ENHANCING COMMUNICATION AND ENGAGEMENT BETWEEN PEOPLE LIVING WITH DEMENTIA AND HEALTH CARE PROFESSIONALS ACROSS THE WELL PATHWAY FOR DEMENTIA

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Published work and a critical commentary submitted in partial fulfilment of the requirements of the University of the West of England, Bristol, for the degree of Doctor of Philosophy by publication (DPhil).

Section A: Commentary

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ABSTRACT

This thesis is a submission of eight published papers with a critical commentary to meet the requirements for a DPhil in accordance with the regulations of the University of the West of England (UWE, Bristol). These papers have resulted from three projects that I have worked on over the last seven years as a trial manager at UWE Bristol.

This thesis demonstrates how my work has generated new knowledge in the field of psychosocial approaches to dementia care. These projects share a common focus of person centred care in dementia. The findings from these projects add to the body of evidence for interventions to improve communication, interaction and engagement between health care professionals and people living with dementia within the different phases of the Well Pathway for Dementia. Project 1 adds to the knowledge around locating the assessment and diagnosis of dementia in primary care with a greater role for GPs and nurses in these processes. In project 2 I studied an intervention designed to improve support and engagement between staff and patients on older psychiatric inpatient units. Finally, in project 3 I researched ways in which the psychosocial threat of dementia can lead to a pattern of selective forgetting which inhibits communication and how nostalgic memories could alleviate this pattern of forgetting which could help people live well with dementia.

Within this critical commentary I demonstrate my intellectual contributions to these projects and papers, how I have developed my research skills and competencies and how I fulfill the six UWE Bristol doctoral descriptors.

DECLARATION OF AUTHORSHIP AND TRAINING

I confirm that the work presented in this doctoral thesis, including the chosen publications and accompanying commentary (except where stated) is the original work of the author. I confirm that none of the published body of work included within this portfolio of selected publications has been submitted for another academic award either in this or any other institution. I confirm that the necessary training requirements (60-120 credits, of which at least 60 are at level M) have been met through accredited learning.

Miss Emily Jayne Dodd, August 2019.

CONTENTS

1   INTRODUCTION & BACKGROUND

My interest in pursuing a career in research came whilst studying for an MSc in Public Health at the University of the West of England (UWE) Bristol. Towards the end of my MSc, in 2012, I was fortunate to secure a position as trial manager at UWE Bristol. Since that time I have set up and managed a number of research projects in dementia care. My role now extends to other academic responsibilities. I develop research protocols, write research grant applications and disseminate research findings through journal articles, poster and oral presentations at conferences. I am currently preparing an Impact Case Study for the Research Excellence Framework 2021.

Both professionally and personally, I have had direct contact with the challenges of caring for and supporting people living dementia. In my first job post-university in 2003 I supported people living with dementia in the community. In my personal life, my paternal grandfather lived with vascular dementia before his death in 2007 and my maternal grandmother is currently living with dementia. I identify as a white British female from a working class background, the first in the family to attend university. My academic background is in psychology (BSc) and public health (MSc).

Prior to my research career I worked as a mental health worker in primary care, providing supported self-help to people with mild to moderate anxiety and depression. Many of the people I supported were living in deprived communities with continuing complex social problems. I began to question the usefulness of the interventions I had been trained to deliver when very often, I perceived, the clients' mental health difficulties were a valid response to their social situations. This sparked my interest in public health and prevention of ill health as an important factor to improve health and wellbeing alongside the treatment of such conditions. I believe the reason why I take a psychosocial, person-centred approach to my dementia research is because, as with mental health problems such as depression and anxiety, a person living with dementia does not operate in isolation but relies upon and functions within a wider social system, including health and social care services which impact on their wellbeing. This influence is evident in the qualitative papers in this thesis where findings are focused on the importance of providing interventions and

environment where communication and engagement between health care professionals and people living with dementia can flourish.

The purpose of this thesis is to evidence how my research has contributed to the generation of new knowledge in psychosocial approaches to dementia care, particularly related to the theme of communication between health care professionals (HCPs) and people living with dementia. In order to demonstrate how my work on this research programme has consistently met the six UWE Bristol doctoral descriptors for the award of DPhil, I provide a reflective commentary on eight of my published papers (in section B) that have been generated from three projects. These projects and papers are detailed in table 1. I have made substantial contributions to drafting of all these papers. Further information about my contributions to each paper can be found in chapter 3.

Paper number	Published paper (see section B)
	Project 1: Primary Care Led Dementia services (PiCLeD)
1	**Dodd, E.**, Cheston, R., Fear, T., Brown, E., Fox, C., Morley, C., Jefferies, R., and Gray, R. (2014) An evaluation of primary care led dementia diagnostic services in Bristol. *BMC Health Services Research*, 14,pp592
2	**Dodd, E.**, Cheston, R., Cullum, S., Jefferies, R., Ismail, S., Gatting, L., Fear, T., and Gray, R. (2015) Primary care led dementia diagnosis services in South Gloucestershire: Themes from people and families living with dementia and health care professionals. *Dementia*. *The International Journal of Social Research and Practice.* 15(6)pp1586-1604
3	**Dodd, E.**, Cheston, R., and Ivanecka, A. (2015) The assessment of dementia in Primary Care. *Journal of Psychiatric and Mental Health Nursing*, 22 (9). pp. 731-737
	Project 2: Protected Engagement Time (PET) on older adult psychiatric wards
4	Nolan, F. M., Fox, C., Cheston, R., Turner, D., Clark, A., **Dodd, E.,** Khoo, M-E., and Gray, R. (2016) A feasibility study comparing UK older adult mental health inpatient wards which use protected engagement time with other wards which do not: study protocol. *Pilot and Feasibility Studies*, 2:7
5	**Dodd, E.**, Cheston, R., Fox, C., Procter, C., Heneker, S., Gray, R., and Nolan, F. (2017) Protected Engagement Time on older adult mental health wards: a thematic analysis of the views of patients, carers and staff. *International Journal of Mental Health Nursing* 27(2) p608-618
	Project 3: Managing the threat of dementia
6	Cheston, R., **Dodd, E.,** Christopher, G., Jones, C., Wildschut, T., and Sedikides, C. (2018) Selective Forgetting of self-threatening statements: mnemic neglect for dementia information in people with mild dementia. *International Journal of Geriatric Psychiatry*, 33(8), pp1065-1073.
7	Cheston, R., **Dodd, E.**, Hart, I., and Christopher, G. (2019) The recall of dementia related and neutral words by people with dementia: The ironic process of thought suppression *International Journal of Geriatric Psychiatry* 34, p756-764
8	Ismail, S., Christopher, G., **Dodd, E.**, Wildschut, T., Sedikides, C., Ingram, T., Jones, R., Noonan, K., Tingley, D., and Cheston, R. (2018) Psychological and Mnemonic benefits of nostalgia for people with dementia *Journal of Alzheimer's Disease* 65(4) p1327-1344

Table 1: Bibliography of published papers submitted in support of the award

In this commentary I demonstrate that my work meets the criteria that UWE Bristol requires of postdoctoral researchers. Namely, that they[1]:

1. Have conducted enquiry leading to the creation and interpretation of new knowledge through original research or other advanced scholarship, shown by satisfying scholarly review by accomplished and recognised scholars in the field

2. Can demonstrate a critical understanding of the current state of knowledge in that field of theory and/or practice;

3. Show the ability to conceptualise, design and implement a project for the generation of new knowledge at the forefront of the discipline or field of practice including the capacity to adjust the project design in the light of emergent issues and understandings;

4. Demonstrate a critical understanding of the methodology of enquiry;

5. Have developed independent judgement of issues and ideas in the field of research and / or practice and are able to communicate and justify that judgement to appropriate audiences;

6. Critically reflect on their work and evaluate its strengths and weaknesses including understanding validation procedures.

The following section provides background and context for the subsequent commentary chapter. This section demonstrates my critical understanding of *the current state of knowledge in this field of theory and/or practice*, the second doctoral descriptor.

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[1] Taken from the UWE Graduate School Handbook part 2.

1.1 What is dementia?

The term 'dementia' describes the progressive and cumulative loss of cognitive abilities that arise as a result of any one of a number of different disorders affecting the brain for example Alzheimer's disease. Initial problems may be experienced in specific areas, such as encoding new memories, or in verbal fluency. These problems become more severe and widespread with declines in other cognitive abilities such as concentration, problem solving abilities, communication and reasoning. Over time, almost all areas of cognitive functioning are affected. These changes in cognition can impact on a person's personality and behaviour and reduce their ability to function independently in everyday life. Common psychological symptoms that people living with dementia may encounter include low mood, anxiety, anger, agitation and withdrawal. As dementia progresses, so the person will become increasingly reliant on others for their overall care.

1.2 How common is dementia?

Worldwide around fifty million people are living with dementia, a number that is expected to triple by 2050 (Prince, et al., 2016). The World Health Organisation (WHO) describes dementia as a public health priority (WHO, 2012). The increasing number of people living with dementia is, in part, due to a global aging population alongside dementia predominately affecting people in older age. That said, dementia can affect younger people with around 1 person in every 1000 under the age of 65 developing dementia (Alzheimer's Disease International, ADI, 2018). The prevalence of early-onset dementia (64 years and under) in the UK in 2014 was 42,325 (Prince, et al., 2014).

There are 209,600 new cases of dementia each year in the UK (Matthews, et al., 2016). In 2014, it was estimated that around 850,000 people had dementia with an estimated one million people living with this condition by 2025 in the UK (Prince, et al., 2014). However, incidence of dementia in the UK is falling explained by a public health life-course approach to reducing risk factors associated with dementia (Matthews, et al., 2016).

1.3   What are government policies to tackle dementia?

National strategies and policies to manage the global public health issue of dementia vary widely between countries. Wright and O'Connor (2018) conducted a review of global policies and strategies on dementia. The UK, Finland and France are examples of countries that have developed dementia policies whereas Germany and Turkey were identified as having no national policy for dementia. This variation is reflected in the ADI (2017) overview of international action plans for dementia. Main policy topics consistently identified in this overview were awareness raising and campaigns to prevent dementia, early detection and diagnosis, post diagnostic support, treatment and care (ADI, 2017). In countries such as the UK, the United States of America and the Netherlands, investment in dementia research is a major priority (ADI, 2017).

1.4   Should research focus on treatment or prevention?

As the prevalence of dementia roughly doubles for every five years after the age of 65 (Jorm and Jolley, 1998) delaying onset by taking a public health approach to address modifiable risk factors is warranted (Norton et al 2014). From an economic perspective, delaying average onset by up to 36 months could save £34.9billion per year in the UK (Knapp, et al., 2014). Australia and Finland in particular have taken a public health view of dementia through prevention campaigns that focus on brain health promotion.

In the UK, research investment has focussed upon the biomedical approach to finding new treatments and cures for dementia through the creation of the Dementia Research Institute. This work spans six universities and seven hundred researchers. Research such as this has been on-going since the introduction of anticholinesterase inhibitors in the late 1990s with no new medications coming to market. Therefore, it could be argued that research on prevention of dementia as well may be of additional benefit.

Looking at dementia through different perspectives will yield different definitions and hence different ways of approaching dementia. The next section critically evaluates the biomedical approach to dementia.

1.5 What is the biomedical approach to dementia?

The causes of dementia are pathological, and can occur as a result of many different diseases. The main disease pathologies associated with the condition are Alzheimer's, vascular dementia, dementia with Lewy bodies (DLB) and frontotemporal dementia (FTD). Alzheimer's disease is the most common condition associated with dementia, accounting for around two-thirds of cases in older people (Alzheimer's Research UK, 2019). Alzheimer's disease is characterised by neuronal loss and synaptic degeneration due to build up in the brain of the proteins, amyloid and tau (Mandell and Green, 2011). Vascular dementia is the second most common cause of dementia. It is associated with damage to blood vessels leading to the interruption of blood supply to certain areas of the brain. The term mixed dementia is generally used to describe people exhibiting both Alzheimer's disease and vascular dementia pathology and symptoms.

DLB is associated with Parkinson's disease but classified as a separate disease. As with Alzheimer's disease, a build up of protein around nerve cells is implicated in this type of dementia. Significant symptoms in DLB include visual hallucinations and Parkinsonism; rigidity and slow movements (Fong and Press, 2011).

FTD is a much rarer form of dementia most commonly diagnosed in people at a younger age. There are three variants of FTD and as the name suggests this type of dementia particularly affects the frontal and temporal lobes of the brain. Given this pattern of pathology in these areas of the brain, linguistic deficits, personality and behavioural changes are common in people with FTD.

While framing the changes that occur as a result of, for instance, Alzheimer's disease solely in terms of a neurological process has led to advances in treatment and understanding, many researchers and clinicians have suggested that a wider, biopsychosocial approach is necessary. There are three key ways in which a focus on neurological functioning at the expense of psychosocial processes associated with dementia has been criticised.

1.5.1 Critique 1: A focus on what is lost

Within the UK, Kitwood has been the most influential critic of the biomedical approach (Kitwood, 1997; Brooker and Kitwood, 2019). Kitwood argued this approach framed the individual solely in terms of a neurological disease process, whilst ignoring the importance of social and psychological processes. This often leads to a "tragedy discourse" about dementia, which further marginalises people living with the condition (McParland, et al., 2017). Instead, Kitwood advocated the need for a new, person centred model of dementia care, which positioned dementia as a dialectical interaction between internal, neurological change and the social psychological world surrounding the individual (Kitwood, 1989; Kitwood, 1990).

Looking at an aspect of dementia care through different perspectives has implications both for how we understand how people with dementia communicate and behave and how we respond to this behaviour. An example of this difference in approach can be seen in what the biopsychosocial model frames as the behavioural and psychological symptoms of dementia (BPSD), but which within a person centred approach are typically represented as challenging behaviour. If these behaviours are framed as symptoms of an underlying disease, then this can lead onto them being seen as a problem that needs to be managed. Thus, responding to these behaviours using a biomedical approach would be more likely to lead to the use of medication or constraint as a first response. Seeing such behaviours as purely due to the disease process often means that other factors, such as how the care giver's own behaviour and care practices might be influencing the behaviour of the person living with dementia are less likely to be considered (Stokes, 2001). However, if BPSD are interpreted as behaviours that communicate an unmet need, rather than just a symptom caused by a neuropathological disease process, then this opens up the possibility of a different response. The behaviour is no longer seen as a problem to be managed or taken away but as a method of communication that needs to be understood, of an underlying need that has to be met (Cohen-Mansfield, 2008).

Increasing numbers of researchers have used psychosocial approaches to viewing dementia in order to develop a greater understanding of behaviours that challenge and how to manage such situations effectively. For example, Miesen (Miesen, 1999;

Miesen and Jones 2004) has studied the common phenomenon of parent fixation behaviour using the psychological theoretical framework of Bowlby's attachment theory (Holmes 2014) to argue that such behaviour is a mechanism for the person with dementia to communicate a need for returning to a state of security and safety. Similarly, James (2011) has incorporated psychological formulation into the Newcastle Model of challenging behaviour. This model provides a framework for caregivers to reflect on and make sense of what might be the reasoning for the person's behaviour.

1.5.2 Critique 2: A focus on decline

Many authors have typically chosen to describe the progressive nature of dementia in terms of a series of stages, for instance as mild, moderate or severe dementia. While this carries a certain 'common-sense' validity, there are risks in this approach (Lyman, 1989; Harding and Palfrey, 1997). Lyman (1989) argues that if all changes in the behaviour of someone living with dementia are attributed to an inexorable, progressive neurological deterioration from one stage to another, then psychosocial factors, such as whether the person who is living with dementia is reacting to a new context, or has experienced a decline in their physical health, will be ignored. Focussing on decline, then, rather than taking a more nuanced, person centred approach makes it more likely that all behaviour will be viewed as the consequence of neurological deterioration. This in turn may result in unduly pessimistic care and fewer opportunities for those living with dementia to engage in meaningful activity. Project 2 of this thesis is one example where implementing a person centred intervention in older adult psychiatric wards attempts to increase opportunities for interaction, engagement and communication between nursing staff and patients staying on the ward.

1.5.3 Critique 3: A focus on dementia diagnosis

Given that damage to nerve cells and structures in the brain are implicated in dementia, a specific diagnosis of the disease underlying dementia symptoms can only be confirmed at post-mortem. Therefore, the diagnosing clinician uses a range of methods and tools to provide a probable diagnosis of the underlying disorder. There have been cases where brain atrophy is present at post-mortem with no dementia symptomatology and conversely, individuals previously diagnosed with dementia

presenting with 'normal' neuropathology at post-mortem (Kitwood, 1997). Similarly, there have been cases with and without a diagnosis of dementia presenting with mixed Alzheimer's and vascular pathology at post mortem (Cognitive Function and Ageing Study, 2001). Therefore the relationship between pathological change and level of impairment of the person is complex suggesting that dementia presentation is influenced by a range of factors including how individuals age over time, level of prior education and other personal and contextual factors (Whitehouse and George, 2008).

The biomedical approach structures how clinical services for people with dementia have been organised, tending to prioritise assessment procedures leading to the reliable and accurate diagnosis of dementia. This biomedical focus has led to over 200 specialist multidisciplinary memory clinics operating in England where GPs refer people suspected of dementia for assessment and diagnosis. Thus, resources tend to be unevenly distributed or front loaded into assessment and diagnosis whilst neglecting post diagnostic support.

