PROFESSIONAL DOCTORATES

Receiving an uncertain diagnosis
experiences and discourse

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Receiving an Uncertain Diagnosis: Experiences and Discourses

Sian Pierce

Bangor University

Submitted in part fulfilment of the final degree award

Doctorate in Clinical Psychology

June 2015

Contents

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Acknowledgements

Thank you to my supervisors, Dr Carolien Lamers and Dr Kate Salisbury. Your guidance, encouragement and enthusiasm over the past two years has been invaluable.

Thank you to the seven participants who took part in this study for sharing their time and experiences with me, and thank you to the clinicians who helped to recruit them.

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Finally, I would like to thank my family – Mum, Dad, Carys and Rhiannon. You have always supported and believed in me, and I could not have done this without you all.

Thesis Abstract

Receiving an Uncertain Diagnosis: Experiences and Discourses

With watchful waiting being increasingly considered as a reasonable alternative for curative treatments for some men with localised prostate cancer, this review aimed to explore the psychological impact of this treatment decision. The review showed that initially aspects of psychological wellbeing were negatively affected, possibly due to uncertainty around treatment choice and the ongoing experience of living with cancer. However over time men appeared to adjust and reported similar wellbeing scores to men in other treatment groups. Men with localised prostate cancer therefore need to be appropriately supported to manage the uncertainty related to watchful waiting.

In continuation of the exploration of uncertainty in illness, seven people with a diagnosis of Mild Cognitive Impairment (MCI) were interviewed. MCI has an uncertain prognosis, whereby the cognitive changes may progress to dementia, remain stable or return to normal over time. The interviews were analysed using discourse analysis, in order to identify how the language used revealed societal views, shared meanings and positions taken by people. Three main discourses emerged. A discourse of 'Not Knowing' appeared for MCI. In the absence of a coherent discourse around MCI, participants positioned themselves between 'Knowing' about ageing and dying, and 'Not Wanting to Know' about dementia. How a diagnosis of MCI is shared and how further information is presented needs to be considered by clinicians, so that the person with a diagnosis of MCI can find a more supportive position, rather than finding themselves oscillating between discourses related to ageing and dying, and dementia.

Contributions to theory development, future research and clinical practice were considered in respect to prostate cancer and MCI. The overlapping theme of uncertainty was discussed in relation to both conditions and how this can inform shared learning and clinical practice.

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The Psychological Impact of Watchful Waiting on Men with Prostate Cancer

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Abstract

Active and aggressive treatments, with physical side effects, are no longer the only option for treating prostate cancer. Watchful waiting is becoming viewed as a reasonable alternative, whereby men are able to conservatively monitor disease progression with the knowledge that if the disease progresses, palliative treatment options remain available. This review aimed to identify the psychological consequences of watchful waiting on men with prostate cancer. An electronic search of the literature was conducted, and 14 studies identified that met inclusion criteria (12 quantitative and two qualitative studies). Watchful waiting was found to have little impact on sexual problems. Improvements in anxiety and depression scores were found when watchful waiting was compared to men in hormone therapy. However, significantly poorer scores were found in the watchful waiting group in the areas of quality of life, anxiety and depression, both over time and compared to other treatment groups, although this was not shown in all studies. In the two qualitative studies, uncertainty was found to play a role in both the decision making process and the ongoing experience of living with cancer. Initially, uncertainty around watchful waiting may negatively impact on psychological wellbeing, however over time men adjust to this treatment choice with outcomes generally similar to men in other treatment groups. Heterogeneity of studies, in regards to design, measures and data collected, was a limitation of this review. Future research into this area should focus on more consistent data collection and reporting, allowing men to make a more informed choice, and physicians to psychologically support these men appropriately.

Keywords: Anxiety, Depression, Mental Health, Prostate Cancer, Quality of Life, Sexual Functioning, Uncertainty, Watchful Waiting.

Research Highlights

- Watchful waiting initially impacts negatively on aspects of psychological wellbeing.
- Uncertainty in watchful waiting may influence psychological wellbeing.
- Over time men tend to adjust to the uncertainty and watchful waiting treatment.
- Men should be supported to manage the uncertainty around treatment choice.

Introduction

Western culture values taking action to treat physical illnesses, and public messages such as 'fighting cancer' mean that when diagnosed, a military mentality is encouraged, leading to an active stance to treat and intervene as quickly as possible (Payer, 1996; Harrington, 2012). However, active and aggressive treatments are no longer the only route patients are offered, depending on the diagnosis and prognosis. An increasing number of conditions now have the treatment option of 'watchful waiting', where ongoing monitoring of the condition takes place, but no active intervention or treatment is undertaken until the condition meets certain criteria. Conditions where this approach might be indicated include prostate cancer, small abdominal aortic aneurysms (Katz, Littenberg & Cronenwett, 1992), and renal tumours (Kouba, Smith, McRackan, Wallen & Pruthi, 2007). The psychological impact of a watchful waiting regime for men diagnosed with localised prostate cancer is the focus of this review.

Prostate Cancer

Prostate cancer is the most common cancer in men in the United Kingdom, accounting for 25% of all new cancers in men. Incidence rates rise sharply from 50-54 years, reaching an overall peak in the 75-79 age group (Prostate Cancer Incidence Statistics, 2011). Recently, early detection of prostate cancer, through the use of Prostate Specific Antigen (PSA) screening, has led to an increase in incident rates (Klotz, 2005). Hence, diagnoses are often made when tumours are non-palpable and localised to the prostate gland, and ten years or more may pass before the prostate cancer progresses to be clinically symptomatic (Wilt & Partin, 2003). As a result of these advances, men with indolent tumours can be over treated (Bailey & Wallace, 2007; Hegarty et al., 2010). All treatment strategies for localised prostate cancer carry significant risks of adverse effects, such as sexual dysfunction, urinary incontinence and bowel problems (Wilt & Partin, 2003), which can significantly reduce quality of life (Harlan et al., 2003).

In the past, studies and reviews into optimal treatment methods for prostate cancer have focussed on morbidity and survival rates. However, the preferential treatment remains undefined (Namiki & Arai, 2010), and some studies have suggested that survival rates are generally similar across treatment groups, including watchful waiting (Drachenberg, 2000; Wilt et al., 2012). Physical side effects of treatments can have an enduring impact on both physical and psychological wellbeing. As a result, prolonged life expectancy is not the only

consideration when a making a decision about treatment for prostate cancer. Quality of life has also become an important factor in the decision making process (Litwin, Lubeck, Spitalny, Henning & Carroll, 2002; Couper, 2007).

Psychological Consequences of Watchful Waiting as a Treatment Option

The issues above have led physicians and some patients to choose not to aggressively treat the prostate cancer, and instead intermittently observe its progress. The literature has focussed on two primary observation and monitoring protocols for men with prostate cancer: active surveillance and watchful waiting. Active surveillance delays curative treatment (such as radical prostatectomy) until it is warranted based on indicators of disease progression (Weissbach & Altwein, 2009). In comparison, watchful waiting is a conservative management strategy for men who are more likely to die from comorbidities. Palliative treatments (such as hormone therapy) are available, where there is symptomatic disease progression (Parker, 2003; Klotz, 2005). However, historically these terms have often been used inconsistently and interchangeably in the literature without specific definitions (Ganz et al., 2012), confusing the literature on observation (Ip et al., 2011). This review's focus is watchful waiting, whereby the term means regular observations with the provision of palliative treatment if the disease progresses.

The decision to adopt a watchful waiting approach by physicians and patients considers a number of factors, including age, other medical conditions and tumour qualities, and it is considered to be an option for elderly men with less aggressive tumours or patients with limited life-expectancy (Heidenreich et al., 2008). Previously, men chose watchful waiting with the expectation that they would die from causes other than prostate cancer. Now men choose watchful waiting in order to actively evaluate the cancer progression with the knowledge that palliative treatment remains an option (Wallace, Bailey, O'Rourke & Galbraith, 2004).

Whilst watchful waiting allows men the option of monitoring their prostate cancer, with fewer physical side effects from the cancer and aggressive curative treatments, and potentially without a reduced life expectancy, these men live with the knowledge that they have cancer. In light of the current beliefs around cancer (Payer, 1996; Harrington, 2012) and the desire for treatment and cure, how do men who have been offered watchful waiting

manage their psychological wellbeing, and what are the psychological consequences of this treatment option?

Method

Search Strategy

Electronic searches were carried out using PsycINFO, Pubmed, and Web of Knowledge databases, across all years (up to February 2015), to identify relevant material.

The keyword combinations used in the search were:

- "prostate cancer" AND
- "watchful waiting" "expectant management" "conservative management" AND
- "quality of life" "psych*" "anxiety" "depression" "wellbeing"

Studies were included based on inclusion and exclusion criteria:

- Available in English.
- Reported data from men with localised prostate cancer.
- Quantitative studies must include psychological wellbeing measures from one or more of the following categories: quality of life, anxiety, depression, uncertainty, sexual functioning.
- Qualitative studies must include reports of the psychological aspects of watchful waiting.
- Data was reported from patients undertaking watchful waiting treatment for prostate cancer, whereby watchful waiting was defined as a conservative management strategy where the aim was purely palliative.
- Studies reporting a definition of active surveillance (delayed curative treatment) were excluded.

Across the three electronic databases, 675 studies were identified, using searches with combinations of the terms detailed above in the abstract, title or topic. Based on the above inclusion and exclusion criteria, 629 studies were excluded. The remaining 46 studies were assessed using full text for eligibility using the above criteria. Fourteen papers were included in the review (Figure 1).

Insert Figure 1.

Quality Assessment

There is no consensus on the criteria to be used for the critical appraisal of the methodological quality of studies in reviews which include qualitative, quantitative, and mixed methods studies. However, the Mixed Methods Appraisal Tool (MMAT; Pluye, Gagnon, Griffiths & Johnson-Lafleur, 2009; Pluye, 2011) is a recently developed tool that has demonstrated an intra-class correlation of 0.8 based on pilot testing (Pluye et al., 2009). Scores vary from 25% (* - one criterion met), to 100% (**** - all criteria met) (Appendix 1.1). Quality assessment scores using the MMAT were calculated for the 14 studies included in this review and are reported in Table 1. Nine studies met 100% of criteria, four studies met 75% of criteria, and one study met 50% of criteria.

Data extraction and synthesis

Data was extracted from the 12 quantitative studies on the study design, sample characteristics and psychological wellbeing measures. As a result of the variety of measures used, and data collected and reported in the studies, there was no clear way of grouping the studies by design. Instead, all data regarding psychological wellbeing was extracted and grouped into four outcomes relevant for this review: quality of life, anxiety, depression, and sexual problems.

Qualitative data on psychological wellbeing was gained from two studies included in the review. A thematic analysis of the results of the two studies was undertaken. Data from the results sections were coded, and grouped into two themes: “an uncertain treatment decision”, and “coping with uncertainty”.

Results

Study characteristics

Characteristics of the studies are reported in Table 1. The studies were completed between the years of 1999 and 2011.

Participants

Overall, 6403 men diagnosed with prostate cancer with a mean age of 67.7 (calculated from 11 studies reporting mean age) took part in the 14 studies across all treatment groups. The mean age of men undertaking watchful waiting was 70.2 (calculated from ten studies reporting mean age). Six of the 14 studies used age as an exclusion criterion; one study included participants aged under 70, four studies included participants aged under 75, and one study included participants aged under 89.

Nine studies were conducted in the United States, one study in Australia, three in Sweden and Finland, and one in the Netherlands.

Design

Of the twelve quantitative studies, two were randomised control trials, nine were cohort studies, and one study was cross-sectional with a cohort sample subset. Eleven of the quantitative studies made comparisons between treatment groups, whilst one study only followed patients undergoing watchful waiting. Of the two qualitative studies, one used a fundamental qualitative description method and one study used a phenomenologic hermeneutic approach.

Interventions

A number of treatment options for prostate cancer were compared with watchful waiting, including radiation therapies, hormone therapies and surgery.

Measures

Eight studies used the Medical Outcomes Study Short Form-36 (Rand SF-36, also known as the MOS SF-36; Hays, Sherbourne & Mazel, 1993; Ware, Kosinski, Dewey & Gandek, 2000), which is a valid and reliable measure with test-retest reliability and good internal consistency (Ware & Sherbourne, 1992). It measures eight health concepts which can be grouped into physical health and mental health component summaries. The data from the mental health component summary is included in this review, and is defined by questions related to mood and anxiety symptoms.

The University of California at Los Angeles Prostate Cancer Quality of Life Index (UCLA; Litwin et al., 1998) was used by four studies and has six subscales. Two aspects of sexual

problems are assessed; sexual functioning and sexual bother. When validating the UCLA, Litwin et al. (1998) found that although participants often reported that sexual function was poor, they had adjusted to the change and were not particularly bothered. As this review is focussing on the psychological aspects of sexual problems, only the data for sexual bother is reported in this review.

Two studies used a study specific questionnaire (Johansson et al., 2011; Steineck et al., 2002), which included 141 questions exploring psychological symptoms, sense of wellbeing, and quality of life on a seven point visual digital scale, which was validated in an unpublished pilot study. Five measures were used to assess quality of life (Table 2), two measures were used to assess anxiety and depression (Table 4), and four measures were used to assess sexual problems (Table 6).

Insert Table 1.

Quantitative findings

Quality of life

Quality of life was assessed by six studies included in the review, using a range of questionnaires. The findings are reported in Table 2.

Insert Table 2.

Through post hoc analysis, Galbraith, Ramirez & Pedro (2001) found that at 12 months, men undergoing watchful waiting reported lower health related quality of life than those undergoing mixed beam ($p=0.02$) or proton beam radiation ($p=0.05$). By 18 months watchful waiting participant's scores had improved and there was no longer a significant difference between watchful waiting participants and other treatment groups.

Johansson et al. (2011) found high self-assessed quality of life reported at a median of 4.1 years by 69% and at a median of 12.2 years by 24% in the watchful waiting group, and by 70% and 36% in the radical prostatectomy group respectively. Data analysed longitudinally found a reduction in quality of life reported by 64% of men in the watchful waiting group and

61% of the radical prostatectomy group ($p<0.0001$ for both groups for difference between first and second follow up).

Four studies, reported no differences in overall quality of life scores for men undertaking watchful waiting (Katz & Rodriguez, 2007; Mols et al., 2006; Siston et al., 2003; Steineck et al., 2002). Mols et al. (2006) however found that men in watchful waiting, radiotherapy and hormone therapy scored significantly worse ($P<0.001$) on the physical subscale compared with patients in the radical prostatectomy group. Patients in the watchful waiting group scored significantly better on the psychological subscale than patients who received curative treatment ($P<0.05$). However, there were no significant differences between groups on the total quality of life scores.

Anxiety and depression

Anxiety and depression was assessed by nine studies included in the review. Six studies used the SF-36, and three studies utilised other measures. One study used both the SF-36 and another measure.

SF-36

The findings over time are reported for the mental health component of the SF-36 in Table 3.

Insert Table 3.

