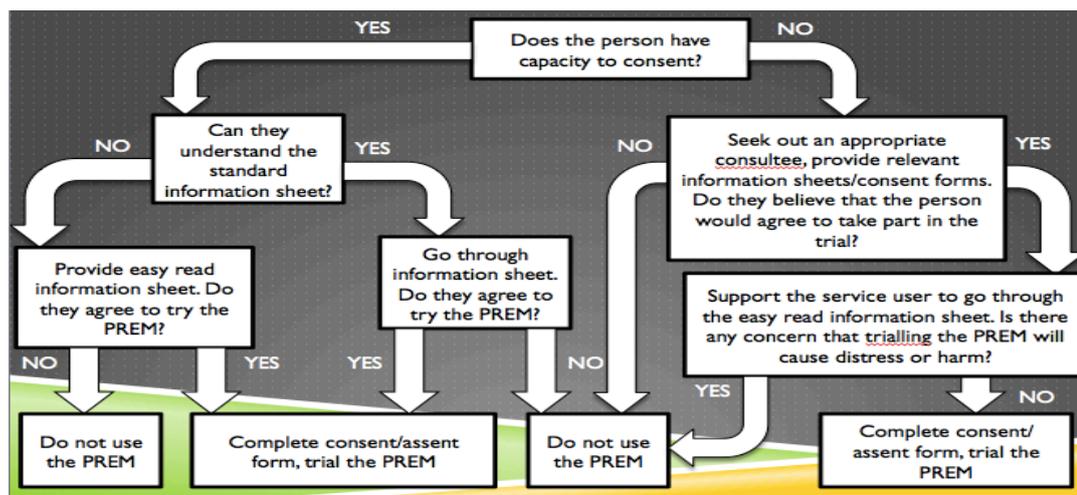
If the person has the capacity to consent for themselves, you should ask them to complete the consent/assent form for service-users. This can be stored in their clinical file. There are two information sheets provided: a standard version and an

easy read version. Use your judgment to decide which sheet is more appropriate for use.

Personal consultees

If a person does not have capacity to consent for themselves, a personal consultee can be asked for their view on whether the person should be included in the research. The guidance provided in relation to the Mental Capacity Act (2005) states that a consultee can be a family member, carer or friend (not someone who is being paid to care for that person). A consultee should be someone whom the person who lacks capacity would trust with important decisions about their welfare. In choosing an appropriate consultee, every effort must be made to take into account the wishes of the person who lacks capacity about who to consult.

The consultee is being asked to advise on whether the person would have wanted to take part in research of this nature. They are not being asked for advice on their personal views on participation, nor are they being asked to consent on behalf of the person who lacks capacity. This is explained in the information sheet for consultees, which is provided with this pack. When making decisions based on the views of a consultee, any relevant previous statement or wishes from the person in question should be taken into account. Non-verbal forms of communication should be considered.

If you are seeking the views of a consultee, they should be provided with the consultee information sheet alongside the information sheet for service-users (they should see the same information that the service-user would see if they were making the decision about whether to participate without assistance). Once the consultee agrees to act in this role, you should ask them to sign the consent form for consultees.

Assent for people who do not have the capacity to consent for themselves

Even if the service-user is unable to consent, they should still be presented with the same information sheets and supported to understand what the PREM is. It is recommended that a supportive assent process is undertaken with these people. This involves regularly checking in with them and making sure there is no indication that they object to taking part. If the service-user expresses any distress or you have any reason to believe that trialling the PREM with them could cause them harm in any way, do not trial the PREM.

ADMINISTERING THE PREM

Once you have obtained consent either from the service-user or a personal consultee, you can administer the PREM. Before you start to administer the PREM, make sure that any sensory impairments are addressed with aids, if they have them. For example, if they wear glasses or use a hearing aid, instruct them to use these aids when completing the PREM.

The instructions for administering the PREM are as follows:

1. Display the introductory pages of the PREM one by one, reading the words out loud. If you are uncertain about whether the person has understood what

you are asking them to do, check in with them to ensure that they are clear and are happy to proceed.

2. Turn to the next page of the booklet to show the service-user response form (the page with the pointing scale). Explain to them:

"I will be asking you to respond using this. You have to point along the line to tell me your answer. If you want to answer yes, point here (indicate yes)*. If you want to answer no, point here* (indicate no). *If your answer is somewhere in between yes and no, point to where you think it is* (indicate somewhere in the middle of the line)*.*

3. You should then test out their understanding of the response sheet. Say:

"Just to check that you can use this OK, I'll ask you to answer a couple of questions. Is your name (use a different name from clients)*? Answer yes or no.*

Once they have responded, say:

"That's great. One more question, is your name (service-user's name)*?*

If they appear not to understand the response form, provide further explanation, demonstrating how to use it. Once you are satisfied that they understand the response form and can use it, move on to the first question.