At present, there are drugs, called anticholinesterase inhibitors that are available that treat some of the symptoms and can slow the progression of Alzheimer's disease and can be prescribed for DLB (National Institute for health and Care Excellence, NICE, 2018). No drug treatments have yet been licensed for any other causes of dementia. These drugs do not address the underlying neurological causes of dementia and consequently, do not constitute a cure for dementia. The value of diagnosing dementia has been questioned given this lack of a cure or treatment options, that the neurological changes associated with dementia are often hard to distinguish from the process of ageing and the stigma and fear attributed to such a diagnosis (Whitehouse and George, 2008). Consequently, in the absence of pharmacological treatments that offer a cure, a diagnosis of Alzheimer's disease or another form of dementia is often the key to accessing practical, social and psychological support. The programme of research laid out in this thesis adds to the body of psychosocial research that aims to identify evidence based interventions to support people living with dementia to adjust to the diagnosis and enable them to live well with dementia. For instance, Project 1 of this thesis looks at increasing the role of GPs in assessment and diagnosis of dementia and how this could improve early and timely diagnosis. Locating assessment and

diagnosis in primary care may free up secondary care resources to deliver post-diagnostic support.

1.6   What are examples of psychosocial approaches to dementia?

Psychosocial approaches extend the biomedical approach to providing care, emphasising that people with dementia are individuals interacting in a social world and are more than their illness. This reframing process has led to the development of two, major theories of identity. "Personhood" (Kitwood, 1997) and "selfhood" (Sabat and Harré, 1992) reframe dementia not as a disease of loss and decline but to place the neurological reality of cognitive deterioration within the context of psychological and social worlds.

1.6.1   What is personhood?

Kitwood's development of the person centred care paradigm of dementia care has personhood at its heart. Kitwood defined personhood as "a standing or status that is bestowed upon one human being by others in the context of relationship and social being. It implies recognition, respect and trust" (Kitwood, 1997 p8). Consequently, maintaining personhood in people with dementia is central to providing person centred care. More recently, Brooker (2003) developed the acronym VIPS (Values, Individual, Perspective, Social) as a way of defining the practice of person centred care and to explain the elements that should be included in delivery. These elements emphasise the importance of *valuing* people with dementia, treating those with dementia like any other human being, with dignity and respect. Person centred care emphasises the importance of treating people as an *individual*. All humans have a personal history, personality and an approach to life (Killick and Allan, 2001). These aspects of being an individual continue despite living with dementia and should be kept in mind when providing care in order to meet the needs of the person with dementia. Additionally taking on the *perspective* of the person living with dementia, is important which emphasises the subjective experiences or the psychological aspects of the person with dementia. The final element concerns a positive *social* environment and the importance of relationships with other people. Personhood can only truly be maintained if other people are engaging, interacting and communicating with the person with dementia. VIPS has since been developed into a framework used

internationally to enable services to provide person centred care (Brooker and Latham, 2015).

1.6.2 What is selfhood?

At the same time as Kitwood was developing ideas around personhood, Sabat and Harré were applying the ideas around selfhood to the experiences of people living with dementia (e.g. Sabat and Harré, 1992). They argued that there are three types of self and that selfhood is expressed through language and within social interaction.

Self one relates to personal identity. This self is used to tell stories about ourselves and share our view of the world (Kelly, 2010). The second self relates to the mental, physical and emotional attributes or characteristics we have and our beliefs about those attributes (Innes and Manthorpe, 2013). Finally self three is the socially presented self (Aquilina and Hughes, 2006). We can have multiple identities or personae depending on the social situation. The socially presented self is the most vulnerable for people with dementia because maintaining it relies heavily on interacting and communicating with other people to corroborate the self that is identified with at the time. The desire to maintain the most appropriate self and subsequent self-esteem for the social situation remains unchanged for the person with dementia. How those opportunities are provided to maintain this self and how other people react during those interactions has implications for maintenance of this self. If others fail to take account of this need to maintain the self, this can lead to perceived negative or undesirable behaviours from the person living with dementia, which only confirms their neurological impairment. This theory puts the onus on the person without dementia to consider the importance of their role and response in such interactions. Therefore selfhood is either maintained or undermined through social relationships and communication with other people.

Selfhood theories are largely built upon observation (Harding and Palfrey, 1997). A systematic review of research conducted on self and identity in dementia found that a sense of self is still maintained in people living with dementia although this may be somewhat weaker when compared to those without dementia (Caddell and Clare, 2010). Many studies identified in this review, however lacked a clear theoretical

framework. The same authors also found that interventions to assist in the maintenance of selfhood are in their infancy (Caddell and Clare, 2011).

1.6.3 What have been some of the criticisms of personhood and person centred care?

Person centred care stresses the importance of viewing the PERSON with dementia, not the person with DEMENTIA, as more than a diagnostic label (Kitwood, 1997). The central ethos is that people with dementia should not be seen as passive recipients of care but as active agents in social interactions, be that through verbal or non-verbal interactions and communications with another people.

Personhood and person centred care have been criticised for a number of reasons. Firstly, it is argued that the philosophical underpinnings of personhood is sometimes oversimplified and lacking in clarity (Dewing, 2008). Others argue it is too idealistic at the conceptual level (Packer, 2000) and that Kitwood's representation of the biomedical approach was too simplistic and critical (Hughes, 2019). Models and frameworks focusing on relationship centred care are being developed and encouraged (Adams, 2005; Nolan, et al., 2006) to counter the argument that focusing on the person with dementia ignores the 'other' person in the relationship. Finally, the research methods underpinning Kitwood's theory have been questioned for lacking transparency, validity and reliability (Adams, 1996; Dewing, 2004; Dewing, 2008).

1.6.4 Are there any practical applications to person centred care?

The VIPS framework (Brooker and Latham 2015) is a practical application of person centred care at the macro level. The central way in which Kitwood applied person centred theory to practice is Dementia Care Mapping (DCM™). DCM™ is a practical, observational intervention at the micro level that he developed to enable settings such as care homes to provide and systematically measure person centred care (Bradford Dementia Group, 1997). While research evidence suggests DCM™ in care homes improves the wellbeing of residents in long term care facilities (Brooker, 2005), a recent large scale high quality cluster Randomised Controlled Trial of care home staff led DCM™ in the UK failed to substantiate these claims. This trial found no evidence that DCM™ improved clinical outcomes such as behaviours that challenge and concluded that it was not cost effective (Surr, et al., 2018). However, adherence to the

DCM intervention was low, with only a quarter of the homes completing more than one of the three cycles of DCM™ which might, in part explain this result. Just as the main focus of DCM™ is on facilitating person centred communication between care staff and people with dementia, so the intervention described in project 2 provides another example of reorganising the way in which care settings are structured to improve levels of person centred care in an institutional setting.

1.7   Summary

In summary, personhood and selfhood are psychosocial approaches that extend the biomedical approach to dementia by focusing on the person with dementia as more than their medical label. One key, shared focus in these approaches is the way in which communication between the person with dementia and others is structured. At the time they were written, these approaches were radically new ways of thinking about dementia. Person centred care especially is now securely embedded in psychological approaches and interventions in dementia care. Kelly (2010) has argued for an integration of selfhood within a person centred approach to caring for people with dementia in institutionalised settings. She argues that by training staff to recognise and support a person's sense of self within person centred practice, this can improve the interactions that HCPs have with the people they care for.

The following section details the dementia policy in England and specifically the Well Pathway for Dementia which emphasises person centred principles across the care pathway. The work outlined in this thesis maps onto this pathway.

1.8   Dementia policy in England

Since the publication of the national strategy for dementia in England in 2009 (Department of Health, DoH, 2009), the Prime Minister Dementia Challenge was published setting out how the three strategy aims could be realised. The strategy focuses on awareness raising and reducing stigma of dementia, improving diagnosis and improving services and care for people living with dementia and their carers. If people are better informed about dementia then the strategy assumes they would be more likely to seek help and get diagnosed at an earlier point in the condition. There are benefits to receiving an earlier diagnosis such as delaying institutionalisation (Gaugler, et al., 2005), which is good for both the person living with dementia and the

economy. The most recent Prime Ministerial Challenge (DoH, 2015) continues to emphasise the need to raise awareness and diagnose early with a greater focus around research. Examples of research priorities laid out in this most recent challenge include investing in a cure or disease modifying therapies, the role and use of assistive technologies and the interactions between genetics and environmental triggers.

1.8.1 The dementia care pathway in England

Guidelines that complement the DoH strategy and the Prime Minister's challenge have also been developed. The recently updated NICE guidance (NICE, 2018) and the Well Pathway for Dementia (DoH 2015) are specifically aimed at the National Health Service (NHS) and social care sectors. In keeping with the topics identified internationally, there are five phases to the Well Pathway for Dementia; 1) preventing well 2) diagnosing well 3) supporting well 4) living well 5) dying well. The National Collaborating Centre for Mental Health (NCCMH[2], 2018) in England has developed evidenced based guidelines for commissioners explaining in more detail how the pathway from phases two to five can be implemented. This document continually refers to the importance of employing person centred care in each step of the pathway therefore extending out from the biomedical approach to incorporate psychosocial approaches.

One challenge to delivering person centred care is the organisational and cultural shift required in health and social care organisations (Kirkley, et al., 2011). In addition, ensuring the health and social care workforce is adequately trained to work with people in a person centred way at every step is a priority in the Dementia Training Standards Framework (Skills for Health, 2018).

1.9 Thesis Structure

The next chapter is a critical commentary to accompany eight selected papers (see table 1 above) that I have co-authored and which contribute to the wider field of psychosocial dementia research (for an extended bibliography of all the papers I have co-authored to date, see appendix 3). These papers stem from three research projects. The research set out in this thesis has generated new knowledge that spans and

[2] The NCCMH is a collaboration between the Royal College of Psychiatrists and University College London which develops evidence-based guidance for NHS England NICE.

informs a number of the steps on the Well Pathway for Dementia. Project 1 relates to the 'diagnosing well' phase of the pathway: concerning timely diagnosis particularly in primary care settings. Project 2 relates to 'supporting well' to include enhancing the psychosocial support in an institutional context. Finally, project 3 in this thesis focuses on post-diagnostic support to aid adjustment to diagnosis which maps to the 'living well' phase of the Well Pathway.

The following chapter is organised chronologically with a general introduction to each of the three projects followed by a summary of the findings from the included published papers. With reference to existing literature, I discuss the new knowledge generated from these projects in relation to my overarching theme of communication. I also demonstrate how I meet doctoral descriptor four, *a critical understanding of the methodology of enquiry*, through critical evaluation of the methodology of each project.

In chapter 3 I provide a personal reflection on what I have learnt and how I have developed from the experience relating to each project. I provide a summary of my contributions to each project and the selected papers and how I have met the six UWE Bristol doctoral descriptors for the award of DPhil.

The final chapter outlines my current and future planned research activity.

2 CRITICAL REFLECTIVE COMMENTARY ON SUBMITTED PUBLISHED PAPERS

2.1 Introduction to Project 1: Primary Care Led Dementia services (PiCLeD)

Early diagnosis of dementia is one of the main strands of the national Dementia Strategy for England. Providing an early diagnosis enables people living with dementia and their families to adjust, to make informed choices about support and care and to prolong independence (DoH, 2009). Placing early assessment and diagnosis in primary care could reduce the barriers that might hinder meaningful communication. For instance, being diagnosed by a familiar general practitioner (GP) rather than by an unknown professional in an unfamiliar environment may reduce patient anxiety around suspected memory problems, making it easier for them to attend an appointment. Diagnosis may be quicker in primary care than having to wait for an appointment with a memory clinic. Finally, shifting assessment and diagnosis into primary care means specialists in secondary care are able to focus their attention on the more complex presentations of the condition.

The first research project I worked on after being appointed as trial manager at UWE Bristol was the primary care led dementia services PiCLeD project. The following sections in this chapter provide background to primary care led dementia services in Bristol and South Gloucestershire and discuss three papers that have so far been generated from this project (papers 1, 2 and 3). These studies relate to the 'diagnosing well' step in the Well Pathway for Dementia which I refer to in the previous chapter. This is an on-going project with more detail presented in the future work section of this thesis.

2.1.1 Primary Care Dementia services in Bristol

 In 2012, Bristol Clinical Commissioning Group (CCG) established a pilot project giving GPs a leading role in the assessment, diagnosis and subsequent care of people affected by dementia. This was a major service redesign that was intended to address systemic barriers such as long waiting times for specialist appointments and inequity of access across the city that existed for people accessing assessment and diagnosis services.

Eleven GP practices signed up to take part in the pilot project. The GPs at these practices attended a three-hour training session to identify potential cases, carry out an assessment and to make a diagnosis of dementia. Training was provided by the GP lead for dementia and the memory clinic service manager who was a nurse. Three memory nurses were seconded from the memory clinic to assist the GPs in the eleven practices with this new responsibility. GPs continued to refer patients to the memory clinic for specialist assessment in the case of complex presentations and where patients were aged less than 65 years. The remaining practices (n=44) continued with treatment as usual, referring all patients suspected of dementia to the memory clinic for assessment and diagnosis.

Given this redesign of service, the CCG wanted to identify the impact of this change on patients, carers and staff. I was responsible for the study they commissioned. I supported the Chief Investigator to write the study report for the funder (Bristol CCG). I led on the qualitative analysis exploring the research issues of locating dementia assessment and diagnosis in primary care (paper 1). The next section focuses on this paper.

2.1.1.1 *Paper 1: Qualitative analysis from the PiCLeD project in Bristol*

Dodd, E., Cheston, R., Fear, T., Brown, E., Fox, C., Morley, C., Jefferies, R. and Gray, R. (2014) An evaluation of primary care led dementia diagnostic services in Bristol. *BMC Health Services Research*, 14:592

The aims from the funder were to contrast the primary and secondary care models of coordinating care to see if primary care could provide more patient focused care and a more coordinated approach. The published paper reports on the findings from interviews we conducted with a range of stakeholders: people who had recently been diagnosed with a form of dementia, their family carers and the HCPs involved in their assessment and diagnosis, for example GPs, nurses and psychiatrists. We gathered the experiences of the stakeholders involved in the pilot and those that were continuing with the usual diagnostic pathway of referral to the memory clinic. I organised the interviews, developing the topic guide from our consultations at both the expert and peer panel meetings. This ensured that the questions asked during the interviews were relevant and important to those stakeholders who had direct experience of delivering

and using the services. Before the topic guide was used, I ensured that it was reviewed and agreed by the peer panel.

It was important to invite people living with dementia, as well as those affected by dementia (for example, family and friends) to take part in this research as services that directly impacted on them were being changed. From a person centred perspective, involving people with dementia in the research as participants ensures that their voices can be heard (Goldsmith, 1996). To further the involvement of people affected by dementia, we trained seven peer researchers to carry out the interviews. Detail of this novel methodological approach is explored later in section 2.1.4.

2.1.1.2 A summary of the findings from the thematic analysis

The peer researchers conducted a total of 46 interviews. Twenty-three participants were recruited from the pilot GP practices and 23 from those GP practices still working within the standard model. Thematic analysis or TA (Braun and Clarke, 2006) was used to analyse the interview transcripts. TA is a flexible and relatively straightforward method in identifying, analysing and interpreting meanings in qualitative data (Clarke and Braun, 2017). Four of the team, of which I was one, conducted this analysis whilst two other members sense checked our analysis. The four main themes were: 1) GP's rarely making an independent diagnosis; 2) GPs and memory nurses working together; 3) patients and carers generally experience high quality diagnostic services; and 4) an absence of post-diagnostic support.

2.1.1.3 Communication in triadic consultations

Our findings indicated that people living with dementia and family carers found being assessed and diagnosed by either primary care or secondary care memory clinics acceptable. There were, however, concerns raised by some participants about how GPs communicated and interacted with them during consultations. Some family carers felt they were not being listened to by the GP or were excluded from the assessment process. Triadic consultations, where the GP communicates with both their patient and the family carer at the same time, are common in dementia care. Very often it is family members that first express concerns about an individual's memory. Consequently, when an initial assessment is carried out in a memory clinic, typically more time is given to the process than is possible in primary care, allowing family members to be

consulted separately facilitating their contribution. This constant exposure enables memory clinic staff to develop the skills to be able to listen and empathise with both parties.

In contrast to a specialist appointment, GPs have relatively little time in each appointment to manage such consultations and address the concerns and needs of everyone in the room. The underlying cognitive deficits of dementia add to the complexity of such a consultation as it may take time for the person to understand the implications of the diagnosis. Given the increasing pressure on primary care services, it is likely that assessments of dementia will continue to present challenges for GPs. Not only are specialists working in memory clinics more likely to be used to managing triadic consultations than are GPs, they also have more time in which to do so. Subsequent studies have explored how dementia diagnosis is disclosed and communicated particularly within triadic consultations in memory clinics (Bailey, et al., 2018; Dooley, et al., 2015). Whilst other research has indicated that a range of patient centred communication styles are used when delivering a dementia diagnosis which are related to the individual physician rather than the patient's characteristics (Zaleta, et al., 2010).