The majority of studies did not report any significant differences on the SF-36 over time and between treatment groups (Arredondo et al., 2004; Bacon, Giovannucci, Testa & Kawachi, 2001; Couper et al., 2009; Litwin et al., 2002; Mols et al., 2006). One study (Galbraith, Ramirez & Pedro, 2001) found watchful waiting participants scored significantly lower on the mental health component summary score compared to men in other treatment groups. Watchful waiting participants had lower scores in mental health when compared to proton beam radiation ($p=0.03$) and mixed beam radiation ($p=0.07$) at one year. However, there was no significant decrease in scores in the watchful waiting group over time. By 18 months the watchful waiting participants' scores had increased and there was no longer a difference between watchful waiting and other treatment groups.

Other anxiety and depression measures

Anxiety and depression was assessed using different measures by three studies included in the review, as shown in Table 4.

Insert Table 4.

When assessing levels of anxiety, Couper et al. (2009) found that men in the watchful waiting group had significantly better scores than men in hormone therapy at follow-up ($P<0.05$). When assessing depression, men in the watchful waiting group scored significantly better in comparison to the hormone therapy group at one to two year follow up ($P<0.05$).

Steineck et al. (2002) used a number of questionnaires to measure aspects of anxiety and depression. There were no significant differences between groups, apart from men in the radical prostatectomy group whose scores were slightly lower. Continuing from Steineck et al.'s (2002) analysis of the SPCG-4 data, Johansson et al. (2011) found when comparing anxiety symptoms between watchful waiting participants and a control group, a significant result was found (relative risk=1.42; 95% confidence interval, 1.07-1.88). Depressed mood was reported by similar proportions of men in all groups.

Sexual bother

Sexual problems in men in the watchful waiting group were assessed by eight studies. Four studies used the UCLA, and five studies used other measures. One of these studies used both the UCLA and another measure.

UCLA

Sexual bother from the UCLA over time is reported in Table 5.

Insert Table 5.

Bacon et al. (2001) found sexual bother scores were significantly better for watchful waiting patients compared with radical prostatectomy ($p<0.05$). Similarly, Penson et al. (2003) found at two year follow up, men in the watchful waiting group reported less sexual bother than other treatment groups, although this was a non-significant difference.

In contrast, non-significant decreases in scores were found by two studies. Arredondo et al. (2004) found a clear age effect and larger time trend for the watchful waiting participants when considering both sexual bother, meaning that the decrease after diagnosis was greater than expected from ageing alone. They also reported that the decrease in bother appeared to be slightly steeper in the first two years compared with subsequent years. Lubeck et al. (1999) reported no significant differences in scores in the watchful waiting participants over time, however there was a non-significant decrease in scores between year one and year two.

Other sexual problem measures

Four other measures of sexual problems were utilised by five studies. Often there were multiple questions related to sexual problems, therefore results associated to distress related to sexual problems are reported in Table 6.

Insert Table 6.

Bacon et al. (2001) found statistically significantly better scores ($p<0.05$) for watchful waiting participants when compared to radical prostatectomy patients at one to two years. Furthermore, Galbraith, Ramirez & Pedro (2001) found at six months, surgery patients reported more sexual symptoms than the men in watchful waiting ($p=0.004$). For watchful waiting patients, scores remained similar over the 18 month period.

At one to two years, Steineck et al. (2002) found that the men in the watchful waiting group reported significantly less moderate or great distress compared to men in the radical prostatectomy group (relative risk 1.4; 95% confidence interval, 1.1-1.8). A median of 12.2 years later, Johansson et al. (2011) found no significant differences between groups.

Qualitative Findings

The qualitative studies (Bailey, Wallace & Mishel, 2007; Hedestig, Sandman & Widmark, 2003) identified the experiences and meaning of being a patient with prostate cancer undergoing watchful waiting. Thematic analysis of both studies revealed two themes.

Theme 1: An uncertain treatment decision

The decision making process around whether or not to undertake watchful waiting was characterised by uncertainty and worry. Men questioned whether or not to request a second

opinion after watchful waiting was recommended, worrying that this would add to their conflict about their decision. Some men also spoke about gathering further information that would help reduce their conflict around the choice, whereas other men chose not to be informed and allow other people to make the decision for them.

The decision to undertake watchful waiting was followed by an "emotional aftermath", characterised by uncertainty, fear and worry. Men described living with a constant threat, being uncertain about whether the disease would shorten their lives, with the knowledge that it could "strike" at any time. Many men who had no physical discomfort reported that they found it difficult to believe the cancer existed. Lack of symptoms also meant that there were very few bodily signals to help monitor progression of the disease. Without markers to indicate disease progression, some men went on to attribute usual physical changes to disease progression.

Theme 2: Coping with uncertainty

The men spoke about a number of ways in which they coped and adjusted to living with an uncertain decision choice with an uncertain future. Men made various lifestyle changes, including increasing their social activities, throwing themselves into work or focussing on self-care. Some men tried to deny the cancer by trying to set the threat aside, whilst other men attempted to redefine or minimise the threat. A number of reasons were developed by the men to support their treatment choice, such as being healthy all their lives, infrequently relying on doctors in the past, other treatment options having poor outcomes and fears that aggressive surgery could seriously affect their lives. Men in both studies highlighted the importance of a trusting relationship with their physicians, which allowed them to feel safe, secure and confident in their treatment decision.

Summary of Results

In the 12 quantitative studies included within the review, watchful waiting was occasionally found to significantly lower men's quality of life, and significantly worsen feelings of anxiety and depression, both over time and compared to other treatment groups. However, men in watchful waiting were often reported to have similar or better scores on sexual problem measures compared to other treatment groups. Additionally, improvements in anxiety and depression scores were found when men in the watchful waiting group were compared to men in the hormone therapy treatment group. Longitudinally, only one study (Johansson et

al., 2011) found a significant decrease in scores; a reduction in quality of life scores over time and poorer anxiety scores compared to men in the population based control group. Thematic analysis of two qualitative studies suggested that uncertainty played a key role in the treatment decision making process, how the future was viewed and led men to different coping strategies. Therefore, it is proposed that men initially experience uncertainty around the treatment decision, which negatively impacts on their wellbeing. However, over time, men appear to adjust to living with uncertainty, employing a number of coping strategies which means they have generally similar outcomes to men in other treatment groups.

Conclusion

The 14 studies included in the review suggest that watchful waiting may affect certain aspects of psychological wellbeing, although data is mixed.

The majority of studies found no significant differences between quality of life in men undergoing watchful waiting compared to men in other treatment groups (Katz & Rodriguez, 2007; Mols et al., 2006; Siston et al., 2003; Steineck et al., 2002). In contrast, Galbraith et al. (2001) found reductions in aspects of quality of life in men undergoing watchful waiting both compared to men in other treatment groups, and over time. Longitudinally, reduction in quality of life was found in men undergoing watchful waiting, although this was similar to men undergoing radical prostatectomy (Johansson et al., 2011).

Two studies reported a statistically significant worsening in anxiety and depression scores for men in the watchful waiting group when compared with other treatment groups, however no significant changes were found when watchful waiting scores were compared over time. These were found at up to one year (Galbraith, Ramirez & Pedro, 2001) and at a median of 12.2 years (Johansson et al., 2011). Conversely, significantly better scores were found at two time points (at diagnosis and approximately one year later) when men undertaking watchful waiting were compared to men on hormone therapy (Couper et al., 2009).

Two studies found significantly improved sexual bother scores, between one to two years, when men in the watchful waiting group were compared to men in other treatment groups (Bacon et al, 2001; Steineck et al, 2002). No significant deteriorations in sexual bother or distress were found over time for men undertaking watchful waiting (Arredondo et al., 2004; Johansson et al., 2011; Lubeck et al., 1999; Penson et al., 2003; Siston et al., 2003).

The results from the qualitative studies suggest that men undertaking watchful waiting experience levels of uncertainty that permeate into many aspects of their lives (Bailey et al., 2007; Hedestig et al., 2003). This was evident in both the decision making process, and when the decision had been made. Men, who had made the decision to undertake watchful waiting as their treatment option, reported living every day with the knowledge that they had cancer in their body. Lack of symptoms meant that men found it difficult to monitor their own disease progression and as a result often misattributed physical changes, leading men to employ a number of coping strategies to manage the uncertainty around both the treatment decision they had made, and the uncertain future they faced in terms of disease progression. The physician appeared to play a key role in helping the men trust and come to terms with the decision.

Uncertainty has been shown to be a major stressor for patients coping with life threatening diseases and can affect quality of life (Padilla, Mishel & Grant, 1992). The mixed evidence as to the psychological effects of watchful waiting on men with prostate cancer might be explained in part by the uncertainty that appears to play a role in both the decision making process, and the ongoing experience of living with this option (Bailey et al., 2007; Hedestig et al., 2003). The 'uncertainty in illness model' (Mishel, 1988) has been proposed as a framework for viewing watchful waiting (Wallace, 2003). The uncertainty when diagnosed with a life threatening illness, regarding progression of symptoms and disease, can lead to uncertainty about wider life issues and ability to achieve valued goals. However, patients may then use the uncertainty to reorganise and recreate their life view. Wallace (2003) used this framework for understanding the impact of being diagnosed with prostate cancer, finding that as uncertainty and the perception of danger increased, quality of life decreased. A significant amount of variance (60%) in quality of life in their sample was explained by the combination of both uncertainty and danger perception.

With this in mind, it is possible that the variability in results on psychological wellbeing reported in this review may be accounted for, to some extent, by the differences in levels of uncertainty and danger perception experienced by the men. The qualitative research suggested a number of factors that affect feelings of uncertainty, specifically around questioning whether they had made the right treatment choice (Bailey et al., 2007; Hedestig et al., 2003). Indeed, choosing watchful waiting appeared initially more likely to negatively impact on psychological wellbeing, which might be the result of uncertainty around not

receiving an active treatment. However, as men adjusted to watchful waiting over time, their psychological outcomes became generally similar to men in other treatment groups.

Interestingly, Katz and Rodriquez (2007) proposed that no adverse effects of watchful waiting on quality of life were found in their study as patients were told during the educational process that watchful waiting was as acceptable a choice as the curative treatments offered. In addition, based on Mishel's (1988) 'uncertainty in illness model', Bailey, Mishel, Belyea, Stewart & Mohler (2004) conducted an intervention study with men undertaking watchful waiting for prostate cancer and found that men who received the treatment came to see their lives in a new light, had a reduction in depressive symptoms, and reported increased quality of life.

This review does however have several limitations. There is a high degree of heterogeneity in regards to study design, measures and data collected, which complicated the comparison and synthesis of study results, prohibiting a formal meta-analysis. Indeed, a recent Cochrane review (Hegarty et al., 2010) found just two randomised control trials comparing watchful waiting and radical prostatectomy, one of which was judged to be of poor quality. The quality assessment found 13 of the studies were of good quality (ranging from 75% to 100% criteria met) and one study was of medium quality (50% criteria met). Just two of these studies were qualitative, meaning the thematic analysis was limited.

More consistent research is required within this field, with agreed measures and design, including lengthy follow-up. Further data will firm up the evidence, so that men with prostate cancer can be better informed about their options. A lack of narrative views of the men actually undertaking watchful waiting must be addressed by future research. This would allow a greater understanding of the psychological impact of watchful waiting, and different coping strategies men employ to come to terms with their decision and an uncertain future. Whilst one promising interventional study has already been conducted (Bailey et al., 2004), further evidence is required to validate this finding and other intervention options should also be explored. The qualitative research suggested that men appreciated speaking to other men undertaking watchful waiting and often managed uncertainty through gathering information, which could indicate that a psycho-educational group might be helpful, and a potential direction for future research.

When physicians are aware of the psychological impact of watchful waiting they will be better able to advise, educate and support men considering watchful waiting as a treatment option for prostate cancer. The relationship between the men undertaking watchful waiting and their physician has been shown in the qualitative research to be very important in feeling safe and secure in the treatment decision making process. As a result, physicians must be well informed regarding the psychological, as well as the physical, effects of the different treatment options to maintain the men's trust which will ultimately help the men manage and cope with uncertainty. Accurate information should be conveyed around the likely trajectory of psychological symptoms such as anxiety and depression, so that men can make an informed decision based on both survival rates and future quality of life.

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Figure 1: **Diagram to illustrate study selection**

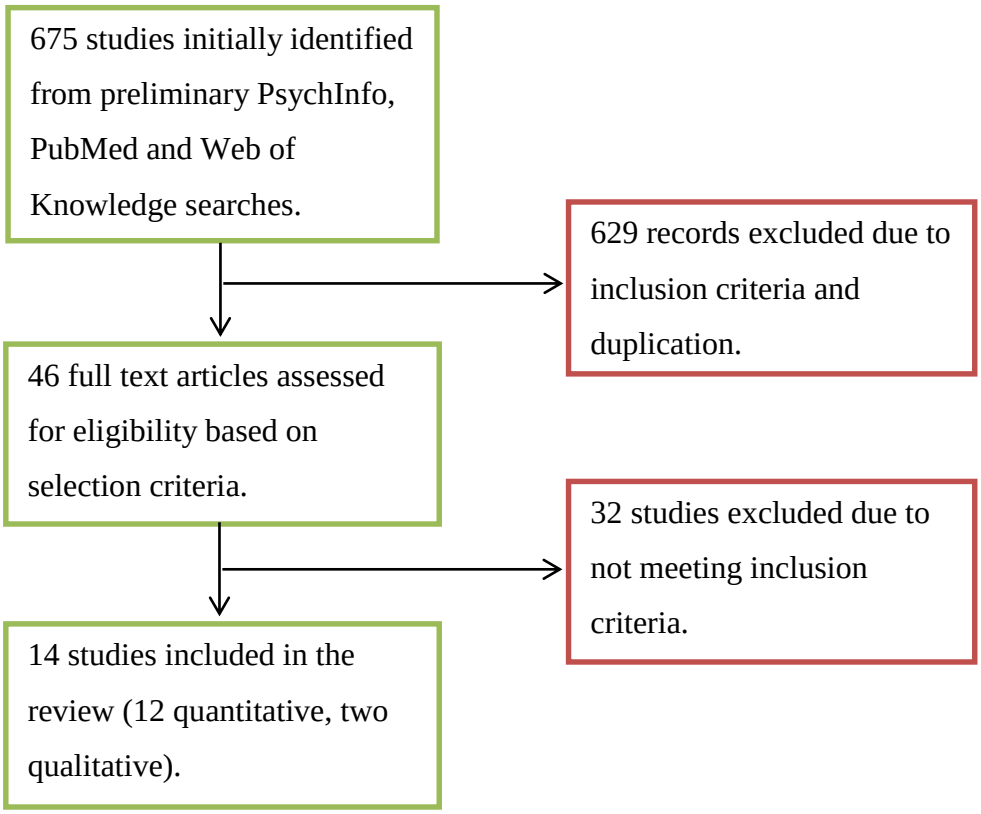

Table 1: ***Findings of the included studies***

Study	Quality Rating	Design	Questionnaires/ Measures Included in the Review	Sample Characteristics N=number of participants (mean age)	Major findings
Quantitative					
Arredondo et al. (2004)	***	• Participants drawn from CaPSURE database. • Men completed between one and 16 questionnaires over a five year period.	• SF-36 • UCLA	• WW – N=310 (74.7)	• Significant deterioration in seven domains of the SF-36 and four of the UCLA scales. • However mental health and mental component summary scores showed no difference over time.
Bacon et al. (2001)	****	• Participants from the Health Professionals Follow-up Study (ongoing cohort study). • Cross sectional analysis. • Included a subgroup	• SF-36 • UCLA • Cancer Rehabilitation Evaluation System Short Form	• WW – n=31 (75) • RP – n=421 (68) • ER – n=221 (75) • B – n=69 (71) • HT – n=33 (78) • Other – n=67 (76)	• WW, ER and HT groups had lower HRQoL scores in multiple domains compared to RP patients. • WW patients had significantly better scores, on sexual problems, marital interaction, and cancer specific HRQoL compared to other groups. • No significant differences over time