4. Turn the page of the booklet so that the first question is displayed to them, with the response sheet in front of them somewhere that they can reach it. Read out the first question:
"Have I listened to you today?"

Await their response. You can encourage them to elaborate on their answer, for example, by saying:

"What made you give that answer?"

Note their response on the scale for the first question on the scoring sheet, alongside any additional comments they made and your own qualitative observations about nonverbal behaviour.

If they do not respond to the question as presented above, then consider using the additional visual prompts provided. You can use these alongside presenting the question verbally, or if you feel that it will be distracting to present both then you can present the visual prompt alone and speak the question aloud, displaying only the response sheet. There are also additional verbal prompts supplied at the end of this guide which you can use to support understanding of each question, if the service-user does not respond to the wording provided in the PREM.

5. Repeat the process, going through each question, using visual/verbal prompts where necessary and checking in with the person's understanding. If the person appears to be fatigued, you can encourage them by thanking them and letting them know how many questions there are left to answer.

DECIDING WHEN TO USE THE PREM

If possible, the PREM should be used at the end of your meeting with the service-user. However, it may be that the person has significant memory impairments or you are concerned about their ability to answer the questions pertaining to the whole session. If you think this is the case, the PREM can also be used at key points throughout the session. Examples might be using it after you have finished a conversation about a particular topic, or just after you have completed a cognitive screen.

ANY QUESTIONS/CONCERNS?

If you have any questions or are unsure of anything when trialling the PREM, please do not hesitate to get in touch using my nhs.net e-mail: hsugarman@nhs.net

Thank you for your support and assistance with this project.

CHECKLIST FOR COMPLETING THE PREM

Identify suitable service-user to complete the PREM with ☐

At an appointment with them, assess their capacity to decide whether they would like to participate in the trial ☐

If necessary: identify a personal consultee to give an opinion on the service-user's participation in the project ☐

Use the flow chart to decide which information sheets/consent forms are required ☐

Once information sheets/consent forms are complete, administer the PREM to the service-user according to the instructions provided ☐

Record the service-user's responses using one of the scoring sheets provided ☐

Record your observations and reflections on using the measure after you have administered it ☐

Once you have trialled the PREM with 3 people, contact Hannah (hsugarman@nhs.net) to arrange for her to meet with you to conduct an interview. ☐

OPTIONAL ADDITIONAL VERBAL PROMPTS

1. Did I listen to you?
   Did I work *with* you and listen to your views?
2. Did I treat you with respect?
   Did I include you?
3. Was I interested in you as a person?
   Did I try to get to know you?
4. Did you think I cared about you?
5. Did I answer all of your questions?
   Did I give you all the information you needed?

Appendix 14: Information sheet for service-users (about the trial of the PREM)

Information sheet
for service users

We want to try to make services better by asking people what they think about their care. We are testing out a new questionnaire.

We would like to invite you to take part in the test of the questionnaire today. The questionnaire asks you a few questions about what you think about the service you get from our team.

You do not have to try out the questionnaire. It is up to you. If you say no, it will not affect your care.

Any feedback you give will be kept confidential, unless you tell us anything that makes us worried about your *or other people's* safety.

If you have any questions, please ask!

Appendix 15: Easy read information sheet for service-users (about the trial of the PREM)

Information sheet

Information for service users (easy read version)

We are trying out a new questionnaire.

We would like to test it out with you.

It asks about your experiences of your care.

We want to know what you think of us!

Your feedback will be confidential, unless anything you tell us makes us worried.

You do not have to try it...it is up to you!

Appendix 16: Consent form for service-users and carers (about the trial of the PREM)

Consent form for service users

ROYAL HOLLOWAY UNIVERSITY OF LONDON

Project title:
Design and trial of a patient-reported experience measure for people with moderate-advanced dementia

Researcher:
Hannah Sugarman (Trainee Clinical Psychologist, Royal Holloway University of London)

Please put your initials in the box if you agree

➔ **I have read the information sheet** ☐

➔ **I have had a chance to think about whether I want to do the questionnaire** ☐

➔ **I have had a chance to ask questions** ☐

➔ **I understand that I do not have to do the questionnaire if I don't want to** ☐

➔ **I agree to complete the questionnaire.** ☐

_____   _____   _____

Name of participant   **Date**   **Signature**

_____   _____   _____

Name of professional   **Date**   **Signature**

Appendix 17: Consultee information sheet

ROYAL HOLLOWAY UNIVERSITY OF LONDON

Study title: Design and trial of a patient-reported experience measure for people with moderate-advanced dementia

Researcher: Hannah Sugarman (Trainee Clinical Psychologist)

Information for Consultee

In this study, we would like to trial a new questionnaire with people with dementia. It will involve asking them some questions about their experiences of care. Your relative/friend has been selected as a potential participant because they are a person living with dementia. We have also attached the information sheet that will be provided to your friend/relative to explain what the study involves.