Consequently, we found the role of memory nurses working in primary care was crucial. They assisted the GPs in this pilot, having been seconded from memory clinics, and brought with them many years of experience, skills and knowledge of carrying out assessments in people's homes with family carers present. This experience could, in part, explain why study participants spoke fondly of the memory nurse involvement and were grateful for their inclusion in the process.

It is common for patients and family carers to have differing perspectives on the reason for the dementia consultation and managing this dynamic requires skill, especially in a ten to twenty minute time slot. If GPs are increasingly encouraged to deliver and communicate a diagnosis of dementia, then training to develop skills to ensure the family/carer feel involved in the assessment process may prove beneficial. A systematic review of 102 qualitative studies of 3,095 participants (Bunn, et al., 2012) of the experiences of people receiving a diagnosis of dementia suggested training for HCPs as one component to ensure the needs of both the person with dementia and the family carer are met.

Following this study Bristol CCG decided to extend primary care led dementia diagnostic services to the remaining practices across the city. They made improvements to the content, format and distribution of post diagnostic information and support opportunities. Our findings, that memory nurses played a significant role in the experiences of stakeholders and complemented the role of GPs, was instrumental in the CCG's decision to continue to resource this role.

2.1.2 Primary Care Dementia services in South Gloucestershire

In 2013, all 23 GP practices in South Gloucestershire were required to join a similar model of working to that in Bristol in which GPs were encouraged to carry out assessment and diagnosis of dementia. However, this service differed from the Bristol model in a number of potentially important ways. First, support for GPs was provided through centrally located memory nurses rather that each surgery being allocated a specific named nurse. Secondly, GPs were also able to make use of a Primary Care Liaison Service (PCLS) in this location. This multi-disciplinary service triaged referrals from other health care providers such as GPs for the secondary care mental health teams including the memory service. The service provided mental health support, brief interventions, advice and signposting for service users, their carers and relatives, GPs, Health and Social Care and third sector[3]. PCLS workers come from a variety of occupational backgrounds: community psychiatric nurses, social workers, clinical psychologists, occupational therapists and consultant psychiatrists. Thus, many of the people referred by their GP initially to the memory service in South Gloucestershire may have had an initial assessment by a PCLS worker.

Shortly after successfully completing the first PiCLeD study, the research team was asked to conduct a similar study of the emergent South Gloucestershire Primary Care Dementia service. This evaluation led to paper 2. For this paper I led and organised the thematic analysis and led on the manuscript journal submission. The next section provides a short summary of the findings from this study and discusses this paper in relation to the theme of communication.

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[3] http://www.awp.nhs.uk/services/community/primary-care-liason/ [accessed 17-07-19]

2.1.2.1 Paper 2: Qualitative analysis of PiCLeD in South Gloucestershire

Dodd, E., Cheston, R., Cullum, S., Jefferies, R., Ismail, S., Gatting, L., Fear, T. and Gray, R. (2016) Primary care led dementia diagnosis services in South Gloucestershire: Themes from people and families living with dementia and health care professionals. *Dementia. The International Journal of Social Research and Practice.* 15(6):1586-1604

Using similar methods to the Bristol study, the same peer researchers who had originally been employed to undertake data collection during the Bristol study interviewed a smaller sample of fifteen participants in South Gloucestershire. Participants included people diagnosed with dementia by their GP, their family members and HCPs including GPs and PCLS workers. Again, using thematic analysis I led a team of four people to analyse the data. I designed a system where each transcript was analysed by two researchers and that each researcher had a mix of stakeholder transcripts to read and analyse. We identified four themes: 1) The journey; 2) What next? 3) Benefits and limits of primary care; and 4) Are GPs getting it right?

2.1.2.2 Communicating a diagnosis

Those people who were living with dementia and their relatives reported being generally satisfied with the diagnosis process and, as in neighbouring Bristol, it was the lack of post-diagnostic support that they found problematic. Providing information and signposting to support services was patchy and the right information was not being communicated effectively and at the right time.

Some of the GP participants in this study were reluctant to use the terms dementia, or Alzheimer's disease, preferring to use euphemisms such as "memory problems". This echoed the findings from the Bristol study where some of the GP participants reported lacking initial confidence in conducting the diagnosis. One GP questioned the usefulness of giving a diagnosis or the "label" of dementia due to the stigma attached to the condition, especially for someone who may have been living with the symptoms for a number of years without a diagnosis. If a GP feels that communicating such a diagnosis would be unduly distressing to the person they may choose to reframe or soften the diagnosis with euphemisms. This reluctant attitude towards diagnosing and disclosing dementia contrasts with that of specialists working in memory clinics who clearly name the condition (Dooley, et al., 2018). Doctors working in these clinics felt

strongly that it is vital for dementia to be clearly named to avoid misunderstandings and that therefore the patient needs to be prepared for this possibility over the course of their attendance at the clinic (Bailey, et al., 2018). Another HCP interviewee in this study felt that providing the diagnosis could open doors to support and services.

Indeed, the extent to which an accurate diagnosis is communicated well is clearly associated with the prior beliefs about the benefits of diagnosis held by the diagnosing HCPs. A focus group study of European multidisciplinary experts (health professionals actively working in dementia care) found that dementia-related stigma particularly held by GPs was the main reason for delays in timely diagnosis (Vernooij-Dassen, et al., 2005). Our research here continues to support this worrying finding that people with dementia may be denied access to appropriate support if their diagnosis is being withheld from them due to the beliefs that diagnosing HCPs hold about dementia.

2.1.3 Summary

In summary the findings from paper one and two contribute new knowledge in how CCGs can utilise primary care staff to diagnose dementia. The research identified concerns that there are limitations in how a dementia diagnosis is communicated in primary care which are consistent with the literature elsewhere (e.g., Koch and Iliffe, 2010). These papers provide evidence that people being diagnosed with dementia and their families can struggle with how this diagnosis and subsequent information about how to live with dementia is communicated and delivered in this setting. GPs initially lack the confidence and sufficient time within traditional surgery appointments to diagnose dementia and to communicate that diagnosis effectively to those living with the condition and their families. The attitudes of some GPs concerning the usefulness of a dementia diagnosis may also determine whether a patient receives an accurate diagnosis or if they are sent away with euphemisms to avoid the stigma associated with the illness. All these factors can limit meaningful communication between GPs and their patients.

The next section will focus on the innovative methodological approach I developed in the design of these two studies. In particular I will focus on how we identified and trained peer researchers to collect the data and how this importantly links the design of the study to a concern with communication that resonates from our findings.

2.1.4 The participatory approach

A participatory approach is based on the belief that the community in which the research is being undertaken also has a role and a stake in the generation of knowledge (Green and Thorogood, 2014). Science is not being done to a community but with a community. The participatory approach that we used to interweave the knowledge and wisdom of those with lived experience of dementia into the research process was characterised by two elements. Firstly, we held expert and peer panel meetings to inform development of the questions for the topic guide. Experts included memory nurses, dementia charity service manager, care home manager and a GP. The peer panel comprised of people affected by dementia, including family caregivers. We were therefore confident that the questions addressed issues relevant to those working in and using the services. Secondly, we recruited peer researchers to collect the research data.

2.1.4.1 Peer researchers - a novel methodological approach to collecting data within dementia research

The inclusion of peer researchers (experts by experience) in this project was at the time a comparatively novel approach to collecting data for this type of research in this setting. We believed the peer researchers provided an important and different dynamic and perspective during the interview compared to using traditional research assistants. All stakeholder interviews in both studies were conducted by peer researchers on their own. This method of collecting data has advantages and disadvantages and raises methodological dilemmas. Amongst the advantages of conducting research with peer researchers is that whilst university employed researchers are likely to be highly experienced and trained professionals, they are often seen by those they are interviewing as external to them and the system they inhabit. This can influence how interviewees respond to questions, especially for people with dementia (Novek & Wilkinson, 2019). Additionally, academic researchers may lack the experience that comes from looking after or caring for someone, so will not have an intuitive level of knowledge of the challenges that this raises. People who are carers hold this level of knowledge and may be more likely to be accepted by the carer interviewee, in particular, as people who understand and can empathise with their situation. This shared understanding can aid communication between

interviewer and interviewee. Peer researchers can also help to break down some of the stigma associated with a condition to those they are interviewing by being a positive role model (Tanner, 2012).

At the same time there are also potential disadvantages to using peer researchers. For instance, they may often lack the skills and techniques necessary to carry out a well-constructed qualitative interview. It would be unethical to ask people to carry out this task without equipping them with the appropriate skills. Consequently, working with the research team I designed a training and support programme for our peer researchers. These were all aspects of this project that I led which initiated my general and continued interest in patient and public involvement in research. I will explain more about how we trained our peer researchers in section 2.1.4.4.

2.1.4.2 Who were our pool of peer researchers?

All seven peer researchers who were employed on this project had experience of caring for someone with dementia. Unfortunately, we were unsuccessful in recruiting someone living with dementia to be part of the research team - people either declined when invited or family members acted as gatekeepers and made the decision that the person living with dementia would not want to take on this role. Our experience is not atypical. A systematic review looking at evidence of involvement of peers in dementia research identified only three papers that reported on this process. (Di Lorito, et al., 2016). However, since we completed the project the DEEP (Dementia Engagement and Empowerment Project) network has been set up.Over the last three years over 30 DEEP groups have been established across the UK. Consequently people with dementia now have greater opportunities to become involved in advocating and leading change and co-producing research, identifying what works well in interactions and communication with people with dementia (see Webb, 2017 and Webb, et al., 2018 for such an example).

The seven peer researchers that we trained and worked with were all women, with an average age of 62 years and with experience of caring for someone with dementia (e.g. husband, parent). Despite my efforts, I was unable to recruit a male peer researcher. I found that it was insightful to have a group of experienced carers working with the team. During the peer panel meetings, the peer researchers provided their thoughts

on early diagnosis and the role of primary care staff. Ordinarily power within an interview situation refers to the interviewer holding the power over the interviewee. A peer researcher can shift the balance of power by making the relationship more even when interviewing a peer (Godfrey, 2004). Our peer researchers interviewed their peers (other carers), people living with dementia and HCPs. One of the peer researchers reported that she felt more at ease when interviewing patients and carers than she did with HCPs. This could suggest that peer researchers need to be supported in developing this relationship, which may not be the case for a professional researcher.

2.1.4.3 How did we identify our peer researchers?

The seven peer researchers were identified through two avenues. Firstly, I drew upon an existing pool of members of the public at the University that interview prospective health and social care students. Secondly, we asked the memory clinic staff to identify suitable people who might be interested in working with us on this project. I drew up a role description to identify what existing skills would be required for the post-holder and each peer researcher was subject to a Criminal Records Bureau (CRB) check. During informal conversations with the peer researchers and the colleagues that suggested their involvement, I felt confident that that the individuals had the capacity and capability to take on the role. We did not specify how many peer researchers we required but knew that we would need to have a pool of people to call upon given their likely caring commitments. One peer researcher, who was identified through a memory clinic, was in part-time paid employment and lived a couple of hours away from Bristol and the family member that she cared for. Despite this she still wanted to contribute which demonstrates her commitment to the project.

2.1.4.4 What training did we provide the peer researchers?

The purpose of the training was to ensure that the peer researchers were appropriately equipped with a basic level of knowledge and skills and that they felt confident to conduct the interviews. We held a one-day training event for the peer researchers, which I organised and co-facilitated. At this training we provided general information on dementia, an overview of the project and addressed potentially difficult issues or situations that may arise during an interview. We explained the

importance of obtaining written informed consent prior to conducting the interview. We gave general tips on interviewing techniques. Peer researchers were encouraged to share any concerns they had either for themselves or for the person they interviewed. I had a debriefing conversation with the peer researchers after every interview as they returned to the University to bring back the Dictaphone. In addition to this support from myself, the peer researchers attended two group supervision sessions provided by the core research team.

During the training two members of the core research team used role-play to give an example of an interview and the peer researchers provided feedback on how the interview could be improved. The peer researchers were reluctant to engage in role-play themselves which is understandable given that they had only just met us and each other that day. Role-play is a daunting experience but it is a useful way to engage people in a process and to gauge their appropriateness for a task.

2.1.4.5   Limitations to the design

A limitation to the qualitative design and to participatory approaches is generalisability. It could be argued that this limits how such evidence informs and furthers theoretical knowledge past the local context (Green and Thorogood, 2014). Although we attempted to interview a range of stakeholders, sample sizes within each stakeholder group were small, particularly in the South Gloucestershire study. These findings, therefore only capture a small number of views from a small sample of the GP surgeries in the area (not all GP surgeries responded to the invite to take part in the study). Additionally, the sample of participants in the Bristol study described themselves as White European. It has been estimated that there are approximately 151 people from Black Asian and Minority Ethnic (BAME) communities living with dementia in Bristol (Cheston, et al., 2017). None of the experiences from these communities were captured in this study. This is a gap of which the research team are aware, and since these studies were completed we have carried out further work to engage with a wider range of communities in Bristol. Further detail about this research is provided in the future and current work chapter of this thesis.

The participatory approach often involves the peer researcher having a role in the analysis of data as well as its collection. For pragmatic reasons associated with the

timescale and deadlines for the research, we did not explicitly involve the peer researchers in the data analysis process, but instead focused our efforts with them on data collection. I kept them informed of the analysis and provided a copy of the findings. One peer researcher assisted in the dissemination of the findings by co-presenting with me at the local mental health Trust's Research and Development conference.

The next section discusses the third and final paper to come from the PiCLeD project.

2.1.5 The role of nurses in primary care dementia services

2.1.5.1 Paper 3: commentary on primary care assessment and diagnosis of dementia

Dodd, E., Cheston, R. and Ivanecka, A. (2015) The assessment of dementia in Primary Care. *Journal of Psychiatric and Mental Health Nursing*, 22 (9). pp. 731-737

After conducting the research projects presented in papers 1 and 2, we believed that it would be helpful to synthesise the evidence and to write a paper that would reach a wider, international audience. I wrote this commentary paper as I wanted to look broadly at how the findings from the two PiCLeD projects built on and continued the narrative for considering the increasing role of the primary care workforce (particularly nurses) in the diagnosis and assessment of dementia. This method of reviewing the literature can be critiqued for having potential researcher bias and selection bias of literature. I was not setting out to answer a specific research question which would have warranted the use of resource intensive systematic review methods. The intention with this commentary paper was to pragmatically lay out the contribution to new knowledge that had arisen from the PiCLeD project. Carrying out a narrative review facilitated rapid communication to the target stakeholder group, which in this case was the international nursing community.

Synthesising the findings and writing this paper gave me the opportunity to consolidate the arguments at the time for the primary care workforce and particularly for the role that nurses play within primary care in the diagnostic process. The findings from our studies highlighted the importance of this role, and we wanted to make sure this was captured and shared more generally. This paper suggests that the skills, knowledge and expertise of mental health nurses and/or memory nurses working

traditionally within secondary care services could be harnessed to work effectively with GPs within primary care. This was particularly highlighted in the Bristol project. Memory nurses shared their concerns that those GPs that were part of the pilot rarely made independent diagnoses but were instead relying on the expertise of the memory nurse in the assessment process.

2.1.5.2 Nurses providing diagnosis

There are services globally which are already starting to harness the skills of the existing nursing workforce. Distributing the responsibility of providing a diagnosis to nurses and allied health professionals has been introduced in memory clinics in the North West of England (Page, et al., 2008; Page, et al., 2011). Nurses have been taking on more responsibility for carrying out assessments during home visits: taking a clinical history and completing a cognitive assessment tool such as the MMSE (Folstein, et al., 1975). Page et al. (2008, 2011) have shown that nurse's accuracy at diagnosing dementia is comparable to their colleagues in the multidisciplinary team. In Australia, a nurse-led open referral service has been piloted in which nurses carry out assessment and diagnosis with supervisory support from the consultant psychiatrist (Minstrell, et al., 2015). Although more research is needed on this service model to assess diagnostic accuracy and patient satisfaction, the open referral system seemed to enable people concerned about their memory to attend an appointment much earlier than if they had been referred by a GP.

2.1.5.3 Nurses and communication

There is evidence that patients feel more comfortable communicating with a nurse rather than a GP (Williams and Jones, 2006). This might be for the reasons discussed earlier such as memory nurses having more time to spend with families during assessment. Mental health nurses in particular already have the knowledge and skills related to dementia. A systematic review including 4,274 nurses from 19 studies (16 quantitative, 1 qualitative and 2 mixed methods) found that these professionals working in a community setting hold more positive and hopeful attitudes about dementia (Evripidou, et al., 2018). Having these attitudes provides a good foundation for person centred communication and care for people who may be presenting with memory problems. Nurses are also shown to be more likely to respond to a patient's

cues and concerns during consultation compared to GPs (Riley, et al., 2013) which may in part explain patient satisfaction with nurses consultations. Nurse consultations are often longer, providing the patient with more time to talk about their concerns (Williams and Jones, 2006). This therefore could overcome the barriers discussed above in section 2.1.1.3.

This section has focused on how the three papers that I have co-authored have added new knowledge to the field of assessment and diagnosis of dementia in primary care, particularly in the 'diagnosing well' step of the Well Pathway for Dementia. The next section discusses two papers that look at the third phase of the Well Pathway for Dementia – 'supporting well' in older adult psychiatric hospitals.