		who were followed prospectively.			on mental health domains.
Couper et al. (2009)	***	• Participants were consecutive attendees at participating clinics in public hospitals (2001-2005). • Completed self-report questionnaires before or soon after initiating treatment (T1), and again 12 months later (T2).	• Brief Symptom Inventory • SF-36	• WW – T1 n=61, T2 n=55 • RP – T1 n=38, T2 n=33 • HT – T1 n=56, T2 n=51 • OET – T1 n=38, T2 n=33	• At T1, the three active treatment groups all reported greater dysfunction compared with the WW group. • At T2, the RP and OET groups did not differ from the WW group on either HRQoL or psychological status. The HT group reported significantly worse HRQoL and greater psychological distress compared with the WW group.
Galbraith et al. (2001)	****	• Men were enrolled in the study at initiation of treatment. • Questionnaires were completed at enrolment and at six, 12 and 18 months.	• Quality of Life Index • Southwest Oncology Group Prostate Treatment Specific Symptoms Measure – treatment related symptoms	• WW – n=30 (73) • S – n=59 (65) • CR – n=25 (71) • PB – n=24 (68) • MB – n=47 (69)	• At 12 months MB and PB men reported significantly better HRQoL than WW men. • Men in WW reported poorer health status throughout the study in physical, emotional, mental and overall general health.
Johansson et al. (2011)	****	• Part of SPCG-4 trial. • Cross sectional data	• Study specific questionnaire.	• WW – n=167 • RP – n=182	• High self-assessed quality of life was reported at four years by 69% and at

		analysed at a median of 4.1 years and 12.2 years after randomisation. • Longitudinal analysis conducted for data available at two time points, with a median of 3.7 years and 13.4 years after randomisation.		• Population based control – T2 n=208 Longitudinal analysis • WW – n=81 • RP – n=85	12 years 24% in the WW group, and by 70% and 36% in the RP group. • A reduction in quality of life during longitudinal follow-up was reported by similar numbers of men in WW and RP.
Katz & Rodriguez (2007)	**	• Questionnaire administered after diagnosis but before treatment, and re-administered at follow-up one to two years later.	• A modified American Urological Association Symptom Score.	• WW – n=20 (68.2) • CT – n=41 (64.6)	• WW patients maintained their HRQoL and was similar to those undergoing CT.
Litwin et al. (2002)	****	• Participants drawn from CaPSURE database. • Questionnaires were	• SF-36	• WW – n=66 (71.3) • RP – n=282 (62.1) • PI – n=104 (70.8)	• Gaps between mental health scores grew wider among the treatment groups over time, with PI patients performing the best, RP patients

		completed at least twice by each participant during the two year follow up period.			performing the worst, and WW patients falling in between.
Lubeck et al. (1999)	***	• Participants drawn from CaPSURE database. • Questionnaires completed at study entry and quarterly thereafter through to two years.	• SF-36 • UCLA	• WW/Observation (term used interchangeably) – n=87 (72.1) • RP – n=351 (62.0) • R – n=75 (70.2) • HT – n=179 (72.4)	• Men in WW had poorer HRQoL in the first year. • However, improvements in these scores during the first year were also observed.
Mols et al. (2006)	****	• The population based Eindhoven Cancer Registry was used to select men who had been diagnosed with prostate cancer. • Questionnaires were sent five to ten years post diagnosis.	• SF-36 • Quality of Life-Cancer Survivors Questionnaire	• WW – n=56 • RP – n=193 • R – n=263 • HT – n=60	• Patients who underwent RP had the best physical HRQoL, followed by patients who received WW and finally patients who received R.

Penson et al. (2003)	****	• Part of SEER programme. • Completed baseline questionnaires six to 12 months after diagnosis, and at two years.	• SF-36 • UCLA	• WW – n=379 • RP – n=1070 • R – n=533 • HT – n=324	• No statistically significant differences in general HRQoL outcomes between the treatment groups.
Siston et al. (2003)	****	• Recruited from Veterans Affairs populations. • Questionnaires given before initiating treatment, and again at three and 12 months.	• European Organization for Research and Treatment of Cancer Quality of Life Questionnaire.	• WW – n=39 • RP – n=29 • R – n=30	• Patients undergoing WW reported more sexual functioning problems pre-treatment than the rest of the study sample. • No significant changes over time in psychological items.
Steineck et al. (2002)	****	• Part of SPCG-4 trial. • Follow-up study • Data collected at least 12 months after surgery and 14 months after randomisation.	• Study specific questionnaire. • Spielberger's Trait measure from the State-Trait Anxiety Inventory. • Centre for Epidemiological	• WW – n=160 • RP – n=166	• No difference between the two groups on the nine psychological variables. • Low or moderate psychological wellbeing and subjective quality of life was reported by similar numbers of WW and RP men.

			Studies measure of Depression.		
Qualitative					
Bailey et al. (2007)	***	• Interviewed men undertaking watchful waiting less than 12 months after diagnosis. • The results were analysed using the Mishel's Reconceptualised Uncertainty in Illness model.	-	• N=10	• Domains of uncertainty, appraisal of danger and appraisal of opportunity were identified and discussed.
Hedestig et al. (2003)	****	• The text was analysed using a phenomenologic hermeneutic approach.	-	• N=7	• Men described living with a constant threat, whilst being uncertain about the effects of the disease the length of their life. • They believed that the disease had changed their lives, and their manhood was restricted by sexual dysfunctions and described as a

	burden.

Scores vary from ** (50%) – two criteria met, to **** (100%) – all criteria met.

HRQoL–Health related quality of life; CaPSURE–Cancer of the Prostate Strategic Urologic Research Endeavour; SEER–National Cancer Institute's Surveillance, Epidemiology and End Results registries; SPCG-4–Scandinavian Prostate Cancer Group Study Number 4

T1-Time 1; T2-Time 2

Measures: SF-36–Medical Outcomes Study Short Form-36; UCLA–University of California at Los Angeles Prostate Cancer Quality of Life Index

Treatment groups: B–Brachytherapy; CR–Conventional Radiation; CT–Curative therapy; ER–External Radiation; HT–Hormone therapy; MB–Mixed beam radiation; OET–other early treatment; PB–Proton beam radiation; PI–Pelvic Irradiation; R–Radiotherapy; RP–Radical prostatectomy; S–Surgery; WW–Watchful waiting

Key for Tables 2, 3, 4, 5 and 6

✓ *– data collected during this time point*
Red – significantly poorer scores in comparison with other treatment groups/significant deterioration in scores over time. *Yellow – no significant difference between groups/no significant changes over time.* *Green – significantly better scores in comparison with other groups/significant improvement in scores over time.*
B–Brachytherapy; CR–Conventional Radiation; CT–Curative therapy; ER–External Radiation; HT–Hormone therapy; MB–Mixed beam radiation; OET–other early treatment; PB–Proton beam radiation; PI–Pelvic Irradiation; R–Radiotherapy; RP–Radical prostatectomy; S–Surgery; WW–Watchful waiting

Table 2: ***Quality of life over time***

Study	Questionnaire	Comparison group	Pre-treatment/ at diagnosis	Up to 1 year	1 to 2 years	3 to 5 years	5 to 10 years	7 to 17 years
Galbraith et al. (2001)	Quality of Life Index	WW compared with S, CR, PB, MB	✓	✓ WW scores poorer than MB & PB	✓			
		WW over time	✓	✓	✓			
Johansson et al. (2011)	Study specific	WW compared with RP				✓		✓
		WW over time				✓		✓ WW scores deteriorated
Katz & Rodriguez (2007)	Modified American Urological Association Symptom Score	WW compared with CT			✓			
		WW over time			✓			
Mols et al.	Quality of Life-	WW					✓	

(2006)	Cancer Survivors Questionnaire	compared with RP, R, HT						
Siston et al. (2003)	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire.	WW compared with RP, R	✓	✓	✓			
		WW over time	✓	✓	✓			
Steineck et al. (2002)	Study specific	WW compared with RP			✓			

Table 3: ***Mental health component of SF-36 over time***

Study	Comparison group	Pre-treatment/at diagnosis	Up to 1 year	1 to 2 years	5 to 10 years
Arredondo et al. (2004)	WW over time	✓	✓	✓	✓
Bacon et al. (2001)	WW compared with RP	✓		✓	
	WW over time	✓		✓	
Couper et al. (2009)	WW compared with RP, HT, OET	✓ WW scores better than HT		✓	
	WW over time	✓		✓	
Galbraith et al. (2001)	WW compared with S, CR, PB, MB	✓	✓ WW scores poorer than MB & PB	✓	
	WW over	✓	✓	✓	

	time				
Litwin et al. (2002)	WW compared with RP, PI	✓	✓	✓	
	WW over time	✓	✓	✓	
Mols et al. (2006)	WW compared with RP, R, HT				✓

Table 4: ***Anxiety and depression scale scores over time***

Study	Questionnaire	Subscale	Comparison group	Pre-treatment/at diagnosis	1 to 2 years	7 to 17 years
Couper et al. (2009)	Brief Symptom Inventory	Anxiety	WW compared to RP, HT, OET	✓	✓ WW scores better than HT	
			WW over time	✓	✓	
		Depression	WW compared to RP, HT, OET	✓ WW scores better than HT	✓ WW scores better than HT	
			WW over time	✓	✓	
Johansson et al. (2011)	Study specific	Anxiety	WW compared to RP, C			✓ WW scores poorer than C
		Depression	WW compared to RP, C			✓

Steineck et al. (2002)	Study specific	Anxiety	WW compared with RP	✓	
		Depression	WW compared with RP	✓	

Table 5: ***Sexual bother measured by UCLA over time***

	Comparison group	**Pre-treatment/at diagnosis**	**Up to 1 year**	**1 to 2 years**	**5 to 10 years**
Arredondo et al. (2004)	WW over time	✓	✓	✓	✓
Bacon et al. (2001)	WW compared with RP			✓ WW scores better than RP	
Lubeck et al. (1999)	WW over time	✓	✓	✓	
Penson et al. (2003)	WW compared with RP, R, HT			✓	

Table 6: ***Sexual problems scores over time***

	Questionnaire	Comparison group	Pre-treatment/at diagnosis	Up to 1 year	1 to 2 years	7 to 17 years
Bacon et al. (2001)	Cancer Rehabilitation Evaluation System Short Form	WW compared with RP			✓ WW scores better than RP	
Galbraith et al. (2001)	Southwest Oncology Group Prostate Treatment	WW compared with S, CR, PB, MB	✓	✓ WW scores better than S	✓	
	Specific Symptoms Measure	WW over time	✓	✓	✓	
Johansson et al. (2011)	Study specific	WW compared with RP, C				✓
Siston et al. (2003)	European Organization for Research	WW compared with RP, R	✓	✓	✓	

	and Treatment of Cancer Quality of Life Questionnaire.	WW over time	✓	✓	✓	
Steineck et al. (2002)	Study specific	WW compared with RP			✓ WW scores better than RP	

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Knowingly Not Wanting to Know:
Discourses of People Diagnosed with Mild Cognitive Impairment

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Abstract

Mild Cognitive Impairment (MCI) is a heterogeneous clinical state whereby assessed cognitive changes over time may progress to dementia, remain stable or revert to back to normal. This study aimed to identify, through discourse analysis, how people with a diagnosis of MCI used language in order to reveal the societal views and shared meanings of the diagnosis, and the positions taken by people. Seven people with MCI were interviewed, and three discourses emerged during analysis. One of the discourses revealed was 'Not Knowing' about MCI. Furthermore, in the absence of a coherent discourse related to MCI, participants went on to position themselves between a more familiar discourse; 'Knowing' about ageing and dying and 'Not Wanting to Know' about dementia. Clinicians must consider how information is presented to people about MCI, including where MCI is positioned in respect to normal ageing and dementia.

Keywords: Ageing, Dementia, Discourse, Mild Cognitive Impairment.

Introduction

People are given a label of Mild Cognitive Impairment (MCI), if they are found to show a mild decline in either single or multiple cognitive domains, such as memory, attention, visuospatial or executive functioning abilities. Their global cognitive abilities remain intact, alongside their ability to undertake activities of daily living, unlike when given a diagnosis of dementia (Gauthier et al., 2006). However, MCI is a label that describes a heterogeneous clinical presentation, and the cognitive changes over time may progress to a dementia, remain stable or improve to a previous state of functioning. The percentage of people who develop a dementia after being given a diagnosis of MCI is thought to vary from 2% to 31% (Bruscoli & Lovestone, 2004).

The term MCI was originally created for research purposes and is relatively unknown to the general public. Therefore, a lack of societal knowledge around MCI may impact on the meaning assigned to it by people (Dale, Hougham, Hill & Sachs, 2006). Limited understanding of a diagnosis can cause uncertainty, and people given the diagnosis of MCI are at risk of either over or under estimating the significance of it (Lingler et al., 2006). Thus far the majority of research into MCI has focussed on characterising the rates, predictors and potential modifiers of progression to specific dementia types (Petersen et al., 2001).

In order to improve understanding of the effects of being given a diagnosis of MCI, research is beginning to focus on the narrative accounts of these individuals. Primarily negative emotions have been associated with being given a diagnosis of MCI, including sadness, frustration, reduction in self-confidence and embarrassment, whilst people have also expressed uncertainty around the nature of the diagnosis (Joosten-Weyn Banningh, Vernooij-Dassen, Rikkert & Teunisse, 2008; Lingler et al., 2006; Roberts & Clare, 2013). Furthermore, a number of the qualitative studies have found that people with MCI are likely to attribute their problems to various causes, such as normal ageing, approaching dementia or somatic causes (Beard & Neary, 2013; Berg, Wallin, Nordlund & Johansson, 2012; Corner & Bond, 2006; Joosten-Weyn Banningh et al., 2008; Lingler et al., 2006). As a result, various coping strategies have been employed by people with MCI, with conflicting evidence as to whether problem and emotion focussed coping strategies are used more often than dysfunctional coping strategies (McIlavane, Popa, Robinson, Houseweart & Haley, 2008; Roberts & Clare, 2013).