We feel your relative/friend is not able to decide for himself/herself whether to participate in this research.

To help decide if he/she should join the study, we'd like to ask your opinion whether or not they would want to be involved. We'd like to ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know if they have ever mentioned any feelings about participating in research, or if you know of any advance decisions they have made about this. If they have made any advance decisions about their wishes to participate or not participate, their past wishes will be used to guide our decision about whether to include them in the research.

If you decide your relative/friend would have no objection to taking part, we will ask you to read and sign the consultee declaration on the last page of this information leaflet. We'll then give you a copy to keep. We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/friend should be withdrawn.

If you decide that your friend/relative would not wish to take part it will not affect their care in any way. We will understand if you do not want to take on this responsibility.

Consultee information sheet to be provided alongside information sheet for participants.

228

Appendix 18: Consultee declaration form

For administrative use only:
Centre number: Study number: Participant ID number:
Version number: 2   Date: 20/11/2015

Consultee Declaration Form

Study title: Design and trial of a patient-reported experience measure for people with moderate-advanced dementia

Researcher: Hannah Sugarman (Trainee Clinical Psychologist)

	Please initial below
I_____ have been consulted about _____'s participation in this research project. I have had the opportunity to ask questions about the study and I understand what is involved.	
In my opinion he/she would have no objection to taking part in the above study.	
I understand that I can request he/she is withdrawn from the study at any time, without giving any reason and without his/her care or legal rights being affected.	

_____   _____   _____
Name of Consultee   **Date**   **Signature**

Relationship to participant:

_____   _____   _____

Person undertaking consultation (if different from researcher):

Name   **Date**   **Signature**

_____   _____   _____

Researcher   **Date**   **Signature**

This project has been approved by an NHS Research Ethics Committee (London – Harrow, ref: 15/LO/1369), the Psychology departmental ethics committee at Royal Holloway and the local research and development team.

Appendix 19: Interview schedule for interviews with professionals

1. What were your experiences of using the PREM to get feedback from people with dementia?
   a. Talk me through your process of using the PREM
   b. Was it the same or different with different people you trialled it with?

2. What was the quality of the feedback you were getting?
   a. How were you able to identify meaningful feedback?
   b. How did you know you were receiving good quality/honest feedback?
   c. What was good about using the PREM?

3. How could the feedback you obtained using the PREM be used to improve practice?
   a. At an individual level
   b. At a service level

4. What if any, were the challenges you found when trying out the PREM?
   a. What could be the obstacles in using the PREM in its current form?

5. Do you have any suggestions for further improvements to the PREM?

Probes (for each question)

- Can you tell me more about that?
- When you said X, can you tell me what you mean by that?
- *How* questions, e.g. how did you find that X helped?
- *When* questions, e.g. when was it best to use the PREM as part of a session?
- *Where* questions, e.g. where was a good place to set up the PREM?
- *What* questions, e.g. what made you realize it was easier to do X?
- (Nonverbal – encouraging nods, gestures to provide more information)
- So you found that it was easier when using X with X? (clarification probes)
- Was it more meaningful when you used it in this way compared to this way? (contrast probes)
- If needed: ask specifically about items, response sheet, introduction, pictures

Appendix 20: Example of a coded section of data

These pages display extracts of one interview, showing the initial coding that was completed using NVivo. The top half of the page displays the codes that were generated throughout this interview. The coloured codes correspond to the highlighted text in the transcript below.

Deciding when and where to use the PREM
Prior knowledge of someone's personality, communication style or ability
Characteristics of the sample
People could understand the PREM
How feedback could be used to identify potential changes at a service level
People might initially appear to understand, masking confusion
People couldn't understand or engage with the PREM
The PREM provided a mechanism for feedback even if PLWD didn't use it as intended
Carers using PREM with PLWD instead of staff
The need to be flexible in administration due to challenges delivering PREM in standardised way
Are people being honest

Challenges of using outcome measures to get feedback

Understanding, memory, attention and language

Strategies or methods to try to understand their experiences

The PREM could be awkward, irritating or distressing for PLWD to complete

Ideas for improvements

Obstacles posed by cognitive or communication impairments and BPSD
People could provide feedback - positive experiences
How staff could use feedback individually to modify practice
Things that supported communication
People with advanced dementia without speech would struggle to use the PREM
People having a 'bad day' or who had deteriorated
Agitation or BPSD
How existing therapeutic relationship affects administration of PREM
Identifying when it is or is not appropriate to use the PREM
Having time to do the PREM
Coding Density

Staff interview 3

H: What were your experiences of using this PREM to get feedback from people with moderate-advanced dementia?