2.2 Introduction to project 2: Protected Engagement Time (PET) on older adult psychiatric wards

Alongside working on the primary care projects, my other main responsibility when I started at UWE Bristol was to set up and manage the Protected Engagement Time (PET) study. PET is a psychosocial intervention used across the country in psychiatric wards, albeit in slightly different ways, to reduce boredom for patients and to improve the amount of high quality contact and interaction between patients and ward staff. Task oriented responsibilities such as paperwork and liaison with other HCPs limits the time that nursing staff have to engage and interact with patients on psychiatric inpatient wards. Implementing PET is one way in which wards are attempting to remove these and other organisational barriers that inhibit patient engagement, communication and interactions. The aim of PET is to reorganise ward routines to provide nursing staff in particular with a time in their day in which they can be free from practical and administrative tasks. This frees up time for nurses to engage with patients and build a relationship with them. This interaction can be through a number of ways but verbal or non-verbal communication will be at the heart of any engagement activity and/or interaction HCPs have with those in their care.

2.2.1 The PET study

The PET study was a National Institute for Health Research (NIHR) funded multi-site feasibility study as part of the Research for Patient Benefit (RfPB) funding stream. Five older adult psychiatric wards for people living with dementia that offered PET were compared to five similar wards that did not offer PET across three sites. Research assistants (one at each site) were employed to carry out data collection. The aim of this feasibility study was to identify the prevalence of PET on older adult wards, how it is utilised and to establish whether the use of PET in its current form on wards improved the interactions between staff and patient and the quality of care that was provided. Finally, the study aimed to identify the main components of PET to construct a standard model for future evaluation.

Overall, the PET study was a complex and ambitious project comprising four modules using a mixture of qualitative and quantitative methods. The study was designed so that each module could be conducted separately and written up as a discrete project

but that the data from each module could be synthesised to answer the overarching questions (Morse 2010). The module and subsequent paper that our local team led on (module three) has been published and is included in this thesis (paper 5). I also include the published protocol in this thesis (paper 4).

2.2.1.1   Paper 4: The PET study protocol

Nolan F. M, Fox C, Cheston R, Turner D, Clark, A, **Dodd E,** Khoo M-E and Gray R (2016) A feasibility study comparing UK older adult mental health inpatient wards which use protected engagement time with other wards which do not: study protocol. *Pilot and Feasibility Studies*, 2:7

This is an important paper for inclusion in this thesis as it lays out the comprehensive programme of work I was initially responsible for as trial manager. As a co-author on this paper, I took the lead in writing the discussion section. The next section briefly explains modules one, two and four of the study, the methodologies that were used and my role in delivering the project.

2.2.1.1.1   Module one – national telephone survey of wards using PET

The first module was a national telephone survey of older adult psychiatric wards to determine the prevalence and use of PET across the country. I managed a group of student interns/volunteers (in Bristol) and clinical studies officers (CSOs) (in London) who completed the telephone survey with over 200 senior ward staff. I interviewed the Bristol interns (one psychology placement student and a psychology graduate) prior to them conducting the surveys. I organised for them to attend Good Clinical Practice training, trained them in the procedures specified in the protocol and oversaw their work on this survey. I also set up a SharePoint site to manage the data collected across the two sites. The survey had previously been designed and used in a study researching PET in adult psychiatric inpatient units. It was slightly modified to take account of the older adult setting. The questions were wide ranging and sought to find out how and when PET was being implemented and how it was being communicated to patients. Many of the questions on the survey were closed, numerically rated questions alongside some open-ended, free text questions e.g. *"what do you think are the benefits to having PET on your ward".*

Surveys can be susceptible to sources of bias. I made extensive efforts to ensure our sample was representative of the older adult wards across the country. I had an existing list of NHS Trusts and where the management or boundaries of Trusts had changed, then the team and I sought out new Trusts and wards by telephoning and speaking to someone at the Trust Headquarters. Over a 14-month period, we contacted 260 wards and completed 199 telephone interviews with ward staff. Some wards declined to take part in the survey (n=11), others (n=23) were closed or did not meet the inclusion criteria (e.g. one ward was for people with learning difficulties). I reduced the possibility of a non-response bias by ensuring that the research team conducted the survey on the telephone with a senior member of staff rather than sending out the survey link via email for self-completion.

2.2.1.1.2 Module two – Prospective cohort comparison study of PET and non-PET wards

The second module comprised the main part of the study; a prospective cohort comparison of five wards which utilised PET with five wards that did not use PET, across the three sites. Four of these wards (two PET and two non-PET wards) were situated in the local area for which I was responsible. I recruited and supervised the work of the two researchers (the first resigned a few months into the post). I visited the recruiting wards with the researcher to introduce the study and initiate study set up. I liaised with the Clinical Research Network (CRN) to obtain further support with the telephone survey and recruitment of participants. The use of randomisation procedures to minimise bias were unavailable here as the two conditions were naturally occurring cohorts. As such, neither the participants nor the researchers could be blinded to condition.

A battery of both validated and non-validated questionnaires were completed across the ten participating wards by patients, carers and staff. Where patients were judged as not having capacity to consent for themselves, a nominated consultee (ordinarily a family carer) was contacted to ask for their advice as to whether the patient would have agreed to take part in the research before developing dementia. If it was felt to be appropriate, then the consultee was asked to complete an assent form.

Using non-validated, bespoke questionnaires has the advantage of collecting data on the outcomes of interest in a specific context but can be open to researcher bias. Validated questionnaires are an important tool to ensure confidence in the quality of the tool. The reliability (how stable the findings are over time and free from bias) and validity (that the tool is measuring what it claims to measure) of the tools are measures of quality. For this study, we used the validated Dementia Health Related Quality of Life (DEM-QoL; Smith, et al., 2005) as the primary outcome measure. We used both the patient and proxy versions of this questionnaire as some of the patient participants were unable to complete the questionnaire due to their severe cognitive impairment. The DEM-QoL is a 28-item four-point Likert scale questionnaire. The DEM-QoL proxy is a 31-item, four-point Likert scale questionnaire. The researcher completes both questionnaires with each participant. Both questionnaires have been shown to perform well in psychometric tests of validity, reliability and response burden (Bowling, et al., 2015).

Other validated measures were used in this module to gather data on staff-patient interactions and communication (Camden Content of Care Questionnaire; Lloyd-Evans et al., 2010), agitation and challenging behaviour (Cohen-Mansfield Agitation Inventory; Cohen-Mansfield, et al., 1989) and staff impressions of ward environment (Ward Atmosphere Scale; Moos, 1974).

Other data collected in this module included observational data from the ward, health economics and service level data relating to adverse incidents. I supervised the local researcher and problem-solved any difficulties she was experiencing during the observational data collection. I liaised with the IT (information technology) departments of each participating NHS Trust to collect service level data.

2.2.1.1.3   Module four – developing a model for PET

The final module used a concept mapping exercise with patients, carers and NHS staff to identify the important components of PET and develop a measure of good practice for PET. Concept mapping is a mixed methodology participatory research method (Kane and Trochim, 2007). The first step is to engage with stakeholders and members of the community in question to assist in the categorisation and rating of data. In this case, the statements to be rated were taken from the responses from the telephone

survey in module one. Once this step has been completed, the data are entered into the concept mapping software to produce a concept map in order to visually represent the associations between the concepts.

I led, organised and arranged for three concept mapping groups at our local site to complete this exercise. These included a range of stakeholders: psychiatrists and junior doctors from one PET ward, Clinical Psychologists from another PET ward as well as people who had experience of being mental health patients. Seventy-one statements were grouped and then prioritised by the participants. I collated this data ready for analysis by a researcher who was experienced in concept mapping analysis.

The local team led on the analysis and write up of the data collected in module three. The next section discusses the findings from this published paper.

2.2.1.2 Paper 5: The qualitative analysis of staff, patient and carer experiences of PET

Dodd E, Cheston R, Fox C, Procter C, Heneker S, Gray R and Nolan F (2017) Protected Engagement Time on older adult mental health wards: a thematic analysis of the views of patients, carers and staff. *International Journal of Mental Health Nursing* 27(2) p608-618

Module three used a qualitative approach to capture the experiences of PET from the perspective of patients, their family carers and staff members. A total of 28 participants were interviewed. Participants were recruited from a total of three wards, one ward that implemented PET from each of the three sites that were part of the study. Our local site recruited to target for this module (n=12). Working with the researcher, I led on the data analysis for this paper. We used NVivo to manage the identified codes and themes that we independently generated. For this paper I wrote the methodology and results section, and led on the manuscript journal submission.

The three themes identified in the analysis were: 1) The patient is at the heart of care; 2) PET depends on the staff; 3) Tensions in how PET operates. Our research provides some evidence that staff do value the time that PET frees up for them and make efforts to engage with patients in ways that are appropriate to the level of cognitive decline that each patient presents. Balancing the varying cognitive and physical needs

of patients is a challenge with such an intervention. The staff who participated in the research identified that only by truly getting to know the patient, their likes and dislikes, can the time be utilised effectively. Our findings suggest that a one-size-fits-all approach for PET does not work when engaging with patients with dementia. Flexibility in implementing PET is required in order for patients to get the best experience out of the interaction. For example, some patients are more comfortable with group activities than are others and an individual's cognitive impairment may make engagement in such activities difficult. Providing alternative engagement opportunities such as staff and patient communicating on a one-to-one level ensures that the interaction is person centred.

However, staff may benefit from additional training particularly in communication skills to have the confidence to make the most of the protected time. Elsewhere it has been argued (McCabe, 2004) that nurses are equipped to communicate effectively with patients in a person centred way but systemic or organisational barriers may prevent these skills from being used and maintained. We found support for this view in that for PET to work, there was a consensus that everyone within the organisation had to acknowledge the importance of the intervention and respect the time being protected on the ward for example non-ward staff not interrupting PET activities.

Patients in the severe stages of dementia who are admitted to psychiatric wards may no longer be able to verbally communicate their needs. Nurses are less likely to spend time with those with such severe cognitive impairments (e.g. Ekman, et al., 1991). Providing protected time with a clear emphasis on engaging and interacting in a person centred way with those with the most severely impaired patients could reduce the time these patients spend on their own and improve their overall-wellbeing (Norbergh, et al., 2001).

2.2.2 Methodology and methods used in projects 1 and 2

These two projects were developed from a qualitative paradigm. We ultimately wanted to explore and understand stakeholder experiences and interpretations of the new services for people newly diagnosed with dementia (project 1) and protected engagement time on older adult psychiatric wards (project 2). This worldview argues that there is no one truth and each of us has an individual interpretation of the world.

It was these individual interpretations that we wanted to explore, hence using this methodology.

As a pragmatic researcher, I chose the approaches and methods used in this thesis to best answer the research questions. I take a straightforward, practical approach to analysis. One of the benefits of thematic analysis is its flexibility and how it can be independent of theory and epistemology (Braun and Clarke 2006). On reflection, as I have developed as a researcher, I now spend more time considering my epistemological stance compared to when I started this job in 2012. I am currently very interested in critical realist approaches to evaluation and hope to use this methodology in the future.

The three studies that have employed qualitative approaches derive from a contextualist theory (Braun and Clarke 2006) through which we wanted to understand the reality of how people experienced using and working in the health service settings or context. The PiCLeD projects were commissioned evaluations. The analysis therefore was conducted within a tight timeline to provide evidence to commissioners about service use and acceptability for their decision making around delivery of services. In contrast to this practical use of analysis and data, project two, the PET study, was researcher-led. There was less time pressure to carry out the analysis of this module of the study than for the PiCLeD projects. This provided me with the opportunity with the analysis team, to carry out a deeper level of theorising about the underlying meanings in the data.

2.2.2.1 Steps in the qualitative data analysis process

Data analysis within all three papers was carried out by a team of researchers, predominately but not exclusively, with a psychology background. For all projects I followed the six phases of thematic analysis of Braun and Clarke 2006. For all the papers, I read the transcripts numerous times, familiarising myself with the data (phase 1). For papers 1 and 2 I generated initial codes (phase 2) by hand, using highlighter pens to draw out particular words, phrases or sentences. The focus for this project was on identifying codes in the dataset that focused on building up an argument for or against the primary care model of assessment and diagnosis. I then sorted these codes into preliminary or candidate themes (phase 3). The team carrying

out the data analysis then met to discuss each others' identified candidate themes (phase 4) and through this discussion, the themes were refined and agreed (phase 5). For paper 2, the four individuals carrying out the analysis read only half the transcripts each. After the initial meeting to discuss preliminarily identified themes, the team then worked further on our assigned transcripts to identify whether these themes were evident across the whole dataset. A final analysis meeting was held to further refine and agree the themes identified across the dataset. Thus analysis was an iterative, collaborative and collective process.

We used a similar iterative method for the analysis of paper 5 using Nvivo. The analysis was conducted by three researchers. I coded half of the transcripts and, independently, the researcher who collected the data coded the other half, both identifying codes. A third researcher read and analysed ten transcripts as a validity check. The three researchers met to discuss the identified codes and how these combined to make candidate themes. Independently we revisited the manuscripts to ensure the candidate themes worked across the dataset. Following this process, a final discussion led to defining and naming the themes and sub-themes. In contrast to the analysis carried out in the papers from the PiCLeD project, this analysis was a bottom-up approach with the themes more strongly linked to the data. A final element to this process involved our analysis being scrutinised and reviewed by members of the multidisciplinary project team who were able to provide other perspectives on our findings. For all papers I wrote and commented on drafts of the reports (phase 6).

2.2.3 Conclusion

Project 2 provides an excellent example of the types of obstacles and challenges that can arise when conducting real world research and how I have contributed to psychosocial research in a hospital setting. The next section discusses the final three papers submitted in this thesis taken from a research programme that explored the potential for psychological self-protective mechanisms to mitigate the threat of dementia to self.

2.3   Introduction to project 3: Managing the threat of dementia

The first two projects outlined research that explored whether organisational service change facilitates better support for and communication between people living with dementia and HCPs. However, in addition to the structural obstacles to communication outlined above, there are other reasons why communication can be problematic. Due to the debilitating symptoms that people experience when they are living with dementia, many people are fearful of developing the condition (Cheston and Bender, 1999). Being told that you have a progressive illness such as dementia is an anxiety-provoking and emotional experience. Dementia represents a threat to the self (O'Connor and McFadden, 2012; Cheston and Christopher, 2019) as it is a deteriorating illness that is not curable, which leads to increasing dependency and, ultimately, to death. To manage this threat, self-protective mechanisms or motives act to protect the person from the anxiety that would otherwise arise and bring a return to psychological homeostasis (Sedikides, et al., 2016). One such example of a self-protective motive which has been widely described within social psychological literature within the general population is the selective forgetting of material threatening to the self, known as the Mnemic Neglect Effect or MNE (Green, et al., 2004; Green, et al., 2008; Sedikides,. et al., 2016; Cheston, et al., 2015). We were interested in whether MNE might account for the difficulties some people have in acknowledging they have dementia. We speculated that if the MNE was present, then this might throw new light on a range of important clinical issues, including the development of awareness about a diagnosis of dementia.

The research programme as a whole was made up of two studies funded from separate sources. The Alzheimer's Society funded us to study whether the MNE could also be shown to affect recall of dementia related material by people living with dementia. Subsequently, Alzheimer's Research UK funded us to explore whether recalling a nostalgic memory improved the recall of threatening statements study. Both studies draw upon Terror Management Theory (TMT) to frame dementia as an existential threat (Greenberg, et al., 1990). Figure 1 provides a graphic summary of the project).

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                    ┌──────────────────────┐
                    │     PROJECT 3:       │
                    │   MANAGING THE       │
                    │   THREAT OF          │
                    │   DEMENTIA           │
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PROJECT 3:

MANAGING THE THREAT OF DEMENTIA

Study 1:

The Mnemic Neglect Effect study

Study 2:

The Nostlagia study

Experiment 1: MNE study

people with dementia recalling dementia related *statements*

Experiment 2: Thought supression

People with dementia and healthy volunteers recalling dementia and non dementia related *words*

Experiment 3: people with dementia recalling self referent dementia related statements following nostalgia induction

Reported in **Paper 6**

Reported in **Paper 7**

Reported in P**aper 8**

Figure 1: Summary of studies, experiments and papers generated from project 3

This study design involved translating social psychological lab-based experiments conducted with largely undergraduate participants into a clinical context in which we carried out adapted forms of the study with people with a diagnosis of dementia. While my role in both studies was as the trial manager, project 3 presented me with a very different set of challenges to those that I had previously encountered with projects in health settings.

In the next section, I will briefly describe the mnemic neglect and nostalgia studies and then explore how the published papers I have included in this thesis fit into the theme of communication that spans my research.

2.3.1 Project 3; study 1; experiment 1: the Mnemic Neglect study

The mnemic neglect study comprised two experiments. In the first experiment participants were asked to recall 24 dementia related statements that were either highly threatening or were less threatening. Before embarking on this experimental procedure, it was necessary to establish which statements about dementia could be classified as either "highly threatening" or "less threatening". I managed the set up and data collection of this pre-study. Using an online survey powered by Qualtrics, a total of 248 people (UWE Bristol staff and students, and members of the public recruited via

social media) rated 64 dementia-related statements in terms of the extent to which they represented a threat to wellbeing. From this, we identified the twelve most threatening and twelve least threatening statements that could then be used in experiment 1[4].