The exploration of the narrative accounts of individuals with a diagnosis of MCI has so far primarily focussed on the lived experience of MCI, which has increased understanding of the diagnosis at an individual and personal level. However, with limited knowledge about MCI in the public domain, there has been little focus on how this diagnosis is constructed at a societal and communal level, despite the social consequences and implications of predicting a possible diagnosis of dementia, potentially a long time before functional symptoms are experienced. Given that a diagnosis of any 'memory problem' can create social problems for affected individuals, making sense of and understanding the MCI illness identity is of great social significance (Beard & Neary, 2013).

Through interviewing people with a diagnosis of MCI, this study aims to identify how people draw on societal shared meanings of MCI, as expressed in their use of language, thus increasing the understanding of how they position themselves in respect to their previously reported attributions of the diagnosis to aspects like dementia and ageing. Understanding the different discourses that people with MCI draw on and move between, might shape the understanding of how they construct the diagnosis.

Conceptual Background

A discourse is the narrative of a phenomenon as it has become shaped through shared meanings, norms and values, personal and group identities and negotiated interactions (Harper, 2012). Discourse analysis attempts to understand how people use language to construct versions of the social world (Burck, 2005). It does not aim to capture participants' authentic meanings, intentions or experiences, but rather analyses language as social text, whereby in different speech situations and social contexts the individual draws upon a variety of linguistic resources (Potter & Wetherell, 1987; Talja, 1999). Language is considered a means of constructing, rather than mirroring, reality (Harper & Thompson, 2011).

When language is studied for its discourses, it is studied for its functions, both intended and unintended (Wetherell & Potter, 1988). Language reflects a form of social action whereby involvement in social interactions is managed by people through discursive activities, such as to justify, categorise, rationalise, explain, attribute, name and blame. In addition, people can use language to position themselves in a variety of ways. Different positions entail different degrees of accountability and can have a variety of functions, such as to distance

the speaker or to authoritatively endow what is being said (Harper & Thompson, 2011). All of these functions of language are used by people within particular contexts to achieve social and interpersonal objectives (Willig, 2013).

Method

Participants

Seven people participated in the study. All were British, Caucasian and English was their first language. Just one participant spoke Welsh as a second language. Demographic data were recorded (Table 1; Appendix 2.1).

Table 1: ***Demographic details of participants***

Participant*	Age	Marital status	Highest level of education
Gwen	78	Married	Secondary school
Clive	76	Married	College
Andrew	79	Married	College
Jack	72	Married	Secondary school
Margaret	77	Married	University
Simon	61	Married	College
William	60	Divorced	College

*All participants' details and accounts are presented under a pseudonym and any identifying details have been removed, anonymised or generalised in order to preserve confidentiality.

Procedure

Bangor University School of Psychology, and NHS Research Ethics Committee and Research and Development approval was sought and granted. Clinicians from memory clinics across North Wales, where people are diagnosed with MCI, identified potential participants who fitted the inclusion and exclusion criteria (Appendix 2.2):

- A diagnosis of MCI which has been confirmed by the Memory Clinic multi-disciplinary team,
- The ability to fluently communicate verbally in English,

- The ability to give informed consent to take part in the study,
- Aged 55 or over.
- No co-morbid diagnosis (including a mental health diagnosis or physical health diagnosis),
- No language difficulties (such as aphasia).

In order to maintain confidentiality, clinicians initially contacted the potential participant to gain consent to send out a participant information pack (Appendix 2.3) with further details of the study and an invitation to contact the first author for further information. If they were interested, the potential participant sent a reply slip to the first author with their contact details. Before initiating the interview, informed consent was gained (Appendix 2.4).

The first author conducted all interviews, either at the participant's home or at the participant's local NHS memory clinic. An outline schedule (Appendix 2.5) was developed based on existing literature, with questions moving from externalising, to establish the participants' knowledge and understanding of the MCI term, to personalising, to determine personal meaning and the development of their ideas, and specifying, to explore the perceived advantages and disadvantages of the diagnosis. Further prompting occurred in an exploitative manner in order to encourage participants to elaborate on their views in a reasonably naturalistic conversation (Potter & Wetherell, 1987). Interviews lasted between 44 and 52 minutes. Participants were given an information sheet at the end which detailed sources of support, should they need it (Appendix 2.6). The consent form and all information sheets were provided in both English and Welsh.

Data Analysis

Interviews were transcribed by the first author and checked for accuracy. Vocal tones, pauses and hesitations were later included:

Bold: said with emphasis/louder voice. *Italics*: said softer/quieter/under breath.
!: vocal intonation became higher.
(.) noticeable breathing space, (..) 3-5 second pause, (…) more than 5 second pause.

There is no widely agreed method for discourse analysis, however the analysis in this study was based on Potter and Wetherall's (1987) procedures. The data was first thematically

coded to help "squeeze an unwieldy body of discourse into manageable chunks" (Potter & Wetherall, 1987, p.167). At this stage, coding of the analysis had a pragmatic intent, rather than analytic. The purpose was to organise data into broad themes to produce sets of instances of occurrence that could later be analysed. The following initial themes emerged from the data based on recurring words, phrases and ideas: ageing, death/dying, dementia, expertise, hierarchy of illness and MCI. This formed a basis for the more detailed discourse analysis, where further close reading of coded data sets took place.

The analysis of the data focussed on the variation and similarities across the data sets. Following Potter and Wetherell (1987), data was examined with two questions in mind: "Why am I reading the passage in this way? What features produce this reading?" (p.168). Attention was paid as to how certain phrases or terms were used, the context of and reason for their use, the intended or unintended function or purpose of their use, and how language influenced positioning of the participant (Appendix 2.7: Sample interview transcript and analysis).

Findings

Three discourses emerged during the analysis of the interview material. The first discourse revealed was participants 'Not Knowing' about MCI. As a result, participants drew on and moved between two other, more familiar discourses; 'Knowing' about ageing and dying, and 'Not Wanting to Know' about dementia (Appendix 2.8: Further transcript examples illustrating the discourses).

Not Knowing

When participants were invited to describe MCI, their speech was characterised by pauses, hesitations, repetitions and changes in tone.

> Margaret: (.) *I think* (.) it's ur (.) the way it's affected me is that (.) I'm not remembering, facts from (.) from the present.
> Clive: I don't really know, but I know it's to do with my, memory loss, short memory, short term memory loss.

These features of the participant's speech caused the content to feel disjointed. Margaret paused frequently, which suggested an underlying uncertainty about what to say and how to say it, whilst speaking the occasional word quietly appeared to reflect an uncertainty about what MCI meant. In contrast, Clive was more fluent when he described MCI but he repeated certain words, as if he wanted to ensure that he got the phrasing correct. The repetition appeared to show how unfamiliar he seemed to be with the wording. Similarly, the term "mild cognitive impairment" was infrequently used by participants, and when it was used, it was with hesitation and uncertainty.

> Simon: …And all this, all this (.) mild cognitive, you know disorder…

More often, participants used different terms to explain their difficulties, such as "stroke" (Gwen) and "bang on me head" (Simon), which has previously been reflected in the narrative accounts of people with a MCI diagnosis (Lingler et al., 2006; Roberts & Clare, 2013). Lack of use of the MCI term could suggest that people with the diagnosis were not able to draw on a particular discourse related to MCI, either because they were not familiar with it, or there was no coherent discourse available.

This lack of knowledge and lack of discourse about MCI appeared to be related to whether they had spoken about MCI with family or friends. When asked about this, the participants appeared to disengage from the conversation, replying with short answers. The majority of participants reported that they had not spoken about the MCI diagnosis with their family or friends in any detail, almost dismissing it.

> Simon: Don't bother really. [No] No.

If the participants had shared the MCI diagnosis, it was only briefly touched upon, as participants suggested that they and other people had "other interesting things to talk about" (Margaret). MCI had been constructed by the participants as a diagnosis which appeared to be of little interest to them and others, and thus appeared to have been given little space in their lives or within their social identity. In contrast, one participant, William, had shared the MCI diagnosis with his friends and explained to them that it was affecting his memory.

> William: All my friends know about it. [Right] They all make allowances for me, they're very good like that.

"All" of William's friends knew about the MCI diagnosis, although he did not give "it" a name. However, the use of "they" versus "me" suggested a sense of being separate and different from his group of friends. His friends now "make allowances" for him, implying that he was treated differently by his peers, who might now see him as 'damaged goods'. He accepted this and appeared to view this positively, rather than being resistant to the allowances made, stating that his friends were "good like that". William echoed a societal view and discourse that making "allowances" for people who were cognitive impaired or disabled was a 'social good', something that ought to be done and is viewed as socially desirable and positive. The phrasing William used suggested that the diagnosis meant impairment and had not only changed how he viewed himself, but also how he was viewed by his friends.

The participants' lack of knowledge about MCI often caused them to query who the experts were – who had the knowledge about MCI? The participants put many people in the position of expert throughout the interviews, including the interviewer.

> Clive: … And then I found out really what, what I've got and what that means, I think.
> Interviewer: And what do you think that that means?
> Clive: It means I'm struggling with memory. [Yeah] I think that's what it does mean, doesn't it? [Yeah] Or is it something more complicated?

Clive initially took a hesitant expert role, indicating that he knew what the MCI diagnosis meant. When asked further about this by the interviewer, he began to answer with certainty and without hesitation. However, he then became quickly less certain, and put the interviewer in the position of expert by asking the interviewer a question. The participants looked towards other people, including physicians, in perceived 'expert' roles. However, they responded with an intuitive knowledge about what was wrong with them, in an attempt to strongly reaffirm their own expert status.

> Jack: And the diagnosis was just a confirmation of what I already suspected.
> Margaret: Well in a sense it was a bit of a relief cos I already knew that it was that I was suffering from it.

Jack and Margaret suggested that they knew that something was different and something had changed, even though they were not able to specify what "it" was or use the MCI terminology. This was said with certainty, without pause or hesitation, and was reflected by many of the other participants. Despite the participant's uncertainty and lack of knowledge about MCI, they viewed themselves as the expert when monitoring their own cognitive changes.

Participants held no coherent discourse around MCI. In this seemingly confused position, participants began to turn to other discourses in order to assist them with the construction of the diagnosis.

Knowing – Ageing and Dying

In the absence of a coherent discourse, around a diagnosis given to them by experts in a memory clinic, participants turned to a more familiar discourse to help them ascertain their positioning – that of ambivalent ageing and certainty of death. This appeared to be a discourse participants were familiar with and knowledgeable about.

> Margaret: It's just this awful long haul down to (.) old age isn't it and death (.) you sort of think how nice it would be if you could just sort of press a button and say right that's it I'm going, and there's a lot of that of course in, in the press isn't there. [Yeah] When I was a lot younger I didn't think along these lines. But now I've reached (.) this age (.) I suppose (.) *I think about it quite a lot*.

When speaking about ageing and dying, participants were more fluent in their speech. In contrast to pauses when talking about MCI, which suggested uncertainty and lack of discourse, pauses or hesitations when talking about ageing and dying appeared to serve a different function. As the content of speech was more fluent, pauses implied that these topics were difficult to talk about, showing the emotive but familiar nature of these discourses, particularly when talking about death and dying. In this passage, Margaret suggests that even (a chosen) death would be preferable to a slow cognitive decline.

Participants put themselves in a variety of positions when talking about ageing. Use of pronouns allowed participants to either distance or associate themselves with the ageing process. As Margaret demonstrated above, she began by talking in the second person "you",

thereby detached herself from the talk about death and implied assisted dying. She then later moved to talking in the first person "I", personalising and taking ownership of what she had previously said.

Participants moved between reluctantly identifying themselves as ageing and getting older to distancing themselves from being identified by others as an older person.

> Jack: …I just realise I'm not getting any younger, I've got to start slowing down a little bit.
> Gwen: …they were terrified of debt weren't they. The older people.

Jack used "I" to identify himself as ageing which gave him permission to slow down, whereas Gwen used "they" to distance herself from the older generation. It is "they" who were terrified, "the older people", in a category of their own. Categorisation of old age was also mentioned by several participants. Gwen suggested there was no defining line.

> Gwen: She (Gwen's sister) had a big party when she turned 80 and all that you know (.) it just **crept up on me**! (laughs) You know, I don't think of myself as 80!

Gwen's exclamation, that turning 80 had "just **crept up on**" her, reflected a sudden realisation of an ageing process. Being 80 years old appeared to have conjured up an image of Gwen as to what an 80 year old woman should look and behave like, and she did not feel she fitted into this. However, other people might have already categorised and perceived her as old, based on her age alone, rather than on how she felt. In addition, Margaret described retiring and waking up one day as "plain old Mrs so and so, OAP", suggesting that old age as an identity was defined by the absence of employment. Furthermore, retirement had rendered her "plain" and nameless, suggesting that as a result of her age and retiring, she was almost invisible, had no identity and likely little impact or relevance in society. Even when participants returned to a more familiar ageing discourse, the position given to them did not fit with their own perceptions of their social identity.

Ageing and dying were emotionally difficult for participants to discuss, and in this context they tended to distance themselves from being seen as "getting older" (Gwen). However, participants appeared more comfortable with using this discourse to talk about the symptoms associated with MCI as an aspect of normal ageing.

> Jack: …it wasn't a serious matter it was just a mild (.) forgetfulness that (.) to my mind age related.

As Jack stated, participants often viewed their difficulties as related to ageing, and therefore accepted by themselves and society as inevitable and not viewed as "serious". Forgetfulness in ageing was spoken about as a "common thing" (Margaret), "[j]ust that you're getting old" (Gwen), and therefore viewed as something that was normal for an older person. As such, a diagnosis of MCI had limited impact and posed no major threat, apart from the challenges that were anticipated and expected in an ageing discourse.

Participants viewed themselves as holding the expertise on ageing, regardless of whether or not they identified themselves as an older person. However, they felt they were often not heard.

> Andrew: I'm not a **bloody idiot**! [Yeah] And I tell them loud and clear.

Andrew's comment might refer to a perceived view of older people as "**idiot**[s]", suggesting that they lacked capacity and intelligence. His need to speak loudly implied that older people were not listened to and ignored. Andrew tried to fight against this aspect of an ageing discourse, by asserting an alternative discourse of ageing which had to be said "loud and clear". This appeared in contrast to Gwen who was resigned to her position as an older person, however both expressed a discourse in which older people were ignored and removed from society.

> Gwen: But ur (...) it'll get sorted out, I'll get put somewhere, shoved in a cupboard! (laughs)

Here, Gwen implied that older people, especially when they have reached a certain stage in their lives and started to show impairments, were "put" or "shoved", hidden away, like an object that was no longer considered useful or needed and needed to be kept out of sight. Despite laughing at the end of the sentence, this was something she was concerned about, highlighted by the pause near the start of the sentence, perhaps wondering whether or not to express this thought. In contrast, Margaret had a slightly different view of the future, and what it meant to age.

> Margaret: And there's a constant feeling of being at the end of my life now, I'm very aware that I'm 77, and that (.) ur I've got to really enjoy every single moment of what's left, cos I'm, ha, happily married and I've got a lovely family, just keep thinking I'm going to have to leave them all one of these days, sooner rather than later. **That** comes into my everyday feelings. [Okay] A lot. [Yeah] Quite a lot.