HP3: So, my caseload with the people that fitted into that kind of fell into two groups, there was the group that've got really advanced dementia and very little communication left, and there were two of that group that I kind of attempted it with. The first lady appeared to understand when I was asking her if I could administer it with her so we sat down and started to do it, but she then became very very distressed, agitated, making grunting noises, waving her arms round so I stopped.

H: OK

HP3: So, she obviously didn't have any speech, she didn't really understand basic commands, so probably she was too impaired, even for this. And then there was a gentleman who has got sort of moderate to advanced dementia, he still had some speech, and he was brought into the general hospital and I went over to see him, he had known me very well the previous week, still appeared to recognize me, but it became apparent very quickly that he'd deteriorated an awful lot, and was no longer able to understand speech at all, so again I wasn't able to use it with him. And he was too agitated to even look at these individual cue cards or anything.

H: OK, so with both of those then, it was the impairments in verbal communication that were the problem, maybe some attention as well?

HP3: Yes, and I think also both of those were people that had got quite challenging behaviour and were agitated.

H: Right, so their state of mind was quite important. OK. And did you get a sense with either of those people that you were getting any meaningful feedback at all through the process?

HP3: I think, looking back at both of them, the particular session when I tried to do this, no. But I suppose the feedback I was getting, I was getting meaningful feedback, I could see they were distressed, they weren't enjoying the process.

H: Right, yeah

HP3: If I had looked back at those two where I'd had more positive engagements with them, I could probably have, using a different tool to this, if we'd had something observational, type of tool, you know people who were calmer, smiling, able to make eye contact while I was with them in previous visits and things, I don't know so somehow if we had some sort of a tick box tool where, you could tick off when someone's looking at you – whether they're calm, whether they're smiling.

H: Yeah. So at this level, it's more about observing them rather than asking...

HP3: Than being able to get them to give...

H: Yeah, OK. That's useful. And then how about the other people?

HP3: Yeah, the other two were perhaps maybe more at the other end of the spectrum in that actually they were probably both, although they were two of the people that had been identified into falling into what we were looking at, one's a lady with a vascular dementia and also has bipolar disorder, and you know she was able to consent to do it, she was quite willing to do it, but she's still quite high functioning and although she was willing to do it and she didn't get angry or cross about it, she humoured me I felt, in doing the tool you know, a couple of

Deciding when and where to use the PREM

Prior knowledge of someone's personality, communication style or ability

Characteristics of the sample

People could understand the PREM

How feedback could be used to identify potential changes at a service level

People might initially appear to understand, masking confusion

People couldn't understand or engage with the PREM

The PREM provided a mechanism for feedback even if PLWD didn't use it as intended

Carers using PREM with PLWD instead of staff

The need to be flexible in administration due to challenges delivering PREM in standardised way

Are people being honest

Strategies or methods to try to understand their experiences

Challenges of using outcome measures to get feedback

The PREM could be awkward, irritating or distressing for PLWD to complete

Ideas for improvements

Obstacles posed by cognitive or communication impairments and BPSD

How staff could use feedback individually to modify practice

People with advanced dementia without speech would struggle to use the PREM

People having a 'bad day' or who had deteriorated

Agitation or BPSD

Identifying when it is or is not appropriate to use the PREM

Having time to do the PREM

Coding Density

Understanding, memory, attention and language

People could provide feedback - positive experiences

Things that supported communication

How existing therapeutic relationship affe

---

times she said 'ooh this is silly', she wasn't angry or upset about it but she would probably have been able to use a more complex tool.

H: OK, so perhaps she didn't feel like it was pitched at the right level for her?

L: For her, yeah. I mean she wasn't bothered by it at all, she was more than happy to go along with it, but she did make the odd comment that suggested that it was for children, for toddlers, that sort of thing.

H: OK right, yeah. So is she someone who might be able to use the questionnaire that you already have in the service?

L: I think she would, she's got some literacy problems, so she would need support in doing it, but yes she would be able to, I would've said.

H: Then that's important to think about as well, because there might be some people who, seem to fit the criteria that we're looking at but actually in terms of engagement it's more important to use the tool that is suited for them.

L: Yeah

H: In terms of the actual feedback that you were getting when you used this with the people that you felt were able to use it, how meaningful was that?