In study 1, seventy people living with dementia were recruited by four researchers across three participating sites, two were in NHS trusts and one was an independent memory clinic. One of the NHS trust sites comprised three teams with the other made up of five memory clinics. Over one thousand potential participants were screened for suitability. Initially we planned to recruit from two sites but the NHS site with five memory clinics struggled with recruitment. I therefore worked with the CRN to open the third site. This involved managing the amendment process to add an additional site, managing general set up and training the additional Clinical Studies Officers in the protocol but without adding additional cost to the project.

In study 1 we tested whether participants showed a selective forgetting of statements that were self-referent and highly threatening. There are three key contrasts in the Mnemic Neglect paradigm: first participants are randomised into two groups and asked either to remember these statements as if they related to themselves (self-referent) or to another person named 'Chris' (other-referent). Secondly, participants are asked to remember both 12 highly threatening and 12 less threatening statements. Finally, all participants are asked to both recall these 24 statements and also to recognise them from a longer list of 48 statements that includes both those 24 statements they have heard and an additional 24 statements they have not heard. The Mnemic Neglect Effect is said to be present if there is an interaction between condition (i.e. whether the statements are self or other referent) and level of threat. This interaction is present in the recall of the statements, but not their recognition.

2.3.1.1 *Paper 6: MNE of self-threatening statements in people living with dementia*

Cheston R, **Dodd E,** Christopher G, Jones C, Wildschut T and Sedikides C (2018) Selective Forgetting of self-threatening statements: mnemic neglect for dementia

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[4] Subsequently, we developed a Threat of Dementia Scale from thirteen of the pre-study statements. We developed this by comparing our scale with similar scales and carrying out pre and post-test consistency. This is currently a paper in review of which I am a co-author (see extended bibliography in appendix 3).

information in people with mild dementia. *International Journal of Geriatric Psychiatry*, 33(8), pp1065-1073.

This was a randomised experimental memory study. We tested for an interaction between condition (self-referent vs. other referent) and threat (high vs. low) using Analysis of Variance (ANOVA). Analysis took place on data from 62 participants; 31 from the self-referent condition and 31 from the other-referent condition. As hypothesised, we found a significant interaction between condition (self, other) and threat (high, low): participants recalled significantly fewer high threat statements in the self-condition compared to the other-referent condition. This shows that there was selective forgetting for information about dementia that is rated as highly threatening when that information is related to the self. As the MNE paradigm predicts, and consistent with findings from previous research with people without a cognitive deficit, we did not find any difference in recognition of statements between the two conditions. This suggests that all participants heard the statements, but that an underlying psychological process is, in effect, repressing the more threatening self-statements from recall. I contributed to this paper by writing the methodology section, collating data (including entering these onto a spread sheet and drawing up the CONSORT diagrams) and conducting preliminary analysis.

2.3.2 Project 3; Study 1; Experiment 2: Thought suppression study

The second study involved a different procedure and tested whether a separate psychological process was involved. Whereas the MNE paradigm looks at recall for proximal threat (that is statements about dementia that are directed at the self), it is also possible for people with dementia to encounter dementia related information that is distal - that which is not directed at the self. An example of a proximal threat would be when a doctor discloses a diagnosis of dementia to a patient. This information specifically relates to them. By contrast, a distal threat would occur if on their way home, that same person walked past an advert from the Alzheimer Society. This also contains information about dementia, but the information is not directed specifically at the person.

The psychological literature states that where these distal reminders are a threat to self, then thought suppression can occur (Wegner, et al., 1987). Therefore, just as with

MNE and proximal threats, when there is a distal threat, then if they are acting efficiently, protective psychological mechanisms can ensure that the threatening material is not recalled and does not affect the person's psychological equilibrium. However, under some circumstances, for example, when a person's cognitive capacity is over-loaded, the process of thought suppression can not only break down, but acts to ensure that the threatening material is actually more likely to be remembered. Under these circumstances, the process of thought suppression is said to act in an ironic way - that is to have the effect of increasing recall. As people living with dementia by definition have a reduced cognitive capacity, we hypothesised that compared to people who do not have dementia then they might be more likely to experience this ironic effect for dementia-related words. To test this, we asked participants in a thought-suppression task to recall six dementia related words and six non-dementia related words over four trials. These words were validated to confirm the two sets of words differed. This is explained more in section 2.3.5. They were also matched for length, frequency and part of speech.

2.3.2.1 Paper 7: Comparison of dementia versus neutral word recall between healthy volunteers and people living with dementia

Cheston R, **Dodd E**, Hart I and Christopher G (2019) The recall of dementia related and neutral words by people with dementia: The ironic process of thought suppression *International Journal of Geriatric Psychiatry* 34, p756-764

We recruited fifty participants who were living with dementia from one independent memory clinic and 56 participants who were healthy volunteers without a diagnosis of dementia to complete the study. This latter group was recruited from the University's student participant pool, University staff, friends and family of the researchers and through the Join Dementia Research (JDR) register. JDR is a national register of people who volunteer to take part in dementia research. Recruitment for this phase of the study was initiated whilst I was on maternity leave but on my return I collected the data from the healthy volunteer staff participants. Specifically for this paper I wrote the methodology section, and collated the CONSORT diagrams.

We found no differences in the recall of participants with dementia between the two types of words. However, participants in the control condition recalled significantly

more neutral words than they did dementia-related words. However, in the recognition test, people with dementia recognised significantly more of the dementia words than the neutral words. We argued that the most plausible explanation for this is that the cognitive impairment associated with dementia means that the psychological defence mechanism of thought suppression is either ineffective or that it acts in an ironic way to increase implicit awareness. We discuss how this increased implicit awareness of dementia may occur even though there may also be reduced explicit awareness.

The next section outlines the final study in this third project. This study investigated nostalgia as a means to boost psychological resources in order to mitigate threat and manage any distress caused by the communication of dementia-related information.

2.3.3 Project 3; study 2; Experiment 3: the Nostalgia Study

Research with the general population shows that the selective forgetting of the MNE can be mitigated by enhancing psychological resources including self-esteem prior to giving self- threatening feedback (Green, et al., 2004; Green, et al., 2008; Green, et al., 2009). Experimental studies with the general population also show that evoking nostalgic memories can enhance psychological resources (Sedikides, et al., 2015). Nostalgia is defined as a sentimental longing or wistful affection for a period in the past. Nostalgic memories are often personal and directly link with the self. The aim of this study was to see first if nostalgia has the effect of increasing psychological resources in a clinical population with people diagnosed with dementia as it does amongst the general population. Secondly, we aimed to see what effect evoking nostalgia would have on the subsequent recall of threatening statements.

Participants in this study were randomised into two conditions; either to recall an ordinary memory or a nostalgic memory. We then asked all participants, regardless of allocation, to recall the same 24 dementia related statements that were used in the self-referent arm of the mnemic neglect study (see paper 6). We hypothesised that participants in the nostalgia memory condition would recall more of the self-referent threatening statements compared to the participants in the ordinary memory condition. The nostalgia study was conducted in one recruitment site.

2.3.3.1   Paper 8: Benefits of inducing nostalgic memories on the recall of dementia related threatening statements

Ismail S, Christopher G, **Dodd E**, Wildschut T, Sedikides C, Ingram T, Jones R, Noonan K, Tingley D and Cheston R (2018) Psychological and Mnemonic benefits of nostalgia for people with dementia *Journal of Alzheimer's Disease* 65(4) p1327-1344

This paper reports three, separate experiments: experiment three, which I project managed, builds on two previous experiments that were conducted by a PhD student and on the MNE study discussed above in section 2.3.1.1.

Fifty participants with a diagnosis of dementia were recruited from an independent memory clinic; 25 were randomised to recall an ordinary memory and 25 to recall a nostalgic memory. As we hypothesised, participants in the nostalgia condition reported significantly higher levels of psychological resources including social connectedness, meaning in life, self-continuity self-esteem, optimism and positive affect. Importantly, participants in the nostalgia condition recalled significantly more dementia statements and did not show increases in their levels of distress as a result of recalling more self-referent dementia-related statements. We also found that participants scored significantly better in the recognition test. Mediational analyses showed that the increases in two psychological resources (positive affect and meaning in life) as a consequence of the nostalgia induction significantly improved recall and recognition respectively.

2.3.4   Project 3: the impact of social psychological processes on communication

Projects 1 and 2 of this thesis identified institutional barriers to communication and studied whether changes to those systems could help to improve and enable communication between HCPs and the person living with dementia. Those barriers are very much about changes in system processes to aid diagnosis and how that can best be communicated (project 1) and to provide an environment where person centred communication could thrive (project 2). In contrast, project 3 explored potential intra-psychic barriers to communication, namely two psychological processes involving selective forgetting that when acting normally protect the self against anxiety (papers 6 and 7). We also investigated how a third psychological process (nostalgia) can buffer

the self against threat and thus overcome the need for such self-protective mechanisms (paper 8). The findings from this last project have implications in how information about dementia can be best communicated, which are applicable across all the steps in the dementia Well Pathway.

The MNE acts to protecting the self from perceived threat and the anxiety this may cause. This unconscious process of selectively forgetting proximal information about a health condition such as dementia can hinder the processing and subsequent acceptance of dementia-related information being communicated.

Thought suppression is a parallel psychological process that should act to mitigate the impact of threat from distal reminders of the condition and thus reduce distress or anxiety. Paper 7 argues that the cognitive impairments from dementia reduce the ability for people living with dementia to use thought suppression effectively. Instead, at least for some people, thought suppression may act ironically, to enhance the implicit recognition of dementia-related words. While the MNE acts to reduce conscious awareness of proximal information about dementia, the ironic impact of thought suppression can act to enhance implicit awareness of dementia. We believe that these findings have important clinical implications. For instance, the reduced explicit awareness of dementia, combined with an enhanced implicit awareness of the condition may play a role in some forms of challenging behaviour - and thus communicate an unmet need for security and reassurance.

Finally, the findings in paper 8 provide preliminary evidence that encouraging participants to reflect on a nostalgic memory can increase psychological resources. Such psychological resources could help people buffer the self against the negative aspects of living with dementia and thus improve recall without at the same time increasing distress. In addition, talking about past nostalgic memories assisted people to remember more self-referent and highly threatening information about their condition without at the same time becoming more distressed.

Taken together, these three papers, contribute to a key aspect of dementia research and practice: how people living with dementia adjust to and come to terms with their diagnosis. While a lack of acceptance of the diagnosis has been associated with a deterioration in global functioning (Aalten, et al., 2005) and worse clinical outcomes

(Clare, et al., 2004), the process by which people living with dementia come to accept their diagnosis is now widely recognised as having psychosocial elements. Understanding how psychological processes such as the MNE and thought suppression impact on acceptance and recall of a diagnosis of dementia, and by extension on how best to communicate such highly threatening information will inform methods to help people manage this threat. In addition, being diagnosed with dementia can erode psychological resources such as self-esteem, social connectedness, optimism and meaning in life. Communication with family, friends or HCPs using nostalgic memories to draw upon past achievements and experiences may provide some buffer to manage and facilitate acceptance in people living with the condition. Using nostalgia in this way can assist in the maintenance of selfhood and delivering person centred care. These are central research topics that we continue to investigate (see chapter 4 for more information on current and future work).

The next section examines the methodology and methods used in this project.

2.3.5 Methodology and methods used in project 3

We used experimental methods to test hypotheses in project 3. The methods come from the positivistic paradigm. The worldview from this paradigm is that everything in the world is knowable and that the researcher's position is to design and implement a good quality study to discover the facts and truths (Wisker, 2008). This contrasts with the qualitative approaches used in papers 1, 2 and 5 of this thesis. Qualitative worldview holds that there is not just one truth but that we make our own meanings from the experiences we encounter. Having experience of working with both methodological approaches provides evidence I meet the fourth doctoral descriptor related to methodology and that I have developed broad skills through my research. The strengths of project 3 are that the methods had already been used by colleagues in the general population. We made some adaptations to the original methods to accommodate the cognitive impairments that arise because of dementia. Originally, participants are asked to complete the recall after the full 24 statements are read out. In our experiments, we split these statements into four blocks of six statements and asked participants to recall the words they had heard after each of these blocks of six statements.

There are a number of important methodological features to this work, all of which I led in my role as trials manager. I developed the study process and wrote the instruction manual the researchers used alongside the protocol. We validated the materials to be recalled (statements for the study reported in paper 6 and the dementia and neutral word pairs in the study reported in study 7) using two online surveys with a large response from staff and students. I was responsible for managing the online surveys, promoting and managing the recruitment. As this was the first time these procedures had been used with participants who are living with dementia, it was not possible to conduct a sample size calculation and therefore we based our estimate of how many participants to recruit on sample sizes from similar studies that had taken place in social psychology with non-clinical populations. To minimise selection bias participants were randomised to either take part in the self-referent or other-referent conditions. They were also blinded to which condition they were assigned to but fully debriefed after the experiment. The researchers collecting the data were blinded to the participants' allocation up until they were required to start the memory tests. The researcher who conducted data input and analysis was blinded to reduce reporting bias.

Although the protocols for the studies were not published in peer review journals, I ensured that the research plans were registered on the International Standard Registered Clinical/soCial sTudy Number (ISRCTN) website. Pre-registration of research is important for transparency, can reduce publication bias and can reduce researchers 'Hypothesising After the Results are Known' (also known as HARKing; Kerr, 1998).

2.4   Ethical considerations of the projects presented in this thesis

All of the projects presented in this thesis were granted appropriate ethical and governance approvals. Project 1 was considered an evaluation and therefore only required ethical approval through the University Faculty Research Ethics Committee (FREC). In addition, I obtained research governance approval from the two local NHS Trusts that were assisting with recruitment of participants.

NHS ethics application and Health Research Authority approvals for research governance was submitted through the online Integrated Research Application System (IRAS) for projects 2 and 3. I obtained an NHS research passport to allow me to

conduct research in the NHS and a Disclosure and Barring Service check to enable me to work with vulnerable adults.

Prior to my employment at UWE Bristol, I worked as a clinical trial coordinator at the Bristol Royal Infirmary where we ran Clinical Trials of an Investigational Medicinal Product (CTIMPs). I had therefore received training to comply with the International Conference on Harmonisation (ICH) of Good Clinical Practice (GCP) Guideline. GCP is a set of internationally recognised ethical and scientific quality requirements. Although none of the projects in this thesis involve CTIMPs I continue to follow the principles set out in the GCP guidelines.

2.4.1 Obtaining valid informed consent

Obtaining valid informed consent is one of the most important ethical considerations when conducting research with human participants and this was collected from all those taking part in these projects. This was especially important given that many of the participants were people living with dementia and therefore were deemed a potentially vulnerable population.

In projects 1 and 3, we only recruited participants who were deemed to have capacity to consent to take part in the research and who were within the mild to moderate stages of dementia. In project 1, there was a level of initial triage of potential participants by the GP and/or memory clinic. Participants were eligible if they had a recent (six months or less) diagnosis of dementia and were either invited by the GP (via letter) or the memory clinic staff (via phone call) to take part in the study. I spoke to each person on the phone to explain the study and ensure that they understood what was involved in taking part. The peer researchers were trained to explain the study again prior to taking consent and to only take consent from those that they felt confident understood what was involved. They did not report any concerns that the person with dementia seemed unaware of what they were signing up to.

Consent and data in projects 2 and 3 were collected by research assistants and clinical studies officers who were experienced in collecting consent from people living with dementia. They had also attended the CRN training on collecting informed consent.

For all projects people were given information verbally about what participation in the study entailed and this information was further provided in a written information sheet. Individuals were given time to decide whether they wanted to take part. They were informed that they could withdraw at any time during the study and that this decision would not impact on any current or future care they received.

2.4.2 Recruiting participants who lack capacity

In project 2, given the setting, we did not want to exclude people from taking part in module two of the study who may have been living with severe dementia and therefore potentially lacked the capacity to provide informed consent. It would be discriminatory and could bias the results to have excluded such patients from the study given that a systematic review of 35 studies of psychiatric settings reported 45% of patients on such wards were deemed to lack decision making capacity (Lepping, et al., 2015). Therefore, the NHS ethics committee granted approval to collect consent from a nominated consultee where someone was deemed to lack capacity to consent to the research by the clinical team. This consultee was ordinarily a close family member or friend that visited the patient regularly whilst staying on the ward and knew the person well enough to advise whether the person would have wanted to take part in the research. The researchers working on this study first consulted with the clinical staff about a potential participant's capacity to understand the research and whether they would be able to consent to take part in the study. Given that patients and carers were both recruited to this study, initial contact made by the researcher very often was with both parties and included patients with and without capacity to consent. This method of using consultees or surrogates with those lacking capacity has been identified as best practice as it ensures the ethical principle of respect for persons (Black, et al., 2013) and ensures that as many people as possible have the opportunity to take part in research. Nevertheless, where participants subsequently expressed obvious signs of not wishing to take part, then this was respected by the researcher and the decision was made to withdraw a participant from the study and no further data was collected. This collaborative approach worked well for this low-risk questionnaire study and is in line with recommendations of how to seek assent and respect dissent when conducting research with those that may lack the capacity to consent (Black, et al., 2010).