Margaret appeared to express an obligation "I've got to", rather than a desire, for contentment and gratefulness in light of an impending death. Death was not overtly named but expressed as an euphemism, "I'm going to have to leave them all one of these days". However, Margaret's repeated use of "I" enabled her to position herself as someone with knowledge and wisdom about the future, without needing to explicitly name death. Furthermore, her emphasis of "**[t]hat**" suggested that it was in fact ageing and dying that were given more importance by her, rather than the impact of being diagnosed with MCI.

Ambivalent ageing and certain death appeared to provide the participants with a well-formed and well known discourse to draw upon. Although this discourse functioned as a legitimate way for participants to normalise and almost dismiss the diagnosis of MCI, integrating their symptoms as part of ageing and impending death, it also created the uncomfortable position of being viewed as limited use and not to be attended to.

Not wanting to know – Dementia

Ageing and dying, however, was not the only discourse drawn upon by the participants. As participants showed an awareness of the possibility that MCI could deteriorate, they went on to consider a discourse around dementia as applicable to them.

> Simon: Well I do worry if it gets worse. [Yeah] Urm (.) I wouldn't want to end up like they say a cabbage (.) you need your faculties don't you in life (.) urm (.) *that's* (.) I try not to think about it really. [Okay] Cos you know (*indecipherable*). [Pardon?] Just hope it doesn't go worse. [Yeah] (.) Just plod on.

Again, speech was less fluent when talking about dementia, with frequent pauses, changes in tone, and short sentences. Similar to an ageing and dying discourse, the non-verbal features reflected that this was a difficult, sensitive topic, as illustrated by Simon, who tried "not to

think about it", and found it difficult to consider a possible decline. He also suggested that one's faculties were needed for living and that living with impaired cognitive ability would not be constituted as living. This echoed Margaret's comments about preferring death over a life with slow cognitive decline. Although Simon did not name dementia explicitly, his use of wording, "cabbage", suggested that he was referring to a dementia discourse.

> Margaret: And that awful word Alzheimer's looming up.

Margaret reflected how powerful labels, such as Alzheimer's, could be and how the diagnosis itself could conjure socially constructed negative connotations and stigma. She described the diagnosis as an "awful word" and gave it a metaphorical life of its own, "looming up", almost as though the word could threaten her own identity. The terms dementia and Alzheimer's have become deeply value-laden words, which now elicit strong feelings, such as profound dread (Zeilig, 2014).

A number of highly emotive words and phrases were used when participants' drew upon a dementia discourse, such as "suffer" (Clive), "fool" (Clive, William), "awful affliction" (Clive), "cabbage" (Andrew, Simon), "lunacy" (Jack), "brain dead" (Jack), and "lost her" (Margaret). Some of the words and phrases were used by several participants, some of whom knew people who had been given a dementia diagnosis (Clive's mother, Jack's father, several of Margaret's family members and her friend), suggesting a well-formed and familiar discourse which offered undesirable and unwanted positions. Participants also named the media as their prime source of information and holding the expertise around dementia.

> Margaret: There's a lot being written about it, and I tend to read it if I see it in the, particularly in the newspapers you see, articles about it, I read those (.) but I try not to think about it too much.

The media is viewed as influential in shaping discourses (Kirkman, 2006) and was seen as the expert by many of the participants. They referenced it as a source of knowledge, both about the effects of the condition and how to "stave it off" (Margaret) or "avoid it" (Margaret).

Participants struggled between the two available discourses – ageing and dying or dementia.

> Margaret: And you sort of wonder, at what point, you know you've got Alzheimer's rather than you know a bit of senile dementia, what where is the cut-off *point*.
> Interviewer: Yeah, what do you think the cut-off point is?
> Margaret: *Well I don't know, I don't know* really. (.) Now that would worry me, that would worry me very much. (.) I'm not sure (.) perhaps there isn't a cut-off point, perhaps there's a gradual deterioration, *I don't know*.

Margaret initially used "you" to detach herself from the statement when she wondered about the possibility of MCI converting to dementia. When asked specifically about what she thought, she gave a personal response, in the first person. However, responding in the first person, relating the possibility of dementia to herself and therefore tentatively integrating it into a personal discourse, caused her speech to become disjointed. She paused and repeated herself several times throughout her answer, possibly due to an emerging realisation of where a dementia discourse would position her. As Margaret showed, participants were explicit about dementia being a worry, with its previously mentioned negative connotations, and therefore there was anxiety and a reluctance to consider the related positioning as a person with dementia. The positioning of MCI in relation to dementia was similarly considered and explained by William.

> William: (When asked how he felt about being diagnosed with MCI) Actually it was a relief. [Okay] Because I thought it might've been something worse.
> Interviewer: Like?
> William: **Alzheimer's** or something like that. [Right] But when I was told it was mild cognitive impairment, that, that was a relief. [Okay] Because it's not **that**, well I believe it's not **that** serious. [Yeah] So that re, that was, I didn't think I was going, I found out I wasn't going mental. [Okay] That helped a lot!

William started with "actually", suggesting that the opinion he was about to give was a potentially unexpected answer to the interviewer. When asked what he meant by "it", his answer moved from a specific and emphasised "**Alzheimer's**", to vague, "or something like that". However, his speech was then punctuated with repetition and not finishing the sentences, similar to Margaret above. To William, being diagnosed with Alzheimer's was viewed as "going mental", and in comparison, a diagnosis of MCI was a "relief", attempting

to normalise the diagnosis of MCI. However his use of "**that**" repeatedly said with emphasis, suggested that MCI was to a certain degree also a "serious" matter.

Although dementia, like ageing and dying, was a familiar and well-formed discourse for the participants, it only offered undesirable and unwanted social positions. Participants seemed to have some awareness that MCI may convert to dementia, even though they appeared to not to have exact knowledge of a possible prognosis of MCI. In their discourses, participants constructed a negative image of this diagnosis, and through their use of language they actively tried to distance themselves from it.

Discussion

Interviews with people who had been diagnosed with MCI, revealed three discourses associated with MCI: 'Not Knowing', 'Knowing' and 'Not Wanting to Know'. There appeared to be no coherent discourse available to people around MCI, in which they would have been able to position themselves. This left participants searching for the experts who could explain and give them the language. In the absence of reliable experts, participants appeared to look for other discourses that were more familiar to them and that would help them to position themselves as being diagnosed with MCI, two discourses emerged: ageing and dying, and dementia.

The findings of this study have built upon and added to the previously reported narrative accounts of those with MCI. Up until this point, the narrative accounts of those with MCI have primarily focused on exploring the experience of being diagnosed with and living with MCI. Studies have looked at the ways in which people try to make sense of the diagnosis, the coping strategies employed, and how people attribute symptoms (Beard & Neary, 2013; Berg et al., 2012; Corner & Bond, 2006; Joosten-Weyn Banningh et al., 2008; Lingler et al., 2006; McIlavane et al., 2008; Roberts & Clare, 2013). Within this study, participants oscillated between wider available and generated discourses around ageing/dying and dementia, 'Knowing' and 'Not Wanting to Know'. This tension in discourses between ageing and dying versus dementia was evident throughout the participants' interviews, with participants borrowing from these more familiar discourses as a way of helping to find a position regarding their MCI diagnosis. Whilst previous studies have highlighted that people with MCI are likely to attribute memory loss to causes such as ageing or dementia (Beard &

Fox, 2008; Dean & Wilcox, 2012; Lingler et al., 2006), this study revealed that although ageing was seen as ambivalent and death as inevitable, participants attempted to position themselves within this discourse, rather than that of dementia, which only offered a dreaded position. Their use of language showed attempts at distancing themselves from the dementia discourse. However participants seemed aware of the possibility of dementia, despite not fully being informed of the prognosis of MCI.

In western culture, people have access to different discourses to talk about old age, which can be both contrasting and conflicting (Jolanki, Jylhä, & Hervonen, 2000). On the one hand, old age is constructed as an external, inevitable fact. It is no one's fault that old age means decline. This allows people to offer an explanation for why they are no longer as active as they used to be, have failing memories, become more reliant on others, allowed to receive help, and why they have permission to be ill or frail (Giles & Coupland 1991). However, receipt of these social privileges does contain some social risks, such as being viewed as helpless and dependant, or losing authority (Jolanki et al., 2000). An alternative discourse therefore, which preserves authority and allows someone to be treated as "accountable" (Shotter, 1993) is that of being independent and self-reliant. However, in order to do this, people must distance themselves from "the other old", the sick and the frail, or else credibility is lost (Jolanki et al., 2000). Given the dilemmatic discourse of ageing, the participants within this study positioned themselves ambivalently within this discourse. They spoke of decline as expected ("common thing", "[j]ust that you're getting old"), which enabled MCI to be tentatively integrated into an ageing discourse. This gave them permission to acceptably reduce their activities, accept help, and become ill or frail. However, by utilising this discourse, people with MCI risked losing authority and being viewed as helpless or dependant, which a few of the participants then attempted to fight against ("I'm not a **bloody idiot**!") in an attempt to create an alternative discourse.

Terms and phrases used to describe people with dementia such as "there's nobody there", contribute to what has been termed a 'social death' (Sweeting & Gilhooly, 1997), which has become a pervasive view, reflected in novels, films and media reports of people with dementia. The negative connotations and fear associated with dementia, appeared to cause the participants to distance the MCI discourse from that of dementia. As social identities are also constructed by discourses, participants appeared to develop strategies to make the unmanageable manageable (Birenbaum 1992) by referring back to the known but ambivalent discourse of ageing and dying. If all stages of dementia are given the same

discourse (that of the end stages), then people diagnosed with MCI must attempt to differentiate their current position from that available in a dementia discourse in order to avoid being attributed the accompanying spoiled identity (Beard & Neary, 2013; Goffman, 1963). Stigma is deeply social, and for those given aversive labels, these become social problems to be managed. Diagnostic labels and their associated discourses influence and create social identities through which social problems can be managed. A discourse which talks about a diagnosis of MCI as a 'pre-dementia' diagnosis could therefore create tensions.

This study does have limitations. Firstly, the participants were drawn from a number of memory clinics across North Wales, which all operate differently in terms of the sharing of the diagnosis and pre and post diagnostic counselling. Therefore it is likely that participants were given different information and support. Indeed, one participant in this study knew they had been given written information although they had chosen not to read this due to fear that it would confirm that MCI was likely to convert to dementia in the future. Secondly, the participants who responded to take part in this study generally had higher levels of education than the general population, which may reflect a sample of potential participants more likely to respond to an invite to take part in research. This may have had an impact on their choice of language, and therefore the discourses that arose from their interviews. In addition all participants were first language English, with only one participant speaking Welsh as a second language. Thirdly, primarily only the participant's speech was analysed for discourse, rather than analysing the interaction between both the participant and interviewer. Although the interviewer attempted to remain impartial, neutral and not influence the construction of discourse around the diagnosis of MCI, it is acknowledged that this may not have always been possible due to the very nature of interviews. Finally, it is not clear how or whether both verbal and non-verbal features in the interviews may have been related to or were a reflection of the cognitive impairment, rather than as a way of positioning themselves within the discourses. There are few studies that have used discourse analysis to study the language of people who have cognitive difficulties. The sample of participants were heterogeneous in their level of impairment, with some participants more recently diagnosed with fewer cognitive changes, and other participants reporting functional difficulties, which could be a symptom of a deteriorating condition like dementia. However, despite differing levels of cognitive impairment, the content of participants' interviews was noticeably more fluent when they spoke about known discourses (ageing/dying and dementia) than MCI, suggesting that hesitant and disjointed speech was a feature of the discourse rather than that of cognitive impairment.

People with dementia are often regarded as unable to contribute to the social discourse of their condition, or even narrate their own experience of illness (Beard & Neary, 2013). Similarly, people with MCI seem likely to become the victim of this discourse, where people with cognitive impairment cannot contribute to the discourse of the diagnosis they have been given. People with MCI must be given the opportunity to contribute to the social discourse of their diagnosis, and share their experience and knowledge. This study showed that the MCI discourse is not well established outside a research and clinical context, and can only be understood by those diagnosed with MCI in the context of fear of dementia, or the ambivalence of ageing and dying. Whilst an ageing and dying discourse does not threaten the identity of people with MCI, the knowledge that MCI could deteriorate and lead to a dementia discourse does. With a dementia discourse as a potential future option, people with MCI will become fearful of their positioning in the future and could create unnecessary complications and possible compliance with dominant discourses.

With this in mind, clinicians must consider both the amount of and how information is presented to patients about MCI at pre and post diagnostic counselling, including where MCI is positioned in respect to dementia. Pre and post diagnostic counselling are primary opportunities for the clinician to help people with MCI shape the discourse around the diagnosis, which may help them to meaningfully integrate the diagnosis into a supportive discourse, rather than become susceptible to other discourses which each pose challenges. However, this poses a further question – do clinicians have a well-formed discourse around MCI? No studies so far have specifically looked at memory clinic clinician's views of the diagnosis, or the language that they use to speak about MCI and make sense of it for patients. Alternatively, the current lack of discourse around MCI may provide an opportunity for those most intimately affected by it, to contribute to it and shape it.

Over time it would appear that clinical research and medical experts have imposed the diagnosis of MCI on the general public, and into current medical discourse. The findings of this study would suggest that currently there is a lack of discourse around MCI and this provides people with the opportunity to influence the discourse around MCI and decide whether it is a meaningful or helpful social construction and label.

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Contributions to Theory, Research and Clinical Practice

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The overlapping themes of the two papers were that of watchful waiting and uncertainty. Clearly prostate cancer and mild cognitive impairment are very different diagnoses, viewed as sitting in two very different categories, one within the physical health and the other in the mental health domain (although one might argue MCI is a neurological condition and therefore also physical). However there are also some distinct similarities and therefore opportunities for each area to learn from the other.

Watchful waiting in prostate cancer is a defined treatment option that men with prostate cancer can actively choose as a way of monitoring their disease progression. In mild cognitive impairment, there is very little choice regarding treatment options, and people are invited to attend (often annual) reassessments to assess progression. However, the essence of watchful waiting in both conditions are quite similar – in both instances disease progression is monitored at regular intervals, with no treatment given or available until the disease progresses (prostate cancer becomes clinically symptomatic or MCI converts to dementia), and even then the treatment is not curative (men with prostate cancer given palliative treatments and people with dementia given medication in an attempt to slow progression).

The primary difference between the watchful waiting in the two conditions considered in the two papers, is that for men with prostate cancer in watchful waiting this is a choice, while for people with mild cognitive impairment, the watchful waiting is not out of choice, at the moment there appears to be no real clinical alternative. It is therefore possible that the element of choice for men with prostate cancer undertaking watchful waiting in some ways changes and influences the type of uncertainty felt around treatment, in comparison to the uncertainty felt by people with MCI, where there is no choice regarding treatment. The impact of choice on how a person manages a diagnosis of uncertainty and the impact of this on their wellbeing creates worthwhile considerations for both future research and health care providers.