L: Well, the fourth person is a gentleman who has just moved into a nursing home, he's somebody I've known actually for ten years because he initially came into our service with recurrent depression with neglect and suicidal ideation, and has gone on to develop a dementia and he has just moved from his own home into a care home and I've been supporting him with that process, so I then used this tool with him, and as part of his dementia he is still actually very able to communicate, he understands everything that's being said but he has now got some quite significant word finding difficulties so actually for him, this worked really really well, and he said that he liked it and he enjoyed doing it, and it felt right for him.

H: What do you think it was about this that worked so well for that gentleman?

L: I think, for him, it was being able to point along the line, that sort of visual-ness of the tool

H: OK

L: The fact that he didn't have to find the words, he's very conscious of the fact that he's now got some word-finding difficulties, so I think for him that was what worked.

H: OK, so because he had an impairment verbally, a language impairment, it was nice that he didn't have to rely on language

HP3: Yeah, because it's expressive language that he's got difficulties with

H: OK, that's good to hear. What did you think was the quality of the feedback that you were getting from people?

HP3: The only thing I would say, and this wasn't particular to this tool, I think because...it would be interesting to be able to do this on people that were new to me, that were initial assessments.

H: OK

HP3: Everybody that I did this on, well the two people I was able to do it with successfully...people that I'd known for a very long time who like me and probably want to please me, and wouldn't want to upset me, by saying something negative

H: OK yeah

HP3: But I think I would've picked up on body language, like I did with the lady that, she did make the odd comment that she found it a bit patronizing so it

232

Appendix 21: Initial themes generated from the data

Characteristics of the sample

Theme 1
Miscellaneous

Trial of the PREM as research

Practical challenges in using the PREM

Theme 4
Collecting meaningful feedback using PREMs

Challenges of using outcome measures to get feedback

Are people being honest

What helped in engaging PLWD in the feedback process?

People could provide some feedback: positive experiences

Theme 5
Success stories: what helped?

How feedback can improve care

How cognitive or behavioural symptoms of dementia affected trial of the PREM

Theme 2
Discoveries about administration of the PREM through the trial

How existing therapeutic relationship affected PREM

Staff experiences of using the PREM

The PREM could be awkward, irritating or distressing for PLWD to complete

Theme 6
Anticipating challenges

Capturing experiences of people in the very advanced stages of dementia

People couldn't understand or engage with the PREM

Identifying when it is appropriate to use the PREM

Theme 3
Decisions for staff to make when collecting feedback (using the PREM)

The need to be flexible in administration due to challenges delivering PREM in standardised way

Deciding when and where to use the PREM

Problems using the scale to respond

Theme 7
Areas to modify

Ideas for improvements

Problems with individual items

Appendix 22: Additional extracts to evidence themes

Theme 1 subtheme: How does it feel?

HP3: I could see they were distressed; they weren't enjoying the process.

HP3: I felt, in doing the tool you know, a couple of times she said 'ooh this is silly', she wasn't angry or upset about it but she would probably have been able to use a more complex tool.
H: OK, so perhaps she didn't feel like it was pitched at the right level for her?
HP3: For her, yeah. I mean she wasn't bothered by it at all, she was more than happy to go along with it, but she did make the odd comment that suggested that it was for children, for toddlers, that sort of thing.

HP5: I guess it might have been, for her, a bit awkward to say no, 'cause I was actually sitting…kneeling on the floor next to her. Whilst she's in the chair.

HP5: I'm thinking if you're asking somebody who perhaps was more difficult and who you didn't have such a good relationship with. Again, I have got somebody else who I'm thinking of, that, if I was to do it with her…I mean she actually hasn't got dementia, she's got bipolar affective disorder, but I wouldn't be very comfortable sitting that close to her asking her those questions with that, because she can get rather stroppy, and I wouldn't want to be quite that close going through something with her like that.

HP5: I think you're putting them in a really awkward situation, sitting close with them, asking them those questions, where it's you that they're assessing really, or they're talking about.

HP5: No. As I say, I don't know if I'd want to use it with people who sort of, you know in the past who are kind of irritable, who I think it would annoy them
H: What do you think would annoy them about it?
HP5: They could feel they're being patronized
H: So it's about pitching it at the right level?
HP5: Yeah, that's a hard one, isn't it, you know, getting that right. Just, you know, have I listened to you today, you know I can imagine the response of some people, what they'd say, you know some people over the years that I've worked with, I'd just, you know,

HP7: I do find that the questions that we are, you know, putting to people in many different ways, whether it be his particular sort of audit or if it's you know somewhere where our ow other questions, we're trying to sort of ascertain how a person is, it does irritate people