2.5   Chapter summary

This chapter has discussed eight papers that I have co-authored from three different projects relating to psychosocial approaches to dementia. These projects map particularly onto the 'diagnosing well' (project 1, papers 1, 2 and 3) 'supporting well' (project 2, papers 4 and 5) and living well' (project 3, papers 6, 7 and 8) phases in the Well Pathway for dementia. In this commentary I have explored communication between HCPs and people living with dementia as a unifying theme. Communication is central to both theories of personhood (projects 1 and 2) and selfhood (project 3). A second common theme transcending all three projects that I have touched upon concerns the ethical considerations required when conducting research with a vulnerable population, especially the need to ensure genuine, informed consent.

The next chapter details my personal reflections and contributions to each of the projects and papers included in this thesis. Additionally, I lay out how through my work to date I can evidence that I have met the doctoral descriptors.

3   MY CONTRIBUTIONS, PERSONAL REFLECTIONS AND DOCTORAL DESCRIPTORS

The following chapter focuses on the contributions I have made to the three projects and eight papers in this thesis and how this evidences that I have met the doctoral descriptors. Given that I am employed as a trial manager my main roles across the three projects have been to lead the research governance and ethics approval applications, liaise with recruiting sites to establish good working relationships to maximise recruitment, develop the processes by which to deliver a project as per the protocol, train researchers in the study protocol and manage the secure collection and storage of research data. In addition I have played a role in the team in formulating the design of the studies.

The following section provides further evidence of my contributions to these projects and is a personal reflection on my development and learning experiences. This reflection section demonstrates how I have met the final doctoral descriptor.

3.1   Personal reflections on each project

3.1.1   Project 1 – learning from the participatory approach

From my experience of using the participatory approach I have identified changes I would make in using this approach in the future. Firstly, findings would be more rigorous if reflective logs or field notes collected by the interviewer were incorporated as a method of triangulating the data. I would consider including a role-play exercise in any future peer researcher training I facilitate. Although anxiety provoking for most people, role-play provides a safe space in which to practice a new skill, develop confidence in that skill, provides the research team an opportunity to assess the interviewer's abilities and to provide constructive feedback (Binder, 2014). Finally in any future study, I would extend involvement of peer researchers across the research process to include them in the analysis of the data (Stevenson and Taylor, 2019).

Project 1 was a relatively small scale study commissioned and funded by the local CCG. In comparison, project 2, the PET study, was a nationally funded multi-centre study. Recruitment was across three sites and ten inpatient wards. As such, I have chosen to reflect on issues around recruitment and data management.

3.1.2 Project 2 - Participant recruitment

The recruitment targets for patients, staff and carers were set in the original funding application based on the study wards being assessment wards that would have a quick turnaround of patients. We met the recruitment target for staff and carer participants at our local site. However, by the time the study opened to recruitment, service delivery had changed and none of the sites were able to meet the recruitment target for patient participants. A number of wards had become longer stay wards reducing the throughput of patients. I demonstrated my leadership skills by investing in relationships with ward staff and higher management. I kept in regular contact with the wards to ensure lines of communication between those participating and the study team were maintained. This ensured buy-in of the gatekeepers to potential participants. Investing in these relationships with the ward managers and the Trust's Research & Development (R&D) department meant I was able to liaise successfully with the wards to allow the local research assistant to spend a day a week on each participating ward to become a familiar face to staff, patients and family carers. I believe this strategy contributed to successful recruitment at our local site.

At the time our study was open and recruiting, the R&D department had introduced a research champions pilot. This initiative was to further embed research into practice within the Trust by giving a member of the nursing staff protected time to work on research related projects and skills. I made the decision that this was a further opportunity to raise the profile of the PET study on the participating wards. I worked with the champions' coordinator to identify a suitable member of staff on one of the participating wards to support the research assistants and the project.

Project 2 – data management systems

I provided research leadership in relation to the methods used for data collection in module one of this study. During the telephone survey data collection in module one, the researchers were spread over two sites. I proposed that we should use the online survey platform Qualtrics, to collect the data to ensure secure storage in one central place and to reduce data inputting time. Further to this, I proposed that we should collect data via telephone interview with the ward managers to facilitate an optimal response rate.

In addition, I set up a SharePoint site for the team so that sensitive data could be shared across the two sites. This is a good example of where I have developed my problem-solving skills to ensure the smooth day-to-day running of a research project.

In the following section, I reflect on my learning from managing the third project in this thesis.

3.1.3 Project 3 - collaborators

The studies that I managed in project 3 provided me with a range of additional skills and experiences. It was my first experience of working with social psychologists and amongst other experiences it gave me the opportunity to write up experimental studies for publication.

3.1.4 Project 3 – data analysis

This research provided me with the opportunity to work on an experimental study and employ quantitative data analysis. I was fully involved in the preparation and analysis of the data collected for the nostalgia study. I managed a Masters placement student during this process and together we developed our learning around the use of inferential statistical tests. I used the Statistical Package for Social Sciences (SPSS) to conduct t-tests and chi square tests to assess for significant differences between the participants in the two conditions (nostalgia memory versus ordinary memory recall). I also carried out the initial analysis of the data relating to psychological resources and nostalgia using t-tests and an ANOVA to analyse the data relating to the associations between the outcomes and recall of high threat statements.

3.1.5 Project 3 - Research monitor involvement

Public involvement has contributed to all of the projects I have managed during my employment at UWE Bristol. In most cases I have had to actively seek out people to be involved in our research. The Alzheimer's Society, who funded the MNE study, provides projects with a number of research monitors. This is effectively a pool of people who have been affected by dementia that work with research teams, providing valuable input from the public perspective.

We were assigned three monitors and I was responsible for managing their involvement throughout the project. The monitors reported that this was a project that had made full use of their role and they felt fully integrated into the steering committee. The monitors provided comments and feedback on our participant documentation and provided input through attendance at the steering group meetings. Specifically, they suggested that we give home visit as an option for data collection to improve recruitment. They did not assist in the data analysis but together we wrote the lay summary of the findings to send out to the participants following study completion. This experience of working closely with the monitors sustained my enthusiasm for public involvement in research. An advantage to being assigned monitors was that they were already highly skilled and did not require additional training other than ensuring they understood the study. It also meant that the complexities of suitably reimbursing them for their involvement was the responsibility of the funder.

Last year, I submitted an abstract to the Alzheimer's Society annual conference for the mnemic neglect study which was accepted for a presentation in one of the parallel sessions. One of the monitors agreed to co-present at the conference. Delegates fed back how this was a novel way to utilise the research monitors and provided a new perspective on their involvement. Now that the main papers have been published from this project, I plan to work with this monitor to write a research report for the *Journal of Dementia Care*. This journal is aimed at practitioners working in dementia care therefore potentially reaching a different audience to that which may read the journals in which our other papers are published.

3.2   My contributions to the eight submitted papers

I have highlighted my contributions to both the projects and papers throughout the previous chapter. Here, table 2 provides a summary of the contributions I have made to the eight papers that have all been published in peer-reviewed journals that I submit alongside this commentary. I emailed each co-author to ask if they would be willing to review these contributions and confirm agreement. Three authors had moved on providing no forwarding address and emails were returned as undeliverable

from four co-authors. Eleven co-authors have provided letters of support for my contributions. These can be found in appendix 6.

Main contributions to each paper	Project 1 PiCLeD			Project 2 PET		Project 3 MNE/Nostalgia		
	Paper 1	Paper 2	Paper 3	Paper 4	Paper 5	Paper 6	Paper 7	Paper 8
Carried out the thematic analysis of transcripts	✓	✓			✓			
Wrote the first draft of the methodology section	✓	✓			✓	✓	✓	✓
Commented on and made significant edits to manuscript drafts	✓	✓	✓	✓	✓	✓	✓	✓
Led on the manuscript journal submission	✓	✓	✓		✓			
Identified concept for the manuscript			✓					
Wrote first drafts of significant sections (e. g. Literature reviews, results)				✓	✓			
Revised manuscript following peer review				✓	✓			
Collated CONSORT diagrams						✓	✓	✓
Completed preliminary statistical data analyses						✓		✓

Table 2: My main contributions to the eight papers submitted in support of the award

3.3 Meeting the doctoral descriptors

In the final sections of this chapter I demonstrate how I have met each of the six UWE Bristol doctoral descriptors.

3.3.1 Doctoral descriptor 1

Have conducted enquiry leading to the creation and interpretation of new knowledge through original research or other advanced scholarship, shown by satisfying scholarly review by accomplished and recognised scholars in the field

I have carried out a programme of original research across three projects that has generated new knowledge in the field of psychosocial approaches to dementia care. As I have developed as a researcher, I have undertaken greater responsibilities in the steps leading to the generation of this new knowledge. This includes the development of study documentation and training researchers to ensure adherence to study protocols. I have also been responsible for the collection of informed consent and data from research participants. I have used both quantitative and qualitative approaches and analysed data.

I have made significant contributions to all eight papers within this thesis. These papers have been published in peer reviewed journals demonstrating that they satisfy scholarly review.

3.3.2 Doctoral descriptor 2

Can demonstrate a critical understanding of the current state of knowledge in that field of theory and/or practice

Paper 3 provides strong evidence that I meet this descriptor. It includes a commentary and summary on the different ways in which practice is changing to incorporate the role of primary care nurses in dementia care, especially in assessment and diagnosis. I led on reviewing the literature of the national and current international models of primary care led dementia services.

In addition, I demonstrate my critical understanding of current biomedical and psychosocial perspectives in the background chapter of this thesis. I have applied the current literature around communication in dementia care to draw this out as a theme

that runs throughout the projects and papers submitted in this thesis. Finally, I have demonstrated how this new knowledge maps onto and contributes to the main phases in the current Well Pathway for Dementia in England (DoH, 2015; NCCMH, 2018).

3.3.3 Doctoral descriptor 3

Show the ability to conceptualise, design and implement a project for the generation of new knowledge at the forefront of the discipline or field of practice including the capacity to adjust the project design in the light of emergent issues and understandings

In this chapter, and throughout the previous chapter I have detailed how my role as trial manager has been central to the implementation of each of the three projects in this thesis. In project 2, I designed the online survey to collect the data for module one. I implemented data management processes to ensure secure data storage and sharing across the three sites. I led, organised and arranged for three concept mapping groups at our local site to complete this exercise. I contributed intellectually to the conceptualisation of the nostalgia study in project 3 from the outset including development of the grant application.

In project 1, it was necessary to adjust our ambition to recruit people living with dementia as peer researchers as none of the potential contributors agreed to this role. We did however recruit carers as peer researchers. In project 2 the recruitment target of patient participants was revised due to the emerging changes to inpatient wards from which we were recruiting. In project 3, we recruited healthy volunteers to the MNE study and I was instrumental in managing and carrying out the recruitment of this sample. I managed recruitment targets by opening up an additional site when one of the sites was struggling to meet their individual recruitment target.

3.3.4 Doctoral descriptor 4

Demonstrates a critical understanding of the methodology of enquiry

This descriptor is demonstrated in the methodology sections in chapter 2, where I critically appraise and justify the methods used in each of the projects in this thesis. Specifically, I have focused on the participatory approach used in project 1.

I have been fortunate to work on qualitative, observational and experimental studies, providing me with the opportunity to apply different methods of collecting and analysing various types of data. For example, I worked with the expert panel groups in project 1 to develop interview topic guides. I have experience in developing, creating and designing online surveys for projects 2 and 3. I have also used the computer packages SPSS and NVivo to assist with data analysis.

3.3.5 Doctoral Descriptor 5

Developed independent judgement of issues and ideas in the field of research and / or practice and are able to communicate and justify that judgement to appropriate audiences

I have made significant contributions to the papers submitted in this thesis, which evidences my judgement of issues and ideas. Alongside formal written communication of my research through papers and reports, I have presented at a number of conferences. A list of conference presentations and posters I have presented can be found in appendix 4. I continually liaised and communicated with a range of stakeholders and collaborators whilst working on these projects: members of the public as participants in our research, peer researchers, research monitors, clinicians and other HCPs and academics.

3.3.6 Doctoral descriptor 6

Critically reflects on their work and evaluate its strengths and weaknesses including understanding validation procedures

The strengths and limitations of each of the projects have been incorporated into each of the submitted, published papers that I co-authored. I have further explored the strengths and limitations of the methods for each project in the methodology sections in chapter 2. This chapter provides a reflection on how I have developed as a researcher and I have made example suggestions as to how I will take this learning with me into future projects.

4   CONCLUSION

4.1   Current and future research activities

Since the publication of the eight papers included in this thesis, the team have been successful in continuing to secure funding to extend research in the field of psychosocial approaches to dementia care. A list of the successful funding applications I have contributed to can be found in appendix 5. The main areas of research I continue to develop relate to project 1 (primary care led dementia services) and project 3 (developing a nostalgia intervention).

4.1.1   *Impact Case Study development for the Research Excellence Framework (REF 2021)*

Currently I am working on developing an Impact case Study (ICS) for the REF2021 (Unit of Assessment 20; Social Work and Social Policy). Along with a post-diagnostic intervention developed by Prof Cheston, this ICS includes the PiCLeD project (papers 1 and 2). The findings and suggestions in paper 1 in this thesis were the catalyst for definitive changes to assessment and diagnosis in Bristol and are included as part of the underpinning research for the ICS. To date, paper 1 has been cited 23 times and has been included in three reviews of diagnostic pathways (Wells and Smith, 2017; Low, et al., 2018; Reves, et al., 2018) and one review of patient engagement in research in dementia (Bethell, et al., 2018).

Since we completed project 1, interest in primary care led dementia services has grown in the UK. I have been contacted by researchers about the studies from the University of Newcastle who are leading the PriDem programme. This is an Alzheimer's Society funded project to develop and test a good practice model of primary care co-ordinated, post diagnostic dementia care.

4.1.2   *The South Asian Communities Enhanced Dementia pathway (SACED)*

People from south Asian communities are less likely to access the dementia pathway (All Party Parliamentary Group on Dementia 2013). I am a co-applicant on a stage 2 grant application to the NIHR RfPB funding stream. I coordinated the steering group meetings whilst planning this application and liaised with the co-applicants on study costings. In this application, we aim to develop an online toolkit of assessments and

interventions to enhance the Well Pathway for people living with dementia from south Asian communities. If successful, I will be the trial manager for this multi-centre site project, working with co-applicants and South Asian communities from Bristol, Wolverhampton, Bradford and London.

I am currently writing a paper to report the findings of an audit of local case records comparing a sample of 30 anonymised records from BAME communities to a matched sample of 30 records from a non-BAME sample. Our findings support earlier research that diagnosis of dementia is more likely to occur at a later stage for people from south Asian communities (La Fontaine, et al., 2007; Mukadam, et al., 2011).

4.1.3 Overview of systematic reviews of communication training interventions

I have conducted an overview of systematic reviews of communication training interventions for HCPs working with people living with dementia. I took the lead in all aspects of this research and wrote the paper (unpublished). It was difficult to identify specific training interventions that could be particularly recommended due to the lack of detail on the individual interventions within the included reviews. Only two of the reviews reported behaviour that challenges as an outcome and the conclusions from both were inconsistent or marginal. If primary care staff are to be given a greater role in dementia care, then they are a group of HCPs that could benefit from such interventions but this HCP group was absent in these findings as many of the interventions were aimed at HCPs working in institutional settings.

4.1.4 Nostalgia intervention development

Following on from the final paper included in this thesis, I provided significant input and was a co-applicant on two successful grant applications (£4,999 from Alzheimer's Research UK and £9,997 from internal funding) to develop a nostalgia-based intervention.

Firstly, I developed the intervention and workbook from feedback and views we gathered from eight Patient Public Involvement (PPI) representatives (two people living with dementia and six, formal and informal carers). Next, with a colleague, I recruited six husband/wife dyads to take part in a feasibility study of the intervention

to test out the outcome measures and obtain information about the acceptability of the intervention from the users' perspective. The intervention involves working with each dyad to identify nostalgic memories and objects that trigger those memories for the person with dementia and to encourage the dyad to regularly engage with the memories throughout the five weeks. I have written a report of our findings and I will lead on writing a short paper for the *Ageing and Mental Health* journal.

I am a co-applicant on a recent successful grant application (£6,373 from Avon and Wiltshire Partnership Mental Health Partnership NHS Trust) to write a grant application to conduct a larger feasibility of the intervention to be delivered by dementia coaches in the community. Dementia coaches could be dementia navigators, memory nurses, day centre staff, or voluntary sector staff. I will carry out further PPI and stakeholder consultation, identify further outcome measures and lead on writing an RfPB grant application.

4.1.5 Stroke Health Integration Team work

Alongside my dementia research, I am the coordinator for the Stroke Health Integration Team (HIT). The aim of the HIT is to bring together clinicians, commissioners, academics, care and support providers, as well as people who have had strokes and their families to prevent strokes and improve the lives of people affected by stroke in Bristol, North Somerset and South Gloucestershire (BNSSG)[5].