The implications for prostate cancer and MCI theory development, future research and clinical implications will be considered in turn, and links drawn between the two fields.

Implications for theory development

Prostate cancer

Although, the research appears to still be in its infancy for both watchful waiting in prostate cancer and MCI, prostate cancer research is a few steps ahead in specifically exploring uncertainty, how it may impact on people's wellbeing, and how this knowledge can be applied to help men adjust to an uncertain future. Mishel's (1988) 'uncertainty in illness model' has been used as a framework to understand uncertainty in watchful waiting. Uncertainty has been defined as a "cognitive state created when the person cannot adequately structure or categorize an event due to a lack of sufficient cues and thereby cannot determine the meaning of the illness-related events" (Mishel & Epstein, 1997).

Mishel (1988) viewed uncertainty as the greatest psychological stressor for people coping with life threatening illnesses, such as prostate cancer. In these situations, individuals, either directly or indirectly affected by the condition, cannot accurately predict disease outcomes (e.g. severity of illness, symptoms, impact on future). The 'uncertainty in illness model' proposes that uncertainty develops from several life factors and is mediated by personality characteristics and the personal style in which uncertainty is understood (Mishel, 1988). When diagnosed with a life threatening illness, uncertainty around disease and symptom progression can extend to uncertainty around wider life issues and ability to achieve life goals. This extension occurs as a result of uncertainty affecting normal routines, which eventually may lead to a disruption of the person's sense of structure and order. However, uncertainty may then be used by people to reorganise and recreate their life view, suggesting uncertainty can function as a catalyst for people to move from a life view with set choices to a life view with enhanced flexibility and multiple opportunities (Mishel, 1988).

Research into watchful waiting in prostate cancer has found that, based on Mishel's (1988) model, men who initially seemed to experience an increased sense of uncertainty and danger perception reported poorer quality of life (Wallace, 2003). However, over time their perceived quality of life was not significantly different from people undergoing a range of medical treatments. Uncertainty is also a key theme that has appeared in qualitative interviews with men who chose watchful waiting as their treatment for prostate cancer

(Bailey, Wallace & Mishel, 2007; Hedestig, Sandman & Widmark, 2003). The only psycho-interventional study with men undertaking watchful waiting (Bailey, Mishel, Belyea, Stewart & Mohler, 2004), was based on Mishel's (1988) model, and found that after the intervention, men reported an increase in quality of life and ultimately came to see their lives in a new light. This highlights how uncertainty can prove to be a catalyst for change.

The 'uncertainty in illness model' has begun to be used as a theoretical framework for understanding the appraisals made by men with prostate cancer in watchful waiting. However, there continues to be a lack of evidence within this area, which has not significantly progressed since the intervention study in 2004 (Bailey et al., 2004). In order to strengthen the theory, more high quality research needs to be conducted, with larger samples of men and where possible in other conditions where watchful waiting might be a suitable treatment option.

Mild Cognitive Impairment

Whilst MCI in itself is not a life threatening diagnosis, for patients it holds an uncertain future in terms of how it might develop into a possible dementia, stay the same or functioning reverts back to similar levels to before being diagnosed with MCI. It has been suggested that a MCI diagnosis may also escalate people's uncertainty, compelling them to re-evaluate their psychosocial situation (Joosten-Weyn Banningh, Vernooij-Dassen, Rikkert & Teunisse, 2008). Dementia can be viewed as a metaphorical threat to life, and as such people's lives have the potential to dramatically change if the MCI progresses into dementia (Zeilig, 2014). Often people diagnosed with MCI will be cognitively reassessed every six months to a year, watching and waiting for change. This watchful waiting is has similarities with the experience of those waiting with physical illnesses, like prostate cancer.

Given the similarities between the experiences of uncertainty between men with prostate cancer undertaking watchful waiting and people diagnosed with MCI, future theory development in the MCI field could consider the benefit of using Mishel's (1988) 'uncertainty in illness model' as a theoretical framework to understand people's experience of a diagnosis of MCI. Psychological and social factors influence the accurate appraisal of cognitive difficulties in people with MCI (Roberts & Clare, 2013), and therefore a more coherent understanding of the many factors that influence their appraisals and understanding of the MCI diagnosis is essential. Greater theoretical understanding of these factors would

be with the ultimate aim of being able to provide appropriate clinical support and interventions.

Implications for future research

Prostate cancer

Taking a close look at watchful waiting as a treatment option for prostate cancer exposed confusing medical discourses. The term 'watchful waiting' was often used interchangeably with a number of other terms such as active surveillance, expectant management and observation. Historically these terms were used without specific definitions (Ganz et al., 2012), which has confused the scientific literature on observation (Ip et al., 2011). Watchful waiting and active surveillance are distinctly different treatment options. Watchful waiting is a conservative management strategy for men who are more likely to die from co-morbidities, and when symptoms progress palliative treatment options remain available (Parker, 2003; Klotz, 2005). In comparison active surveillance delays curative treatment until it is necessary based on disease progression (Weissbach & Altwein, 2009). Although both delay treatment, when the prostate cancer becomes symptomatic, the treatment options are distinctly different with different functions. This means that it is likely that the two treatment options will have different psychological outcomes, regarding factors like uncertainty. Using these terms interchangeably, with no specific definition means that the subtle differences between these two treatment options may get lost, not only in the discourses of the medical research and clinical practice, but also for patients.

The review conducted also revealed a wide variety of measures and questionnaires used, with variability in what components of the measures were reported. Fourteen different measures and questionnaires were included and reported in this review, which meant that it was difficult for the data to be brought together and direct comparisons made. Indeed one of these measures was a study specific questionnaire that had been validated in an unpublished study and was used by the only randomised control trial reported within the review. Two questionnaires were used more consistently within the studies, however the data reported in the studies was variable, again meaning direct comparisons were difficult to draw. Future research into the psychological aspects of watchful waiting must use specific, validated measures more consistently, in order for direct comparisons to be drawn. Furthermore, measures used in future research could assist with understanding the possible theoretical concepts that may be underpinning the anticipated findings.

As a result of the variety of study designs, a mixed methods review had to be undertaken. The mixed method review is emerging as a new form of literature review, providing rich and detailed understanding of specific research areas (Pluye, Gagnon, Griffiths & Johnson-Lafleur, 2009). However, there is a distinct lack of quality assessment tools for mixed methods reviews that include both quantitative and qualitative studies. Only one tool was found by the first author (Pluye, 2011). Although this tool brought together a variety of research methodologies, only four questions were asked of each study for the different designs (Appendix). This meant that a limited number of quality criteria were considered, and only a limited range of overall scores given, therefore potentially not making a clear distinction between the quality of the studies. If mixed methods reviews are to be treated with the same standard as used in a systematic review or meta-analysis, the lack of quality assessment tools must be addressed.

Mild Cognitive Impairment

Whilst completing clinical interviews was familiar to the first author as a trainee clinical psychologist, completing research interviews as a 'researcher' provided a number of challenges. Firstly, as discourse analysis relies on naturalistic speech, this meant the first author had to be careful not to influence the language used by the participant. It required awareness and monitoring to ensure that no leading questions were asked that would influence the participant's language. Secondly, the research method, discourse analysis, meant learning to look and understand the interviews in a different light. Instead of studying the lived experiences of those with MCI, which fits more comfortably within the realms of clinical psychology, discourse analysis falls under a social constructionist approach. In discourse analysis, language is not seen as a transparent tool in the depiction of reality, instead it is proposed that people use language to build different versions of the social world (Potter & Wetherell, 1987). This alternative viewpoint highlighted how careful researchers need to be with language and terminology used during interviews with participants, as they themselves may influence the participants' discourse. Additionally, clinicians may inadvertently affect the discourse during clinical interviews and this part of the constructed world of the person.

MCI, a research defined concept (Peterson & Morris, 2005), is now considered a diagnosis, and would therefore benefit from a clearer idea of the conversion rate from MCI to

dementia. Conversion rates are reported to vary from 2% to 31% (Bruscoli & Lovestone, 2004), suggesting a huge uncertainty around whether or not people convert to dementia, stay the same or even revert to normal. Whilst the prognosis of MCI remains so uncertain, people with MCI clearly struggle to make sense of the diagnosis. Therefore questions around the helpfulness of the diagnosis must be asked by clinicians giving the diagnoses. Drawing on the discourses of people with MCI – is MCI medicalising normal ageing? This becomes particularly relevant when the scientific basis of the organic nature of dementia is considered confused and unclear in itself (Bender, 2014).

During analysis of the interviews by the first author, it became apparent that alternative qualitative research methods could also be used to analyse the data and produce meaningful results. *I*nterpretative phenomenological analysis and grounded theory approaches had already been reported in the literature; however a more specific version of discourse analysis, Foucauldian discourse analysis, would have shed a different light on the data. Foucauldian discourse analysis is again concerned with language and how language is used, however it goes on to look at the discursive resources available to people, and the ways in which discourse reflects subjectivity and power relationships (Willig, 2013). A medical diagnosis is seen as a reflection of knowledge by an expert, who through this exerts power over the patient, who is manoeuvred into a position of subjectification (Willig, 2013). Throughout ongoing surveillance via regularly repeated reviews and reassessment, further power and control is exerted, and patients begin to monitor their own abilities. This concept was touched upon by participants in the study:

> Gwen: But I've seen myself get up at 2 o'clock in the morning and write a note…
> Margaret: It's reassuring to know that somebody's keeping an eye on you.

While Gwen refers to self-monitoring, Margaret touches on the concept of surveillance; where others monitor her. By creating the MCI diagnostic label, it has socially constructed the perception of a need for increased surveillance of the self, which might reflect the influence and power exerted over current and future generations of older people (Beard & Neary, 2013).

Implications for clinical practice

Prostate cancer

The review highlighted that, for men choosing watchful waiting as a treatment option for prostate cancer, there was a period of initial uncertainty which caused a number of psychological symptoms, such as anxiety and depression, which impacted on their quality of life. This finding would suggest that the opportunity to access psychological support during this period would be highly beneficial for these men, whilst initially being informed of the possible psychological consequences of this choice. Recent National Institute for Health and Care Excellence (NIHCE) guidelines (2014) mentioned the benefit of psychological support for all men diagnosed with prostate cancer, however this document does not state how this support should be set out or indeed who is best placed to do it. Clinical psychology could either provide this service or otherwise is ideally placed in providing consultation and supervision to staff providing the support to the men.

The NIHCE guidelines (2014) define watchful waiting as a viable treatment option for men in the United Kingdom. Indeed, the guidelines point out that if only patient survival is taken into account, then the curative treatment of radical prostatectomy is most cost effective. However, when quality of life was considered by the guidelines, with respect to both the underlying prostate cancer and side effects of treatment, watchful waiting then becomes the more desirable option, both in terms of expected costs and quality adjusted survival.

However, the studies included in this review were often unclear on the choice the men had made in their treatment option, particularly the choice of watchful waiting. Watchful waiting as a choice option was implied rather than explicit in many of the studies. In contrast, two studies were part of a large randomised control trial, which meant the men did not have a choice in this treatment option. As noted in the review, one study (Katz & Rodriquez, 2007) reported offering watchful waiting as a viable treatment option, on par with curative treatments, and possibly as a result of this found that the choice of watchful waiting for these men did not impact on quality of life. Therefore, the way that watchful waiting is presented to men with prostate cancer as a treatment option may affect psychological outcomes. If it is presented as a second class option, then men are potentially at increased risk to experience uncertainty around the treatment decision. Careful pre and post diagnostic counselling is therefore required, with additional attention to the psychological impact of the options available.

Mild Cognitive Impairment

The use of the term MCI also has implications for clinical practice. MCI was originally created for research purposes in order to identify a group of people at risk of developing dementia, and the criteria for MCI has been refined over time (Peterson & Morris, 2005). The diagnosis is now included in DSM-5 (American Psychiatric Association, 2013), under the category of Neurocognitive Disorders, and given the label of 'mild neurocognitive disorder'. This diagnosis does identify a group of people some of whom potentially are in a pre-dementia phase and who could be researched. However, in the absence of a clear aetiology, prognosis or recommended treatments as yet identified (Peterson, 2011) the clinical usefulness of this diagnosis is questionable. Furthermore, there is no evidence to suggest that early diagnosis affects rates of progression or prevents crises (Brunet, 2013). Early diagnosis may instead force people onto a trajectory of disability (Bender, 2014). Instead, the qualitative research into MCI suggests that people try to make sense of the diagnosis within the context of fear and uncertainty, and that people do not know where to position themselves in terms of normal ageing or dementia.

The information that people with MCI are given at diagnosis varies. The one participant in this study who reported being given information, had received a leaflet from the Alzheimer's Society. He reflected that although he thought that the Alzheimer's Society was probably best placed to give the information, he was so concerned that the information would explicitly state that MCI would ultimately lead to dementia, he decided not to read it. By giving people with MCI information created by the Alzheimer's Society, even if of good quality, it immediately strengths the positioning of MCI as close to dementia. People are likely to just see 'Alzheimer's disease' and not necessarily appreciate the uncertainty of the association (Peterson, 2011). During post-diagnostic counselling, people with MCI may not be able to take in all the information given, due to cognitive problems and anxiety. Indeed many of the participants in this study were unable to clearly recall when and what they were told about the diagnosis of MCI.

Whilst clinicians are best placed to give people diagnosed with MCI correct information and support, given the uncertainty of the diagnosis, they may be unable to do so in a coherent manner. This in turn may impact on the discourse people with MCI hold around the diagnosis. Staff themselves may not only lack knowledge around MCI and the possible

trajectories, they might also be reluctant to have open and frank discussions regarding the diagnosis and its meaning with patients. Staff may not have the answers to the patients and families questions, and therefore would not be viewed as an expert. This resonates with the Foucauldian discourse analysis concepts of knowledge and expert power.

Even following diagnosis of MCI, there are limited services available to people diagnosed with this condition, further influencing a discourse and the experience of uncertainty. After diagnosis, the only contact they are likely to have, regarding the diagnosis of MCI, is with mental health services for reassessment, which is likely to be approximately one year after initial assessment and diagnosis. Very little psychoeducational or interventional support is available in the meantime. People are in effect, given a diagnosis which they both struggle to make sense of and incorporate into their identity, as there is no clear discourse around it, and left without contact with services unless their reported difficulties become significantly worse.

It could be argued that services have both a moral and ethical responsibility to support the people who have been given a diagnosis appropriately. A robust theoretical framework into the experiences of people diagnosed with MCI, as previously discussed in 'theoretical implications', may inform appropriate therapeutic interventions for this group of people, to help manage uncertainty and the psychological impact of the diagnosis. The aim of a more robust theoretical framework to understand the experiences of those with MCI would ultimately be to design an intervention aimed at helping people adjust and adapt to the uncertainty of the diagnosis, and potentially improve quality of life. With this in mind, relevant adaptations need to be made so that interventions are accessible to people whose cognitive abilities can be affected, in terms of pace, processing speed, comprehension, recall and execution. Furthermore, a clearer understanding of the conversion rates, and factors contributing to this, might also lead to biopsychosocial interventions that might be able to maintain current levels of competencies or even reverse them.