HP7: I don't think he understood, you know, I could tell he didn't understand because he just stared at it. He seemed quite distressed at that point, um, I saw him becoming quite fidgety, he started to brush his hair, he started to sort of fidget with his clothing, his eyes teared up as well, and at one point he became quite flushed, you know, sort of colouration became quite, almost like embarrassed.…so, I could see then that yeah this man, this is upsetting him, this is something he's not, you know, feeling comfortable with. I felt uncomfortable with it as well at that point, so I'd kind of offered reassurance that I didn't sort of keep asking the point, I just said you know that's fine, it's OK, we don't have to carry on with this, you know, because I could see that there was some distress with him,

HP5: I don't think I'd feel comfortable using it, if it was somebody as I say who you don't have such a good relationship with, or somebody who gets a bit stroppy and irritable. Something like this I feel could irritate somebody who has a bit of a short fuse anyway.

HP5: I don't think you'd have a good relationship if they didn't feel comfortable talking to you, or if you weren't respectful, or if you didn't listen to them

HP4: … so she was kind of having a joke and she didn't mind me asking questions, so that, I think for me it made me feel a little less nervous because I think although its only just a few questions you think how's she going to…is she going to be negative or I don't want to do this but I think, it settled my, not my nerves but kind of how I approached it

HP5: Obviously for this project that we've just done now…I chose somebody who I've worked well with, not because I thought I'd get positive feedback but because I know that she would probably be quite happy to do the questionnaire with me, you know when I broached it with her she was 'oh yes yeah', she was fine with it, whereas if you've got somebody you haven't built up such a good relationship with, it'd make you probably more hesitant to ask about it in the first place.

HP4: Yeah, yeah I think cos if maybe the first time like any assessment, if the first time you use it the person's not interested or stops at question two, and I think you don't wanna carry on…you know it makes it awkward for you, but then you have a bad experience and it makes it harder to then try it with someone else

HP1: [using the response scale] I'd give up because I'd feel sorry for them because they'd look so perplexed

HP6: …I felt rejected…he added well I know you'll be, you'll finish and then go, you'll be asking me questions and then you do nothing about my situation.

HP5:…it was a bit frightening…a bit like, ooh I don't really know if I want to be asking them these questions

HP5: I was nervous before I was gonna do it though! I was! I mean, you know like, I was going all through it before I went out of the house in the morning, and thought oh god I've got to do it, and how am I going to do it, I was quite surprised at how I felt about going up to do it.

H: What do you think was behind that?

HP5: I guess just cos it's something new and you don't know what you're doing, and you just wanna get it right

H: So there's something about making sure the staff feel confident?

HP5: Yeah definitely, definitely. And because it's quite simple, you would think that well its dead simple, so there's nothing to worry about, but that's not true you actually still need to be prepared and have your paperwork in the right order so you look competent and know what you're doing.

HP7: So I could see then that yeah this man, this is upsetting him, this is something he's not, you know, feeling comfortable with. I felt uncomfortable with it as well at that point…because I could see that there was some distress with him

Appendix 23: Focus group findings

FORMAT	
Professionals	Service-users/carers
Keep it simple Involve the carer Two colours make it 'busy' Use large print Colours are good Check in with them frequently Use more than one visual prompt to support sensory impairments Prompt them to use their glasses/hearing aid Find a way to capture nonverbal information The PREM for people with learning disabilities is too complicated, involves a mixture of cues and too much information Avoid writing due to literacy/cognitive impairments Make options concrete, give them a choice Keep the focus on the here and now 1 idea in each question Use cue cards Keep it embedded in the discussion throughout the appointment rather than just at the end Simplify the language	The existing PROM/PREM in the service is hard to read due to sensory impairments Smiley faces are good People with advanced dementia couldn't focus on the PREM for people with learning disabilities There should be opportunities to give examples The colours are good It's good for people to make eye contact

CONTENT	
Professionals	Service-users/carers
Remove certain questions from the existing PROM/PREM, e.g. 'do you have a number to contact someone' Look to the research to find out what is important to people living with dementia Being treated with dignity and respect is important It may not be appropriate to ask were we nice to you in case we were delivering bad news Did we do what they wanted us to do? Feeling happy, safe, well, heard and understood Are we meeting their needs?	You want someone you can talk to if you have problems/a point of contact I like to know what's happening with my care I want to be supported to lead a normal life, keep my independence Give me all the information, treat me with respect, tell me the truth, listen to my opinions, treat me with dignity/compassion, ask me for my views, ask me directly and give me instant feedback/answers Give people their identity, take their opinions with respect, no matter what diseases they've got

Appendix 24: Summary of recommendations about producing accessible materials for older people and people with dementia