I am collaborating with a Senior Research Fellow from the Centre for Public Health and Wellbeing at UWE Bristol to co-produce a research project with the Caribbean community in Bristol that have experienced stroke. As with dementia, people from BAME communities are at increased risk of stroke compared to their white counterparts and are more likely to experience stroke earlier (Heuschmann, et al., 2007; Wang, et al., 2013). The community want to develop a resource to improve communication between HCPs and stroke survivors to meet the needs of this particular group. My strategic knowledge of stroke services in the area and my prior experience of applying for NIHR and charity grants will be useful in this collaboration. I will use the experience and reflections from the participatory approach I gained from

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[5] http://www.bristolhealthpartners.org.uk/health-integration-teams/stroke-hit/ accessed 24-07-2019

working on the PiCLeD project to shape this proposed collaboration. I am also talking with my counterpart in the dementia HIT about how researchers from both HITs can collaborate to advance further cross disciplinary research.

The stroke HIT coordinator role has provided me with opportunities to develop my strategic thinking, leadership and collaboration skills. I have line management responsibility for administrative staff support for the HIT. I managed and led a cross-disciplinary team to deliver the Stroke HIT launch event. This was a complex event requiring communication and negotiation with a range of stakeholders: stallholders, speakers and delegates (academics, clinicians, commissioners and members of the public). The launch event was held in collaboration with an arts-based charity from London so effective communication throughout was essential.

4.2   Concluding comments

This thesis critically reflects on eight published papers that I have co-authored over the course of the last seven years at UWE Bristol. This research and the published papers extend and contribute to the knowledge in the field of psychosocial approaches, particularly in relation to communication between health care professionals and people living with dementia. My research maps onto the Well Pathway for Dementia. As a trial manager I have had a fundamental role within our small dedicated team to ensure the successful implementation of the research undertaken. My academic responsibilities have extended to include writing and developing research protocols and grant applications and disseminating research findings. Through this process I have demonstrated that I am able to meet the UWE Bristol doctoral descriptors. I love my job and I fully intend to carry on with the current and future projects described and to continue my development as an independent researcher in the field of dementia care.

Addendum 28th February 2020

Since the submission of this thesis in August 2019, two funding applications that I am co-applicant on have been successful. I am currently funded through Research Capability Funding from BNSSG CCG to write a grant application with stroke survivors from the local black African and Caribbean community using a co-production approach. The NIHR funded SACED project will commence in July 2020.

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APPENDIX 1: Tables and figures

APPENDIX 2: Abbreviations

ADI	Alzheimer's Disease International
BAME	Black Asian Minority Ethnic
BNSSG	Bristol, North Somerset and South Gloucestershire
BPSD	Behavioural and Psychological Symptoms of Dementia
CCG	Clinical Commissioning Group
CONSORT	Consolidated Standards of Reporting Trials
CRN	Clinical Research Network
CSO	Clinical Studies Officer
CTIMP	Controlled Trial of Investigational Medicinal Product
DCM	Dementia Care Mapping
DEM-QoL	Dementia Quality of Life
DLB	Dementia with Lewy Bodies
DoH	Department of Health
FREC	Faculty Research Ethics Committee
FTD	Frontotemporal dementia
GCP	Good Clinical Practice
GP	General Practitioner
HARK	Hypothesising After Results Known
HCP	Health Care Professional
ICH	International Conference on Harmonisation
ICS	Impact Case Study
IRAS	Integrated Research Application System
IT	Information Technology

JDR	Join Dementia Research
NCCMH	National Collaborating Centre for Mental Health
NICE	National Institute for health and Care Excellence
NIHR	National Institute for Health Research
PET	Protected Engagement Time
PiCLeD	Primary Care Led Dementia
PPI	Patient and Public Involvement
RCT	Randomised Control Trial
RfPB	Research for Patient Benefit
SPSS	Statistical Package for Social Sciences
TA	Thematic Analysis
UWE	University of the West of England
VIPS	Values, Individual, Perspective, Social
WHO	World Health Organisation

APPENDIX 3: Extended bibliography

Published papers:

Cheston, R., **Dodd, E.**, Hart, I., and Christopher, G. (2019) The recall of dementia related and neutral words by people with dementia: The ironic process of thought suppression *International Journal of Geriatric Psychiatry* 34, p756-764

Ismail S, Christopher G, **Dodd E**, Wildschut T, Sedikides C, Ingram T, Jones R, Noonan K, Tingley D and Cheston R (2018) Psychological and Mnemonic benefits of nostalgia for people with dementia *Journal of Alzheimer's Disease* 65(4) p1327-1344

Cheston R, **Dodd E**, Christopher G, Jones C, Wildschut T and Sedikides C (2018) Selective Forgetting of self-threatening statements: mnemic neglect for dementia information in people with mild dementia. *International Journal of Geriatric Psychiatry*, 33(8).

Dodd E, Cheston R, Fox C, Procter C, Heneker S, Gray R and Nolan F (2017) Protected Engagement Time on older adult mental health wards: a thematic analysis of the views of patients, carers and staff. *International Journal of Mental Health Nursing* 27(2) p608-618

Smith T, Clark A, **Dodd E**, Khoo M-E, Heneker S, Cross J, Cheston R, Gray R, Fox C, Nolan F (2017) Feasibility study suggests no impact from protected engagement time on adverse events in mental health wards for older adults *International Journal of mental health nursing* 27 (2) p756-764

Nolan F. M., Fox C., Cheston R., Turner, D., Clark, A., **Dodd E.,** Khoo M-E. and Gray R (2016) A feasibility study comparing UK older adult mental health inpatient wards which use protected engagement time with other wards which do not: study protocol. *Pilot and Feasibility Studies*, 2:7

Moule, P., Armoogum, J**., Dodd, E**., Donskoy, A. L., Douglass, E., Taylor, J. and Turton, P. and Centre for Health and Clinical Research (2015) Practical Guidance on undertaking a service evaluation. *Nursing Standard,* (30)45 pp46-51

Dodd, E., Cheston, R. and Ivanecka, A. (2015) The assessment of dementia in Primary Care. *Journal of Psychiatric and Mental Health Nursing*, 22 (9). pp. 731-737

Dodd, E., Cheston, R., Cullum, S., Jefferies, R., Ismail, S., Gatting, L., Fear, T. and Gray, R. (2015) Primary care led dementia diagnosis services in South Gloucestershire: Themes from people and families living with dementia and health care professionals. *Dementia,* 15(6), pp1586-1604

Dodd, E., Cheston, R., Fear, T., Brown, E., Fox, C., Morley, C., Jefferies, R. and Gray, R. (2014) An evaluation of primary care led dementia diagnostic services in Bristol. *BMC Health Services Research*, 14,pp592

Papers in draft:

Cheston, R., **Dodd, E.**, Christopher, G., Wildschut, T., and Sedikides, C. Selective forgetting of threatening dementia related information by older and younger adults

Cheston, R., **Dodd, E.,** Christopher, G., White, P., Wildschut, T., and Sedikides, C. Development and Validation of the Threat of Dementia Scale

Dodd, E., Pracownik, R., Popel, S., Emmens, T. and Cheston, R. Can primary care led dementia services improve access to diagnosis and assessment of dementia for people from Black Asian and Minority Ethnic (BAME) communities? A small pilot study

Dodd, E., Cheston, R., Cramp, F., Inoges, M. And Gray, R. Does communication training enable Health Care Professionals to reduce challenging behaviour in people living with dementia? A systematic review of reviews.

APPENDIX 4: Conference Presentations

Oral presentations:

"Before you can kill the monster, you have to say its name" British Society of
Gerontology conference, University of Liverpool, 11/07/2019,

Piloting a nostalgia-based intervention, Ageing Better Conference, UWE Bristol,
02/07/2019

Developing a nostalgia-based reminiscence intervention Ageing Better Conference,
UWE Bristol 10/07/2018

*Selective Forgetting for self-threatening feedback: mnemic neglect in people with
dementia* Alzheimer's Society Annual conference, 23/05/2018

Improving Access to Dementia Assessment for people from BAME communities
Dementia Network event 18/04/2018

Involving people in the later stages of dementia as participants in research, Alzheimer's
Society Research Conference, Bristol 01/07/2016

An update of the PET dementia Study, Avon and Wiltshire Mental Health Partnership
NHS Trust Patient and Public Involvement event, Bristol 08/07/2015

Evaluation of Primary Care Led Dementia Services in Bristol (PiCLeD), Bristol Dementia
Research Forum, Bristol 22/01/2014

Protected Engagement Time on dementia wards, Centre for Health and Clinical
Research conference, UWE, Bristol 05/11/2014

*Interim results from a study to compare inpatient mental health wards for older
people, which use Protected Engagement Time, with similar wards which deliver
standard care alone,* International Network for Psychiatric Nursing Research,
University of Warwick, 18/09/2014

Evaluation of Primary Care Led Dementia Services in Bristol (PiCLeD), and Protected Engagement Time on dementia wards Avon and Wiltshire Mental Health Partnership NHS Trust R&D conference 07/11/2013

<u>*Poster presentations:*</u>

Communication in Dementia care: A Programme of Research, Postgraduate Researcher conference, UWE Bristol, 18/06/2019 (came second in the poster competition)

"Before you can kill the monster, you have to say its name" Centre for Health and Clinical Research conference, UWE, Bristol, 05/04/2019

Mnemic neglect in people affected with mild dementia: replicating and extending findings from experimental social psychology, Centre for Health and Clinical Research conference, UWE, Bristol 19/01/2017

Primary Care Led Dementia Services in Bristol (PiCLeD): A participatory mixed methods study, Centre for Health and Clinical Research conference, UWE, Bristol 05/11/2014

A Preliminary Comparison of Dementia Inpatient Wards which use Protected Engagement Time with other Wards Delivering Standard Care Alone, Bristol Research Symposium University Hospitals Bristol NHS Foundation Trust 09/05/2013

APPENDIX 5: Funding Applications

Cheston R, Parveen S, **Dodd E,** Smith P, Jeraj S, Jutlla, K, Truswell D 2019 *The South Asian Communities Enhanced Dementia pathway (SACED) – refining a package of intervention.* [National Institute for Health Research - Research for Patient Benefit - £141,608.00 over 12 months commencing July 2020]

Cramp M, White J, **Dodd, E**, Chacon, A, Clatworthy P, Cheston R 2019. *Inclusivity in Stroke After Care* (ISAC) [Research Capability Funding - £14,041 over 7 months from Bristol North Somerset and South Gloucestershire Clinical Commissioning Group]

Cheston, R., Sedikides, C., Wildschut, T., Ahmad, S., Christopher, G., Ismail, S., and **Dodd, E.** 2019 Developing a nostalgia-based intervention for people living with dementia and their carers: consulting with the public, services providers and academics. [Research Capability Funding - £6,373.50 over 6 months from Avon and Wiltshire Mental Health Partnership NHS Trust]

Christopher G, Cheston R, **Dodd E**. 2018. *Further examination of how high-low threat information is processed in dementia: the implicit-explicit divide* [Internal funding £19,972 over 12 months]

Christopher G, Cheston R, Ismail S and **Dodd E.** 2018. *Nostalgic reminiscence: preliminary steps in developing and evaluating a complex intervention* [Internal funding £9,997.30 over 5 months]

Cheston R and **Dodd E.** 2017 *Primary Care led Services for People with Dementia* [Research Capability Funding - £23,338 over 12 months from Avon Primary Care Research Collaborative]

Cheston R and **Dodd E**. **2107.** *Can hospital volunteers reduce the insecurity of patients with dementia and enhance their well-being* [Research Capability Funding - £11,982 over 9 months from Royal United Hospitals Bath NHS Foundation Trust]

APPENDIX 6: Co-author confirmation letters

The following pages contain the confirmation letters from my co-authors of my contributions to the projects and papers outlined in this thesis.

13 June 2019

To whom it may concern,

As a co-author on the following paper, I can confirm that Emily Dodd contributed to the paper by undertaking the activities listed.

Dodd, E., Cheston, R., Fear, T., Brown, E., Fox, C., Morley, C., Jefferies, R. and Gray, R. (2014) An evaluation of primary care led dementia diagnostic services in Bristol. *BMC Health Services Research*, 14:592

- developed the consent forms, participant information sheets and interview topic guides;

- obtained the relevant regulatory approvals - University ethics approval and Research and Development approval from the local NHS Trusts taking part in the evaluations;

- organised the interviews with staff, patients and carers;

- organised and co-facilitated expert panel meetings;

- led the data management process to ensure the data was collected and stored in a secure manner;

- trained and supervised the peer researchers who conducted the interviews;

- carried out the thematic analysis of the transcripts;

- wrote the first draft of the methodology section;

- provided significant edits to drafts of the manuscript;

- revised the manuscript in response to reviewers comments;

- led the submission of the manuscript to the journal.

Dr Ellie Brown
Research Fellow

Postal address: **Phone:**
Centre for Youth Mental Health,   **0487786465**
53 Poplar Road,
Parkville,
3052, Victoria
Australia

Dr Gary Christopher
Senior Lecturer in Psychology
University of the West of England
Bristol
BS16 1QY

12th July 2019

To whom it may concern

As co-author with Emily on three papers she is submitting for the award of DPhil I can confirm that she contributed to the two papers detailing the findings from the mnemic neglect study[12] by writing the first draft of the methodology sections of the manuscripts, collating the CONSORT diagrams, conducting the analysis of the intrusion error findings and commenting on all drafts of each manuscript. For the Ismail et al (2018) paper[3], Emily conducted the preliminary analyses and drafted the methodology section for experiment 3 and commented on drafts of the paper as a whole, making significant edits to the manuscript.

In addition, Emily carried out a number of duties to ensure the success of the mnemic neglect and nostalgia studies. She:

- developed and submitted the two proposals;

- helped to draft and then revise the application including responding to comments by peer reviewers;

- led the Qualtrics survey which determined the study materials;

- led the research governance of the project. This involved writing and submitting the applications for University ethics, NHS ethics and Health Research Authority approvals;

- liaised with three NHS Trust Research and Development departments to obtain local R&D approvals and set up the study ready for recruitment at each of the three sites for the mnemic neglect study;

- designed and drafted the study documentation; consent forms, information sheets, Case Report Forms, Study Instruction Manual;

- managed the data management process across the recruiting sites;

- coordinated the steering group meetings for both studies;

---

[1] Cheston R, Dodd E, Christopher G, Jones C, Wildschut T and Sedikides C (2018) Selective Forgetting of self-threatening statements: mnemic neglect for dementia information in people with mild dementia. International Journal of Geriatric Psychiatry, 33(8).

[2] Cheston R, Dodd E, Hart I and Christopher G (2019) The recall of dementia related and neutral words by people with dementia: The ironic process of thought suppression International Journal of Geriatric Psychiatry 34(5), p756-764

[3] Ismail S, Christopher G, Dodd E, Wildschut T, Sedikides C, Ingram T, Jones R, Noonan K, Tingley D and Cheston R (2018) Psychological and Mnemonic benefits of nostalgia for people with dementia. Journal of Alzheimer's Disease 65(4) p1327-1344

- managed the interface between the research team and the research monitors for the mnemic neglect study;

- provided protocol training to the Clinical Studies Officers (CSOs) and research psychologists at the recruiting sites;

- visited memory clinics with CSOs to introduce the mnemic neglect study and promote recruitment;

- recruited participants to the healthy volunteer arm of the mnemic neglect study. This involved collecting informed consent and data;

- carried out the close down site visits at each recruiting site following the completion of the studies.

Yours sincerely,

Dr Gary Christopher

Richard Cheston
Professor of Dementia Research
Dept of Health and Social Sciences
University of the West of England
Bristol
BS16 1QY

7th August, 2019.

To whom it may concern

As co-author with Emily on all of the papers that she is submitting for the award of DPhil I can confirm that she contributed to these papers as follows:

- For papers A, B and C, I was the Chief Investigator. As a core member of our research team, Emily developed and submitted the two proposals, helping to draft and then revise the application including responding to comments by peer reviewers. As trial co-ordinator, Emily led the Qualtrics survey which generated the study materials, led the research governance of the project and worked with three NHS Trust Research and Development departments to set up the study ready for recruitment at each of the three sites. Emily led the process of writing and submitting the applications for University ethics, NHS ethics and Health Research Authority approvals, and additionally worked independently to design and draft the study documentation including consent forms, information sheets and Case Report Forms. She also managed the data management process across the recruiting sites and coordinated the steering group meetings for both studies. As part of the study team, she played a full role in discussions around both the theoretical and applied aspects of the study.

- In terms of the writing of these papers, Emily wrote the first draft of the methodology sections of the manuscripts, collated the CONSORT diagrams, conducted aspects of the analysis (e.g. relating to the intrusion error findings) and commentedn all drafts of each manuscript. For paper C, Emily conducted the preliminary analyses and drafted the methodology section for study 3 and commented on drafts of the paper as a whole, making significant edits to the manuscript.

- For papers D, E and F, I was a co-author and member of the study team alongside Emily. I can confirm that she again contributed fully as study manager to the design and implementation of the research, particularly around the recruitment, training and supervision of the peer researchers. Additionally, for papers D and E, she led the thematic analysis of the qualitative data collected in the interviews. This involvement continued into the drafting and writing of the papers, with Emily

leading sections of each paper. There was a similar level of involvement in the writing of paper F.

- For paper H, my recollection is that Emily led the drafting of the majority of this paper, as well as co-ordinating responses to reviewers. As the trial manager, Emily also designed and implemented the data collection process for study G, and again led on the thematic analysis process including the writing of this paper.