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Ethics Appendix

School of Psychology Ethics Application

Application for Ethical Approval

Project Title: How do people with a diagnosis of Mild Cognitive Impairment use discourses to interpret the diagnosis?

Principal investigator: Pierce, Sian

Other researchers: Lamers,Carolien, Salisbury,Katie

Pre-screen Questions

Type of Project
D.Clin.Psy

What is the broad area of research
Clinical/Health

Funding body
Internally Funded
Further details: North Wales Clinical Psychology Programme

Type of application (check all that apply)
Study in the area of health and social care requiring sponsorship from BU. Project requiring scrutiny from an outside body which has its own ethical forms and review procedures

Proposed methodology (check all that apply)
Questionnaires and Interviews

Do you plan to include any of the following groups in your study?

If your research requires any of the following facilities MRI, TMS/ tCS, Neurology Panel, has the protocol been reviewed by the appropriate expert/safety panel?
Not applicable (the research does not require special safety panel approval)

Connection to Psychology, (i.e. why Psychology should sponsor the question)
Investigator is a student in Psychology (including the North Wales Clinical Psychology Programme)

Does the research involve NHS patients? (NB: If you are conducting research that requires NHS ethics approval make sure to consult the Psychology Guidelines as you may not need to complete all sections of the Psychology online application)
Yes, NHS IRAS application attached.

Has this proposal been reviewed by another Bangor University Ethics committee?
No

NHS checklist. Does your study involve any of the following?

Part 1: Ethical Considerations

Will you describe the main experimental procedures to participants in advance, so that they are informed about what to expect?
Yes
Further details: No experimental procedures will be used, the chief investigator will explain the nature of the interview to the participants.

Will you tell participants that their participation is voluntary?
Yes

Will you obtain written consent for participation?
Yes
Further details: Only participants who have capacity will take part in the study. Consent will be explained to all participants, and they will be informed that they are able to withdraw from the study at any point. Participants will only be able to take part in the project if they are able to give informed consent, and this will be part of the inclusion criteria.

If the research is observational, will you ask participants for their consent to being observed?
N/A

Will you tell participants that they may withdraw from the research at any time and for any reason?
Yes

With questionnaires, will you give participants the option of omitting questions they do not want to answer?
Yes
Further details: Only demographic information will be collected, no other questionnaires will be used.

Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?
Yes
Further details: Participants will be informed that any identifiers will be removed and pseudonyms will be used.

Will you debrief participants at the end of their participation (i.e. give them a brief explanation of the study)?
Yes
Further details: Participants will be debriefed at the end of the study. They will also be sent a written summary with the main findings of the study, if they indicated they would like to receive this at the start of the interview on the consent sheet.

Will your project involve deliberately misleading participants in any way?
No

Is there any realistic risk of any participants experiencing either physical or psychological distress or discomfort? If *Yes* , give details and state what you will tell them to do should they experience any problems (e.g., who they can contact for help)
Yes
Further details:
Discussing a recent diagnosis of MCI may be an emotive topic for participants. The normal limits of confidentiality will be adhered to, in that information will only be disclosed if the participant is at risk from themselves or others, in the

Chief Investigators clinical judgement. This will be explained to the participant at the time of the interview. All participants will also be given details of other sources of support on an information sheet that they can take away with them.

Is there any realistic risk of any participants experiencing discomfort or risk to health, subsequent illness or injury that might require medical or psychological treatment as a result of the procedures?
No

Does your project involve work with animals? If *Yes* please complete Part 2: B
No

Does your project involve payment to participants that differs from the normal rates? Is there significant concern that the level of payment you offer for this study will unduly influence participants to agree to procedures they may otherwise find unacceptable? If *Yes* please complete Part 2: B and explain in point 5 of the full protocol
No
Further details: If participants have travelled to the memory clinic for the interview they will be reimbursed for travel expenses.

If your study involves children under 18 years of age have you made adequate provision for child protection issues in your protocol?
N/A

If your study involves people with learning difficulties have you made adequate provision to manage distress?
N/A

If your study involves participants covered by the Mental Capacity Act (i.e. adults over 16 years of age who lack the mental capacity to make specific decisions for themselves) do you have appropriate consent procedures in place? NB Some research involving participants who lack capacity will require review by an NHS REC. If you are unsure about whether this applies to your study, please contact the Ethics Administrator in the first instance
N/A
Further details:
Staff from memory clinics, where the person was diagnosed with MCI, will identify participants who are deemed to ha will therefore be assumed and a diagnosis of Mild Cognitive Impairment does not necessarily affect this. Not having capacity to consent will be part of the exclusion criteria for taking part in the study.

If your study involves patients have you made adequate provision to manage distress?
Yes
Further details: The Chief Investigator is a Trainee Clinical Psychologist and, therefore, has the clinical skills to manage distress during the interview. Supervision of the Chief Investigator will be provided by Dr Katie Salisbury (Clinical Supervisor) and Dr Carolien Lamers (Research Supervisor), both of whom are qualified Clinical Psychologists working in Older Adults Community Mental Health Teams. They are both HCPC registered, and members of the Division of Clinical Psychology and Associate Fellows of the British Psychological Society.
Discussing a recent diagnosis of MCI may be an emotive topic for participants. The normal limits of confidentiality will be adhered to, in that information will only be disclosed if the participant is at risk from themselves or others, in the Chief Investigators clinical judgement. This will be explained to the participant at the time of the interview. All participants will also be given details of other sources of support on an information sheet that they can take away with them.

Does your study involve people in custody?

No

If your study involves participants recruited from one of the Neurology Patient Panels or the Psychiatry Patient Panel then has the protocol been reviewed by the appropriate expert/safety panel?
N/A

If your study includes physically vulnerable adults have you ensured that there will be a person trained in CPR and seizure management at hand at all times during testing?
N/A

Is there significant potential risk to investigator(s) of allegations being made against the investigator(s). (e.g., through work with vulnerable populations or context of research)?
No

Is there significant potential risk to the institution in any way? (e.g., controversiality or potential for misuse of research findings.)
No

Part 3: Risk Assessment

Is there significant potential risk to participants of adverse effects?
No

Is there significant potential risk to participants of distress?
Yes
Further details: The Chief Investigator is a Trainee Clinical Psychologist and, therefore, has the clinical skills to manage distress during the interview.
Discussing a recent diagnosis of MCI may be an emotive topic for participants. The normal limits of confidentiality will be adhered to, in that information will only be disclosed if the participant is at risk from themselves or others, in the Chief Investigators clinical judgement. This will be explained to the participant at the time of the interview. All participants will also be given details of other sources of support on an information sheet that they can take away with them.

Is there significant potential risk to participants for persisting or subsequent illness or injury that might require medical or psychological treatment?
No

Is there significant potential risk to investigator(s) of violence or other harm to the investigator(s) (e.g., through work with particular populations or through context of research)?
No
Further details: Interviews may take place at the participants home, if this is more suitable for the participant. The BCUHB lone worker policy will therefore be adhered to. If a home visit takes place then the Chief Investigator will inform one of the study supervisors. The supervisor will be informed of the time of the interview and when the Chief Investigator is expected to return or make contact with the supervisor. In order to protect confidentiality for as long as possible, an envelope with the details of the participant (name, address and telephone number) will be left at the supervisor's clinic, and will only be opened by the supervisor if the Chief Investigator does not return to the clinic or make contact with the supervisor by a specified time.

Is there significant potential risk to other members of staff or students at the institution? (e.g., reception or other staff required to deal with violent or vulnerable populations.)
No

Does the research involve the investigator(s) working under any of the following conditions: alone; away from the School; after-hours; or on weekends?
Yes
Further details: Interviews may take place at the participants home, if this is more suitable for the participant. The BCUHB lone worker policy will therefore be adhered to. If a home visit takes place then the Chief Investigator will inform one of the study supervisors. The supervisor will be informed of the time of the interview and when the Chief Investigator is expected to return or make contact with the supervisor. In order to protect confidentiality for as long as possible, an envelope with the details of the participant (name, address and telephone number) will be left at the supervisor's clinic, and will only be opened by the supervisor if the Chief Investigator does not return to the clinic or make contact with the supervisor by a specified time.

Does the experimental procedure involve touching participants?
No

Does the research involve disabled participants or children visiting the School?
No

Declaration

Declaration of ethical compliance: This research project will be carried out in accordance with the guidelines laid down by the British Psychological Society and the procedures determined by the School of Psychology at Bangor. I understand that I am responsible for the ethical conduct of the research. I confirm that I am aware of the requirements of the Data Protection Act and the University's Data Protection Policy, and that this research will comply with them.
Yes

Declaration of risk assessment The potential risks to the investigator(s) for this research project have been fully reviewed and discussed. As an investigator, I understand that I am responsible for managing my safety and that of participants throughout this research. I will immediately report any adverse events that occur as a consequence of this research.
Yes

Declaration of conflict of interest: To my knowledge, there is no conflict of interest on my part in carrying out this research.
Yes

Part 2: A

The potential value of addressing this issue

Hypotheses

Participants recruitment. Please attach consent and debrief forms with supporitng documents

Research methodology

Estimated start date and duration of the study.

For studies recruiting via SONA or advertising for participants in any way please provide a summary of how participants will be informed about the study in the advertisement. N.B. This should be a brief factual description of the study and what participants will be required to do.

Part 2: B

Brief background to the study

Further details: Mild Cognitive Impairment (MCI) is a mild decline in either single or multiple cognitive domains, such as memory, attention, visuospatial or executive functioning abilities. However, unlike a diagnosis of dementia, global cognitive abilities remain intact alongside the person's ability to undertake basic activities of daily living (Gauthier, Reisberg, Zaudig, Peterson, Ritchie, Broich et al., 2006). MCI is used to describe a heterogeneous clinical state that over time may progress into dementia, remain stable or revert back to normal. The majority of research into MCI has focussed on characterising the rates, predictors and potential modifiers of progression to specific dementia types (Petersen, Doody, Kurz, Mohs, Morris, Rabins, et al, 2001). A number of themes have emerged through the narrative accounts of people diagnosed with MCI. This has included contextual factors, such as the process of normal aging and individual experiences of those with dementia, alongside media coverage of dementia. People diagnosed with MCI have also reacted to the diagnosis with a range of emotional responses. Studying the discourses of those who have been given a MCI diagnosis will contribute to the understanding of how the language used reflects views in society about people with MCI and how this has impacted on how this group of people react and interpret the diagnosis, alongside the individual and social factors that may play an important role.

The hypotheses

Further details: There are no hypotheses due to the qualitative nature of this study. The results are expected to represent the experiences of the participants as constructed through societal and personal discourses.

Participants: recruitment methods, age, gender, exclusion/inclusion criteria

Further details: This study will aim to recruit 6-8 participants given a diagnosis of MCI in the past 6 months. The participants will be recruited from memory clinics across BCUHB, where a diagnosis of MCI is confirmed by a multi-disciplinary team. Clinical staff working in the memory clinics will be asked to identify potential participants who may be willing to take part in research and who have received a diagnosis of MCI based on the Petersen et al. (2001) criteria. Information packs will be either given or sent to the potential participants, by the memory clinic clinician to maintain confidentiality. The information pacts will cover confidentiality and consent, and include form to be sent back to the researcher if they are interested in taking part or would like further information. Inclusion will be dependent on a diagnosis of MCI given by the Memory Clinic multi-disciplinary team, the ability to fluently communicate verbally in English, the ability to give informed consent to take part in the study, no co-morbid diagnosis (either mental health or physical health), either male or female, and aged 55 or over. Exclusion criteria will be no diagnosis of MCI or diagnosis given by someone other than the Memory Clinic multi-disciplinary team, participants not being verbally fluent in English, deemed to not have capacity to consent, a co-morbid diagnosis (including a mental health diagnosis or physical health diagnosis), language difficulties (such as aphasia), and aged under 55.

Research design

Further details: This study will qualitatively analyse interview transcripts.
The study will use discourse analysis, as described by Potter
and Wetherell (1987), to analyse the transcripts from the interviews. Themes from previous qualitative studies will be used to form the basis of the interview and the interview schedule will be devised in conjunction with the research supervisors. There will be a loose interview structure to enable free conversation, as this is the best way of identifying discourses.

Procedures employed

Further details: The participants will be given the option of having the interview conducted at the local memory clinic or at their home. The participants will take part in a semi-structured interview that will aim to last no more than 1 hour.

Measures employed
Further details: No measures will be used during the interviews, however demographic data will be collected. This will specifically include the participant's gender, age, ethnicity, 1st language, marital status, education, and months living with diagnosis of MCI.

Qualifications of the investigators to use the measures (Where working with children or vulnerable adults, please include information on investigators' CRB disclosures here.)
Further details: The Chief Investigator and both supervisors all have CRB clearance. The clinical and research supervisors have Doctorates in Clinical Psychology, and experience in qualitative research methods, including discourse analysis.

Venue for investigation
Further details: The participants will be given the option of having the interview conducted at the local memory clinic or at their home. If the participant chooses to have the interview at the home, then the BCUHB lone worker policy will be adhered to.

Estimated start date and duration of the study (N.B. If you know that the research is likely to continue for more than three years, please indicate this here).
Further details: Recruitment is estimated to begin in June 2014, and data collection is estimated to end by January 2015. The study end date is likely to be in June 2015, however this is to be confirmed.

Data analysis
Further details: The study will use discourse analysis, as described by Potter and Wetherell (1987), to analyse the transcripts from the interviews. Themes from previous qualitative studies will be used to form the basis of the interview and the interview schedule will be devised in conjunction with the research supervisors.

Potential offence/distress to participants
Further details: Discussing a recent diagnosis of MCI may be an emotive topic for participants. The normal limits of confidentiality will
be adhered to, in that information will only be disclosed if the participant is at risk from themselves or others, in the Chief Investigators clinical judgement. This will be explained to the participant at the time of the interview. All participants will also be given details of other sources of support on an information sheet that they can take away with them. All participants will also be given details of other sources of support on an information sheet that they can take away with them.

Procedures to ensure confidentiality and data protection
Further details: A digital audio recording of the interview will need to be made for the purposes of the research. This will be transcribed by the Chief Investigator onto a password protected laptop upon completion of the interview. The Chief Investigator's personal laptop computer will be used to transcribe the data, however no files will be stored on the laptop. The transcriptions will be stored on an encrypted memory stick, which will be kept in a locked drawer
in Dr Katie Salisbury's Office (Flintshire
Mental Health Services for Older People, Wepre House, Connah's Quay). Paper data (e.g. consent forms, demographic data) will be anonymised and kept in a locked drawer. The data collected will comply with Data Protection legislation. This will be ensured by: •Only collecting necessary data for the study. •Only using the data collected for the specified purpose of the study. •Keeping the data safe and secure. Paper data and the Dictaphone will be kept in a locked drawer, and computerised data will be anonymised and password protected and stored on an encrypted memory stick. •Keeping the data for no longer than necessary. •Explaining to the participant's what data will be collected and why. The paper and transcribed data will be destroyed and deleted after the period of time specified by Bangor University policy and Data Protection legislation.