Source	Title	Recommendations
Morrell, Shifren, and Park (1999)	Processing of medical information in aging patients: Cognitive and human factors perspectives	Delete unnecessary words Avoid using two or more subordinate clauses Plenty of spacing
National Institute on Aging (2016)	Making your printed health materials senior friendly	Limit number of key points Avoid instructions with more than two steps Avoid jargon Use pictures to help illustrate information Be direct and specific Use large typeface, e.g. 18 point Use upper and lowercase letters Create contrast: Dark type on light background or vice versa
Dementia Engagement and Empowerment Project (2013)	Writing dementia-friendly information	Keep language simple but not patronising Only include a few relevant pictures Use bold text to separate information Use sans serif fonts Include plenty of white space around text Use colour to help with interest and concentration
US Department of Health and Human Services (2012)	Thing to know if your material is written for older adults	Format to enhance readability Uncluttered layout with plenty of white space Use the active voice Coach people on how to use the material Use diagrams or pictures, or supplement written material with spoken explanations Test the material with older adults

Appendix 25: Example of notes from cognitive interviews

The table displays the responses given by service-users, carers and professionals during the cognitive interviews when item 1: 'Did I listen to you?' was presented. Responses from different participants are separated by semi-colons.

Probe	Service-users	Carers	Staff
What is it asking about?	Listening to what you say, understanding what you're doing; Well, if I've understood, have I listened or understood	We had experiences in the past where I was telling them information and…they obviously wasn't listening to what I said;	It's asking if the person feels they've been heard; I think if I felt I was able to explain my problem, how I was feeling, given opportunity/time to say what I want to say and not be cut short, given opportunity to e.g. talk with relative not there if that's what you wanted to do; Did the patient feel he was in communication with you properly? About communication, understanding, satisfaction;
Could you repeat this in your own words?		Don't think you could ask this in another way	This is really hard because it's sort of, did you pay attention to me, let me speak, ask me questions then give me time to answer;
Is it clear?	Oh yes;	Yes, brilliant	Yes; Quite clear, but a picture of an ear might possibly help; Yes, very clear;
What time period was it asking about?		By the end of the consultation	The time you walked in their front door and started asking them questions/they came into clinic and you were starting to ask them the questions;
What were you thinking when I asked you this?	Listening to what you've got to say, exactly what you said and trying to understand questions asked, if there wasn't you would just sit through and say yes I understood;	Sometimes when you tell a doctor something, they don't always answer with the answer you were expecting, so you don't know if they've listened to what you've said;	I'd feel reassured by it, think it was important to person that they had heard me;

Probe	Service-users	Carers	Staff
Would it be easy or difficult to decide what answer to give?	Depends really, what we've been talking about; Easy;	Easy; It would be straightforward enough for me because I have a background in form design: brief, to the point, you've got something to answer with; It was easy for me;	Very easy; It would be easy, it's quite black and white - you either listened to me or you didn't, there is a thought about how I perceived the doctor (may not want to do the talking because I want the doctor to pass on their words of wisdom); For myself yes, but for someone who's a bit older and having problems with memory, trying to retain information might be difficult; Easy;
Is there anything that would make this difficult/uncomfortable to talk about?	No, depends on what's been said, at the moment its standard, straightforward	Maybe someone with advanced dementia would probably find that confusing, make harder work of it than it is, misunderstand it; I think it would be uncomfortable, you wouldn't want to upset that person, but if you felt you'd been given the wrong information you should say 'no';	No, don't think so; No;
How easy/difficult would it be for someone with advanced dementia to answer this?	A person with real dementia wouldn't know anyway - did I listen to you;	If they've got advanced dementia, they're not going to know;	I think it's really good format, for most people the question is very basic/straightforward, people who have got receptive language difficulties might have an issue but it is as simple as it could be; I think probably moderate dementia yes, possibly people with more advanced dementia may not because they may not even quite understand the question; This question is simple in writing but meaning might be complex for some people. Particularly people with FTD, very little understanding;