I can be contacted for further details if this is necessary

Your sincerely

Richard Cheston

Papers

A. Cheston R, Dodd E, Christopher G, Jones C, Wildschut T and Sedikides C (2018) Selective Forgetting of self-threatening statements: mnemic neglect for dementia information in people with mild dementia. *International Journal of Geriatric Psychiatry*, 33(8).

B. Cheston R, Dodd E, Hart I and Christopher G (2019) The recall of dementia related and neutral words by people with dementia: The ironic process of thought suppression, *International Journal of Geriatric Psychiatry* 34(5), p756-764

C. Ismail S, Christopher G, Dodd E, Wildschut T, Sedikides C, Ingram T, Jones R, Noonan K, Tingley D and Cheston R (2018) Psychological and Mnemonic benefits of nostalgia for people with dementia. *Journal of Alzheimer's Disease* 65(4) p1327-1344

D. Dodd E, Cheston R, Fear T, Brown E, Fox C, Morley C, Jefferies R and Gray R (2014) An evaluation of Primary Care Led Dementia Diagnostic Services in Bristol, *BMC Health Services Research*, 14:592 doi: 10.1186/s12913-014-0592-3

E. Dodd E, Cheston R, Ismail S, Cullum S, Gatting L, Jefferies R, Fear T, and Gray R (2016) Primary Care Led Dementia Services: themes from families, patients and health professionals, *Dementia: the International Journal of Social Research and Policy*, 15 (6), 1586-1604 (doi: 10.1177/1471301214566476).

F. Dodd E, Cheston R and Ivanecka A (2015) The assessment of dementia in Primary Care, *Journal of Psychiatric and Mental Health Nursing,* **22**, 731-777. doi: 10.1111/jpm.12250

G. Dodd E, Cheston R, Procter C, Heneker S, Gray R, Fox C and Nolan F (2017) Protected Engagement Time on older adult mental health wards: a thematic analysis of the views of patients, carers and staff, *International Journal of Mental Health Nursing,* first published on-line 20th April, doi:10.1111/inm.12342

H. Nolan F, Fox C, Cheston R, Turner D, Clark A, Dodd E, Khoo M-E and Gray R (2016) A feasibility study comparing UK older adult mental health inpatient wards which use Protected Engagement Time with other wards which do not: study protocol. *Pilot and Feasibility Studies,* 2: 7, DOI: 10.1186/s40814-016-0049-z.

Norwich Medical School
Lifecourse and Aging theme Lead

14th July 2019

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Fax: 01603 593752
Email: chris.fox@uea.ac.uk

Dear Sir,

Re: DPhil by publication Emily Dodd

I have co-authored three papers with Emily that she is choosing to submit for the award of DPhil.

1. Dodd, E., Cheston, R., Fear, T., Brown, E., Fox, C., Morley, C., Jefferies, R. and Gray, R. (2014) An evaluation of primary care led dementia diagnostic services in Bristol. *BMC Health Services Research*, 14:592

For the paper above, I can confirm that Emily:

- carried out the thematic analysis of the transcripts;
- wrote the first draft of the methodology section;
- provided significant edits to drafts of the manuscript;
- revised the manuscript in response to reviewers comments;
- led the submission of the manuscript to the journal.

For this project Emily developed the project paperwork, obtained the relevant regulatory approvals, organised the interviews with staff, patients and carers, organised and co-facilitated expert panel meetings, led the data management process to ensure the data was collected and stored in a secure manner, trained and supervised the peer researchers who conducted the interviews.

2. Nolan F. M., Fox C., Cheston R., Turner, D., Clark, A., Dodd E., Khoo M-E. and Gray R (2016) A feasibility study comparing UK older adult mental health inpatient wards which use protected engagement time with other wards which do not: study protocol. *Pilot and Feasibility Studies*, 2:7

Emily prepared the protocol for the Protected Engagement Time study for publication and made edits to the drafts of this manuscript. Emily was also the trial manager at the beginning of this project and therefore completed a number of tasks to ensure the study opened. Specifically, she led the research governance and ethics applications for the project, liaised with the sponsor of the study to manage the budget, organised the management meetings and steering group meetings and led the data management process to ensure the data was collected and stored in a secure manner.

3. Dodd E, Cheston R, Fox C, Procter C, Heneker S, Gray R and Nolan F (2017) Protected Engagement Time on older adult mental health wards: a thematic analysis of the views of patients, carers and staff. *International Journal of Mental Health Nursing* 27(2) p608-618

Emily contributed to this paper in a number of ways. She took the lead role in analysing the data in this paper. She wrote the first drafts of the methodology section and findings sections and made substantial changes to the manuscripts following reviewer comments. Emily submitted the final manuscript.

Any queries please let me know.

Yours Sincerely

G C FOX

Professor of Clinical Psychiatry and Honorary Consultant

Ms. Lauren Gatting

Room 23,

Administration building,

Gartnavel Royal Hospital,

Glasgow, G12 0XH

12 June 2019

Dear PhD reviewer,

Evidence of contribution to the project 'Primary Care Led Dementia services (PiCLeD)' and associated paper 'Dodd, E., et al (2015) Primary care led dementia diagnosis services in South Gloucestershire: Themes from people and families living with dementia and health care professionals. *Dementia.* 0(0) 1-19'

As a co-author on the paper above, I am able to confirm that Emily Dodd led in developing research materials, securing ethical approval, organising interviews with a range of stakeholders, co-facilitating expert panel meetings, protecting and managing the data, training and supervising interviewers and, submitting the final manuscript for the project. I can also confirm that Emily Dodd contributed to the project and paper with analysing the data and writing and editing the manuscript. I give my wholehearted support to Dodd's endeavour to achieve a PhD through publication.

Kind regards,

Lauren Gatting

Institute of Health and Wellbeing, University of Glasgow

Email: L.Gatting.1@research.gla.ac.uk

Ada Ivanecka, PhD

Bratislava, Slovakia

15th August 2019

Emily Dodd

Room 3L07, Frenchay Campus

University of the West of England

Coldharbour Lane

BRISTOL

BS16 1QY

To whom it may concern

Dear Sir or Madam,

I confirm that Ms Emily Dodd made a significant and extensive contribution to the following publication: **Dodd, E.,** Cheston , R. and Ivanecka , A. (2015) The assessment of dementia in Primary Care. *Journal of Psychiatric and Mental Health Nursing ,* 22 (9). pp. 731-737.

In particular, Emily:

- identified the concept for the commentary;
- wrote significant sections relating to primary care dementia services in the local area
- edited the first draft of the manuscr ipt; and
- revised the paper in light of and responding to reviewer comments

Kind Regards

Ada Ivanecka

University of the West of England

Frenchay Campus

Bristol, UK

BS16 1QY.

12 June 2019.

To whom it may concern

Dear Sir/ Madam,

<u>CONFIRMATION OF EMILY DODD'S CONTRIBUTION TO RESEARCH PROJECTS AND PAPERS</u>

I can confirm the following contributions of Emily Dodd to these projects and published research articles:

1. **Primary Care Led Dementia services (PiCLeD)**

Dodd, E., Cheston, R., Cullum, S., Jefferies, R., Ismail, S., Gatting, L., Fear, T. and Gray, R. (2015) Primary care led dementia diagnosis services in South Gloucestershire: Themes from people and families living with dementia and health care professionals. *Dementia. The international Journal of social research and practice.* 0(0) 1-19

- developed the consent forms, participant information sheets and interview topic guides;
- obtained the relevant regulatory approvals - University ethics approval and Research and Development approval from the local NHS Trusts taking part in the evaluations;
- organised the interviews with staff, patients and carers;
- organised and co-facilitated expert panel meetings;
- led the data management process to ensure the data was collected and stored in a secure manner;
- trained and supervised the peer researchers who conducted the interviews;
- carried out the thematic analysis of the transcripts;
- wrote the first draft of the methodology section;
- provided significant edits to drafts of the manuscript;
- led on the submission of the manuscript to the journal;

2. **Nostalgia**

Ismail S, Christopher G, **Dodd E**, Wildschut T, Sedikides C, Ingram T, Jones R, Noonan K, Tingley D and Cheston R (2018) Psychological and Mnemonic benefits of nostalgia for people with dementia *Journal of Alzheimer's Disease* 65(4) p1327-1344

- Led the research governance of the project. This involved writing and submitting the applications for University ethics, NHS ethics and Health Research Authority approvals;
- designed and drafted the study documentation; consent forms, information sheets, Case Report Forms, Study Instruction Manual;
- managed the data management process;
- coordinated the steering group meetings;
- provided protocol training to the Clinical Studies Officers (CSOs) and research psychologists at the recruiting sites;
- carried out the close down site visits at each recruiting site following the completion of the studies;
- conducted the preliminary analyses to experiment 3;
- drafted the methodology section for experiment 3;
- commented on drafts of the paper and made significant edits

Please do get in touch if you need further information.

Yours sincerely,

Dr Sanda Umar Ismail.

Senior Lecturer in Public Health
Centre for Health and Wellbeing
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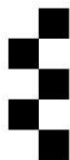
13th June 2019

To whom it may concern

Re: Contribution of Emily Dodd to an NIHR funded study to evaluate protected engagement time in older adult wards in England (Reference PB-PG-0110-21023)

I was Chief Investigator for the above study after the original lead, Professor Richard Gray, emigrated. I can confirm that Emily had a key role in the study implementation and in publishing two linked papers.

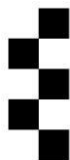A comprehensive list of her activities is found below.

I can be contacted for further details at any time

Yours sincerely

Fiona Nolan

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Wivenhoe Park
Colchester CO4 3SQ
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Emily Dodd: Activities and contribution to the study 'A preliminary comparison of wards for people with dementia which use protected engagement time with other wards delivering standard care alone'

1.   Contribution to publications
    a)   <u>Study protocol:</u>

Nolan F. M., Fox C., Cheston R., Turner, D., Clark, A., **Dodd E.,** Khoo M-E. and Gray R (2016) A feasibility study comparing UK older adult mental health inpatient wards which use protected engagement time with other wards which do not: study protocol. *Pilot and Feasibility Studies*, 2:7

Role: Contributed to drafting the paper and to addressing comments from reviewers prior to publication.

    b)   <u>Qualitative component:</u>

Dodd E, Cheston R, Fox C, Procter C, Heneker S, Gray R and Nolan F (2017) Protected Engagement Time on older adult mental health wards: a thematic analysis of the views of patients, carers and staff. *International Journal of Mental Health Nursing* 27(2) p608-618

Role:

- led on the thematic analysis of the data;
- Led on drafting the methods and results sections;
- Contributed to editing the drafts of the manuscript;
- redrafted and revised the manuscript following reviewer comments to include substantial additions to the introduction and discussion sections;
- led on the submission of the final revised manuscript to the journal

2.   Employed as part time study coordinator which entailed the following duties

- Led on approaching relevant Trusts, NHS research ethics and University research ethics committees to obtain approval to conduct the study.
- Submitted amendments to the study protocol to the NHS REC under supervision of the CI and Local PI
- Managed participant recruitment and recording recruitment data onto the NIHR portfolio system;
- Assisted in recruiting a local research assistant through contributing to aspects of the job description, shortlisting applicants for interview, participating in the interview panel, and in the decision around candidate selection
- Supported the local PI in supervising and monitoring the work of the local RA
- Contributed to liaison with the study sponsor around study implementation and aspects of the budget
- Organised study management and steering group meetings in conjunction with a researcher from another site;
- Led the data management process to ensure the data was collected and stored in a secure manner. This involved setting up a system whereby colleagues from across the three sites had access to data;
- Organised and led 'concept mapping' exercises in the local NHS site;
- Contributed to writing the final report for the funders on the study implementation and findings.

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25th June 2019

Krist Noonan
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0117 378 4266
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To Whom It May Concern,

RE: Ismail S, Christopher G, Dodd E, Wildschut T, Sedikides C, Ingram T, Jones R, Noonan K, Tingley D and Cheston R (2018) Psychological and Mnemonic benefits of nostalgia for people with dementia. *Journal of Alzheimer's Disease* 65(4) p1327-1344

I am writing to confirm that as a co-author on the above paper, Emily Dodd conducted some preliminary analyses and drafted the methodology section for experiment 3 in this paper. She also commented and made edits to the paper.
Emily was the trial manager for this project and happy to confirm she:

- developed and submitted the two proposals;

- helped to draft and then revise the application including responding to comments by peer reviewers;

- led the research governance of the project. This involved writing and submitting the applications for University ethics, NHS ethics and Health Research Authority approvals;

- liaised with NHS Trust Research and Development departments to obtain local R&D approvals and set up the study ready for recruitment

- designed and drafted the study documentation; consent forms, information sheets, Case Report Forms, Study Instruction Manual;

- managed the data management process;

- coordinated the steering group meetings;

- provided protocol training to the research psychologists at the recruiting sites;

Yours sincerely,

Dr Krist Noonan
Research and Development Operations Manager
Avon and Wiltshire Mental Health Partnership NHS Trust

Chair	*Trust Headquarters*	*Chief Executive*
Charlotte Hitchings	Bath NHS House, Newbridge Hill, Bath BA1 3QE	Simon Truelove

'We are a teaching, learning and research trust; we aim to inform you about relevant opportunities, unless you tell us otherwise.'

To whom it may concern

RE: Emily Dodd's contribution to the Protected Engagement Time (PET) project and paper

I worked with Emily on the Protected Engagement Time project and can confirm that Emily carried out the following duties whilst in this role:

• led the research governance for the project - obtained the relevant regulatory approvals; NHS ethics and University ethics approval and coordinated the Research and Development approval for each of the three NHS Trusts sites taking part in the evaluations. Completed and submitted the amendments for the project;

• managed the collection of participant recruitment and uploaded this onto the NIHR portfolio system;

• liaised with the local R&D department to manage the recruitment process of the local researcher and assisted with the interview process of this position; writing the job description, short listing applicants and interviewing candidates;

• liaised with the sponsor of the study to manage the budget;

• Organised the management meetings and steering group meetings;

• Led the data management process to ensure the data was collected and stored in a secure manner. This involved setting up a system whereby colleagues from across the three sites had access to data;

• organised and led the concept mapping exercises in the local site.

As co-author on the paper **Dodd E;** Cheston R, Fox C, Procter C, Heneker S, Gray Rand Nolan F (2017) Protected Engagement Time on older adult mental health wards: a thematic analysis of the views of patients, carers and staff. *International Journal of Mental Health Nursing* 27(2) p608-618 I can confirm that Emily:

• led on the thematic analysis of the data;

• wrote the first drafts of the methodology section and results sections;

• made edits to the drafts of the manuscript;

• redrafted and revised the manuscript following reviewer comments to include substantial additions to the introduction and discussion sections;

• led on the submission ofthe final revised manuscript to the journal

Yours sincerely,

CW

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f2. -:Gac ..AsS\STA ,

14 June, 2019

To whom it may concern

We, the undersigned, can confirm that Emily Dodd acted as the trial manager for the mnemic neglect and nostalgia studies. We confirm that Emily carried out the following tasks:

- developed and submitted the two proposals;

- helped to draft and then revise the application including responding to comments by peer reviewers;

- led the Qualtrics survey which determined the study materials;

- led the research governance of the project. This involved writing and submitting the applications for University ethics, NHS ethics and Health Research Authority approvals;

- liaised with three NHS Trust Research and Development departments to obtain local R&D approvals and set up the study ready for recruitment at each of the three sites for the mnemic neglect study;

- designed and drafted the study documentation; consent forms, information sheets, Case Report Forms, Study Instruction Manual;

- managed the data management process across the recruiting sites;

- coordinated the steering group meetings for both studies;

- managed the interface between the research team and the research monitors for the mnemic neglect study;

- provided protocol training to the Clinical Studies Officers (CSOs) and research psychologists at the recruiting sites;

- visited memory clinics with CSOs to introduce the mnemic neglect study and promote recruitment;

- recruited participants to the healthy volunteer arm of the mnemic neglect study. This involved collecting informed consent and data;

- carried out the close down site visits at each recruiting site following the completion of the studies;

In addition, we confirm that Emily was part of the writing team on two of the published papers that she has included in this DPhil submission. We can confirm that Emily contributed to the two papers we co-authored together in the following way.

- Cheston R, Dodd E, Christopher G, Jones C, Wildschut T and Sedikides C (2018) Selective Forgetting of self-threatening statements: mnemic neglect for dementia information in people with mild dementia. *International Journal of Geriatric Psychiatry*, 33(8).

Emily wrote the first draft of the methodology sections of the manuscript, collated the CONSORT diagrams, carried out the analysis of the intrusion error findings and commented on all drafts of each manuscript.

- Ismail S, Christopher G, Dodd E, Wildschut T, Sedikides C, Ingram T, Jones R, Noonan K, Tingley D and Cheston R (2018) Psychological and Mnemonic benefits of nostalgia for people with dementia. *Journal of Alzheimer's Disease* 65(4) p1327-1344

Emily conducted the preliminary analyses and drafted the methodology section for experiment 3 and commented on drafts of the paper as a whole, making significant edits to the manuscript.

Yours sincerely,

Prof Constantine Sedikides

Professor of Social and Personality Psychology,
Director, Centre for Research on Self Identity

Prof Tim Wildschut

Professor of Social and Personality Psychology