Probe	Service-users	Carers	Staff
How easy/difficult would it be for someone with more advanced dementia to remember if someone was listening to them?	Very hard, I forget some things very quickly and it's very hard, she might say I told you 15 minutes ago, I don't have attention span;	Attention span is very limited so probably wouldn't remember if someone had listened to you; I think even with how he is now it would be a problem because he says things he thinks people want to hear, so person with more advanced dementia might just try to please the person;	It'll depend on the person, short question so I'd hope most people who can understand language still will be able to remember question, might want to practice with them in terms of how they're going to answer it, use some examples to get them to practice, try several times, use something simple to see if they understand e.g. "Is your name X?"; I think sometimes being asked after an event is harder because you've got to remember so much about what went on - are they able to pick up on nonverbal cues, hand signs, for some people it would be difficult to remember if it was at the end of an hour long appointment; Might not immediately recall whole assessment or conversation; If they have very bad short-term memory they might forget what you were talking about;
Can you think of anything that might help someone with more advanced dementia to answer this question?	Apart from did I listen to you and is there anything you want to speak to me about now;	Can't think of any other way you could ask that, is there anything you didn't understand; If it was given by a third party, might help people to be honest;	Using visual prompts could help; Popping some of these questions in to the general conversation; Giving them triggers, key points: today we've talked about X, Y and Z - giving them a summary may help them to remember what you've spoken about to help them to remember if they felt listened to. To get a meaningful response rather than them just wanting to please you; Keeping it in the here and now: 'do you think I'm listening to you?' - get them to directly answer that question;
Would it help to use a picture?	Possibly, yeah;	I think that would detract from the question;	My immediate thought would be having some ears on here, it could be sensory overload but if it was a simple diagram I think it would be alright; Clarity/singularity are main things, so more than one thing might make it more complex, too much input for them. Repeating the simple words more than once works, pause, see whether they have understood the question. Ask them to repeat the question;

Appendix 26: Tables displaying suggested modifications to the PREM from the cognitive interviews

Component	Positive feedback	Ideas for modification	Things to keep in mind
Introduction	It's clear and simple. It would be clear for service-users.	Make it meaningful: say why you're doing it. Change the word feedback as its technical – use something a bit softer. Use fewer words. Keep it in the here and now. Give more of an introduction.	
Item 1: Did I listen to you?	It's clear/straightforward. I'd feel reassured that they were asking this. It's brief and to the point.	Keep it in the here and now. Incorporate a visual cue: ears. Keep it simple.	Some people may want the professional to do all the talking. People in advanced stages may not know/remember if you listened to them or find the question confusing.
Item 2: Did I treat you with respect?	Easy to understand.	Keep it in the here and now, e.g. have I respected you?	The concept of respect has different meanings to different people. People may not understand your role and therefore think you haven't been respectful. Service-users may not be paying attention to how respectful you were, especially if anxious/frightened.
Item 3: Was I interested in you as a person		Did I try to get to know you is a much better way of asking it.	They might be answering 'in the moment', rather than considering the whole session.

Component	Positive feedback	Ideas for modification	Things to keep in mind
Item 4: Did you think I cared about you?	By asking the question, it shows you do care.	People may misunderstand, assume you're talking about care in the practical/personal sense. The current wording could be confrontational.	People who are reserved socially may not be honest.
Item 5: Did I answer all your questions?		It could be leading, assuming that they have questions. Give context: "We've finished talking now. Do you have any questions?"	
Response scale	It's easy to use. Colours are good. The instruction line makes it clear	Check peoples' understanding at the start by asking test question and getting them to respond, e.g. "Is your name David?" It's better without the instruction line (one participant) Red and green have strong positive/negative connotations (one participant).	Are symbols universally understood?
General		Check they aren't just acquiescing/agreeing with you. Check in if they have understood what you mean. Memory problems could affect ability to respond – have the option to use it partway through a session. Provide summaries of what you've spoken about. Use visual prompts to support understanding. Ground in the present, e.g. "today during our meeting…" It's good to have the option to present stimuli visually and verbally/orally. Have an option for qualitative responses too.	You need to tell people they can be honest. Be aware people may try to please you, say what you want to hear. It could be given by a third party. Essential to check understanding: repeat questions, ask them to repeat back to you. Despite the simplicity, they still may need the carer to help.

Appendix 27: Recommendations to inform revisions to the PREM

produced through the current project.

Component	Problem detected	Recommended revision
Item 3: Have I tried to get to know you today?	Wording may be confusing for people if there is already an established therapeutic relationship; Service-users seemed confused by this question.	Re-word if possible.
Item 5: Have I answered your questions today?	May lead people to think they need to ask questions.	Consider whether this could be re-worded or if it can be removed.
Format	More visual cues would assist people, but there should be fewer materials to organise.	Provide more extensive validated visual prompts that are integrated into the PREM.
Scale	People did not understand the scale and were unable to use it to respond.	Develop a more concrete response procedure, perhaps offering three choices (e.g. 'no', 'yes', 'sometimes') for people to point to.
Method of administration	Service-users were uncomfortable providing feedback directly to professionals about their care.	Train carers in administration of the PREM so that they can collect feedback and submit this to the service on behalf of the service-user.
Flexibility	Different people responded to different combinations of stimuli.	Supply several different versions of the PREM to enable presentation of information in different ways; for example, a version with only verbal cues, a version with only visual cues, and a version which combines both.