How consent is to be obtained (see BPS Guidelines and ensure consent forms are expressed bilingually where appropriate. The University has its own Welsh translations facilities on extension 2036)
Further details: Consent will be explained to all participants and they will be informed that they are able to withdraw from the study at any point, via an information sheet which they will receive prior to taking part in the study. They will be given the opportunity to contact the researcher prior to the interview if they have further questions. Written consent will be gained prior to the interview commencing and participants will be reminded that they can withdraw at any time. If participants choose to withdraw then the data on the Dictaphone will be deleted in front of them. All information sheets and consent forms will be translated into Welsh by the University translation services. The referring agents will select those who are deemed to have capacity. Participants will only be able to take part in the project if they have capacity and are able to give informed consent. This will be part of the inclusion criteria.

Information for participants (provide actual consent forms and information sheets) including if appropriate, the summary of the study that will appear on SONA to inform participants about the study. N.B. This should be a brief factual description of the study and what participants will be required to do.
Further details: See attached information sheets and consent form.

Approval of relevant professionals (e.g., GPs, Consultants, Teachers, parents etc.)
Further details: Approval will be gained from each Memory Clinic Team Manager.

Payment to: participants, investigators, departments/institutions
Further details: If participants have travelled to the memory clinic for the interview they will be reimbursed for travel expenses.

Equipment required and its availability
Further details: Expenses for equipment, stationary and payment to participants has been budgeted for and will be paid for by the North Wales Clinical Psychology Programme.

If students will be engaged a project involving children, vulnerable adults, one of the neurology patient panels or the psychiatric patient panel, specify on a separate sheet the arrangements for training and supervision of students. (See guidance notes)
Further details: Supervision of the researcher will be provided for by Dr Katie Salisbury (Clinical Supervisor) and Dr Carolien Lamers (Research Supervisor), both of whom are qualified Clinical Psychologists working in Older Adults Community Mental Health Teams. They are both HCPC registered, and members of the Division of Clinical Psychology and Associate Fellows of the British Psychological Society.

If students will be engaged in a project involving use of MRI or TMS, specify on a separate sheet the arrangements for training and supervision of students. (See guidance notes)
Further details: N/A

What arrangements are you making to give feedback to participants? The responsibility is yours to provide it, not participants' to request it.
Further details: When the study is completed participants will be given a written summary of the findings of the study, if they have ticked the box on the consent form stating they would like to receive the information.

Finally, check your proposal conforms to BPS Guidelines on Ethical Standards in research and sign the declaration. If you have any doubts about this, please outline them.

Part 4: Research Insurance

Is the research to be conducted in the UK?
Yes

Research that is based solely upon certain typical methods or paradigms is less problematic from an insurance and risk perspective. Is your research based solely upon one or more of these methodologies? Standard behavioural methods such as questionnaires or interviews, computer-based reaction time measures, standardised tests, eye-tracking, picture-pointing, etc; Measurements of physiological processes such as EEG, MEG, MRI, EMG, heart-rate, GSR (not TMS or tCS as they involve more than simple 'measurement'); Collections of body secretions by non-invasive methods, venepuncture (taking of a blood sample), or asking participants to consume foods and/or nutrients (not including the use of drugs or other food supplements or caffine).
Yes

School of Psychology Ethics Approval Email

Hi,
Approved but please see reviewer comments on there.

Regards
Everil

Everil McQuarrie,

Gweinyddwr Ymchwil/Research and PhD Administrator,
Ystafell 103/Room 103,
Ysgol Seicoloeg/School of Psychology
Adeilad Brigantia/Brigantia Building,
Ffordd Penrallt,Penrallt Road,
Bangor
LL57 2AS
Ffon/Tel: 01248 383671

Comments from Reviewers

Review 1 – 1/7/2014

Approval Status: Approve without amendment

Review 2 – 1/7/2014

Other issues:	The amendment is fine - the only (tiny) comment I have is that I would suggest removing the comma after someone and before regarding in the "sources of support" document.
Approval Status:	Approve without amendment

Research Ethics Committee Application

NHS REC Form | Reference: 14/WA/1072 | IRAS Version 3.5

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)
Discourses around a diagnosis of Mild Cognitive Impairment

1. Is your project research?

(●) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product
( ) Clinical investigation or other study of a medical device
( ) Combined trial of an investigational medicinal product and an investigational medical device
( ) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
( ) Basic science study involving procedures with human participants
( ) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
(●) Study involving qualitative methods only
( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
( ) Study limited to working with data (specific project only)
( ) Research tissue bank
( ) Research database

If your work does not fit any of these categories, select the option below:

( ) Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?	( ) Yes	(●) No
b) Will you be taking new human tissue samples (or other human biological samples)?	( ) Yes	(●) No
c) Will you be using existing human tissue samples (or other human biological samples)?	( ) Yes	(●) No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

[ ] England
[ ] Scotland
[x] Wales
[ ] Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- ○ England
- ○ Scotland
- ◉ Wales
- ○ Northern Ireland
- ○ This study does not involve the NHS

4. Which review bodies are you applying to?

- ☑ NHS/HSC Research and Development offices
- ☐ Social Care Research Ethics Committee
- ☑ Research Ethics Committee
- ☐ National Information Governance Board for Health and Social Care (NIGB)
- ☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

◉ Yes ○ No

6. Do you plan to include any participants who are children?

○ Yes ◉ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes ◉ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes ○ No

Please describe briefly the involvement of the student(s):
The student is the Chief Investigator, who will carry out recruitment, interviews, transcription, analysis and write up.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ◉ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ◉ No

Integrated Research Application System
Application Form for Research involving qualitative methods only

NHS Health Research Authority

Application to NHS/HSC Research Ethics Committee

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Discourses around a diagnosis of Mild Cognitive Impairment

Please complete these details after you have booked the REC application for review.

REC Name:
Wales REC 5

REC Reference Number:
14/WA/1072

Submission date:
07/07/2014

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

How do people with a diagnosis of Mild Cognitive Impairment use discourses to interpret the diagnosis?

A2-1. Educational projects

Name and contact details of student(s):

Student 1

Title	Forename/Initials	Surname
Miss	Sian	Pierce

Address: North Wales Clinical Psychology Programme, Department of Psychology, 43 College Road, Bangor, Gwynedd
Post Code: LL57 2DG
E-mail: psp0d8@bangor.ac.uk
Telephone: 01248382205
Fax:

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:
Doctorate in Clinical Psychology

Name of educational establishment:
North Wales Clinical Psychology Programme, Bangor University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Katie	Salisbury
Address	Flintshire Mental Health Services for Older People		
	Wepre House, Wepre Drive,		
	Civic Centre, Connah's Quay		
Post Code	CH5 4HA		
E-mail	katie.salisbury@wales.nhs.uk		
Telephone	01978726932		
Fax	01244819571		

Academic supervisor 2

	Title	Forename/Initials	Surname
	Dr	Carolien	Lamers
Address	North Wales Clinical Psychology Programme,		
	Department of Psychology, 43 College Road		
	Bangor, Gwynedd		
Post Code	LL57 2DG		
E-mail	c.lamers@bangor.ac.uk		
Telephone	01248388068		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Miss Sian Pierce	☑ Dr Katie Salisbury ☑ Dr Carolien Lamers

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- ◉ Student
- ○ Academic supervisor
- ○ Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Miss	Sian	Pierce
Post	Trainee Clinical Psychologist		
Qualifications	Bsc. (hons) Psychology		
Employer	Betsi Cadwaladr University Health Board		
Work Address	North Wales Clinical Psychology Programme		
	Department of Psychology, 43 College Road		
	Bangor, Gwynedd		
Post Code	LL57 2DG		
Work E-mail	psp0d8@bangor.ac.uk		
* Personal E-mail			
Work Telephone	01248382205		
* Personal Telephone/Mobile			
Fax			

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title	Forename/Initials	Surname
	Mr	Hefin	Francis
Address	School of Psychology		
	Bangor University		
	Bangor, Gwynedd		
Post Code	LL57 2AS		
E-mail	h.francis@bangor.ac.uk		
Telephone	01248388339		
Fax			

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number:

Protocol Version:

Protocol Date:

Funder's reference number:

Project website:

Additional reference number(s):

Ref.Number Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

○ Yes ◉ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

Mild Cognitive Impairment (MCI) is a mild decline in either single or multiple cognitive domains, such as memory, attention, visuospatial or executive functioning abilities. However, unlike a diagnosis of dementia, global cognitive abilities remain intact alongside the person's ability to undertake basic activities of daily living (Gauthier, Reisberg, Zaudig, Peterson, Ritchie, Broich et al., 2006). MCI is used to describe a heterogeneous clinical state that over time may progress into dementia, remain stable or revert back to normal.

The majority of research into MCI has focussed on characterising the rates, predictors and potential modifiers of progression to specific dementia types (Petersen, Doody, Kurz, Mohs, Morris, Rabins, et al, 2001).

A number of themes have emerged through the narrative accounts of people diagnosed with MCI. This has included contextual factors, such as the process of normal aging and individual experiences of those with dementia, alongside media coverage of dementia. People diagnosed with MCI have also reacted to the diagnosis with a range of emotional responses. Studying the discourses of those who have been given a MCI diagnosis will contribute to the understanding of how the language used reflects views in society about people with MCI and how this has impacted on how this group of people react and make sense of the diagnosis, alongside the individual and social factors that may play an important role.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Staff from memory clinics, where the person was diagnosed with MCI, will identify participants who are deemed to have capacity to consent to take part in the study. Only participants who have capacity can take part in the study. At the time of the interview, the interviewer will explain consent to the participant. They will be informed that they are able to withdraw from the study at any point. If at the time of interview, the interviewer cannot be satisfied that informed consent can be given, the interview will be ended.Participants will only be able to take part in the project if they are able to give informed consent, and this is part of the inclusion criteria.

Discussing a recent diagnosis of MCI may be an emotive topic for participants. The normal limits of confidentiality will be adhered to, in that information will only be disclosed if the participant is at risk from themselves or others, in the Chief Investigators clinical judgement. This will be explained to the participant at the time of the interview. All participants will also be given details of other sources of support on an information sheet that they can take away with them.

Interviews may take place at the participants home, if this is more suitable for the participant. The BCUHB lone worker policy will therefore be adhered to. If a home visit takes place then the Chief Investigator will inform one of the study supervisors. The supervisor will be informed of the time of the interview and when the Chief Investigator is expected to return or make contact with the supervisor. In order to protect confidentiality as long as required, an envelope with the details of the participant (name, address and telephone number) will be left at the supervisor's clinic, and will only be opened by the supervisor if the Chief Investigator does not return to the clinic or make contact with the supervisor by a

specified time.

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

○ Yes - proportionate review ◉ No - review by full REC meeting

Further comments (optional):

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply:*

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☑ Qualitative research
- ☐ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

How do people with a diagnosis of Mild Cognitive Impairment use discourses to interpret the diagnosis?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

• What discourses do people draw on around aging, physical and cognitive abilities, cognitive decline, MCI and dementia, and how does this position people in society?
• How is this reflected in sense of self identity/representations of self?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Mild Cognitive Impairment (MCI) is a mild decline in either single or multiple cognitive areas, such as memory, attention, visuospatial or executive functioning abilities. However, unlike a diagnosis of dementia, global cognitive abilities remain intact alongside the person's ability to undertake basic activities of daily living (Gauthier, Reisberg, Zaudig, Peterson, Ritchie, Broich et al., 2006). MCI is used to describe a heterogeneous clinical state that over time may progress into dementia, remain stable or revert back to normal. Conversion rates from MCI to dementia vary from 2% to 31% (Bruscoli & Lovestone, 2004).

The term itself was originally created for research purposes, and is relatively unknown to the general public which may impact on its meaning to those given the diagnosis (Dale, Hougham, Hill & Sachs, 2006). A lack of understanding can

cause uncertainty around the meaning of a diagnosis of MCI, and people given this diagnosis are at risk of both over and under estimating the significance of the diagnosis (Lingler, Nightingale, Erlen, Kane, Reynolds, Schulz & DeKosky, 2006).

It has however been suggested that caution should be used in terms of using MCI as a clinical diagnosis. It has been argued that an MCI diagnosis has poor predictive ability in the general population, and that the ineffectiveness of the diagnosis in fact clouds efforts to reliably identify emerging dementia (Ritchie, Artero & Touchon, 2001).

The majority of research into MCI has focussed on characterising the rates, predictors and potential modifiers of progression to specific dementia types (Petersen, Doody, Kurz, Mohs, Morris, Rabins, et al, 2001).

A number of qualitative studies have been completed in order to understand the experiential implications of being diagnosed with MCI. Lingler et al (2006) found that a fundamental aspect of living with the diagnosis was understanding and coming to terms with MCI, which included both cognitive and emotional dimensions. Factors that influenced their interpretations included expectations of normal aging, personal exposure to individuals with dementia and concurrent health problems. Similarly, Joosten-Weyn Banningh, Vernooij-Dassen, Rikkert & Teunisse (2008) found four common themes were identified when interviewing people with MCI; changes, attributions, consequence and coping strategies. Coping strategies have been further studied, and it has been found that problem focussed and emotion focussed coping strategies are used more often than dysfunctional coping strategies (McIlvane, Popa, Robinson, Houseweart & Haley, 2008) by both people with MCI and their carer's.

Roberts & Clare (2013) studied awareness in MCI, specifically the psychological impact of living MCI and particularly on the psychological impact of living with memory difficulties and how these impact on daily life. They identified four higher order themes; 'interdependence', 'life goes on as normal', 'disavowal of difficulty' and 'fear and uncertainty'. Interestingly, although the diagnosis of MCI was disclosed following assessment at the memory clinic, no participant used the term MCI which may suggest that the term had no meaning for them.

Berg, Wallin, Nordlund & Johansson (2013) looked more specifically at living with MCI, interviewing individuals who had been diagnosed with MCI over a seven month period. Thematic analysis revealed themes around the life situation and events related to the first visit to the memory clinic, coping with lower cognitive capacity with the aim of enhancing quality of life, and worries about dementia and further cognitive deteriorations.

To increase understanding of the impact of diagnosing people with MCI, the societal and media views must also be considered. There has been a lack of research in this area of MCI diagnosis and therefore the views of dementia may be considered as an alternative, as it is possible that similar discourses will be prevalent.

The language of the media has been shown to have a considerable influence over how dementia is portrayed. The terms used to describe people with dementia include phrases such as 'there's nobody there', which is becoming a pervasive view, reflected in novels, films and media reports of people with dementia (Sweeting & Gilhooly, 1997). Negative media coverage is commonly associated with representations that stereotype people with dementia, and whilst these stereotypes relate to dementia they are also associated more generally with aging (Dant & Johnson, 1991). Kirkman (2006) studied items from newspapers in New Zealand over a 5 year period which contained the word 'Alzheimer's'. Three main discourses were found; biomedicine, aging and gender. These contribute to the ways people with Alzheimer's disease continue to be stereotyped in media representations.

Alongside the media views, health care workers perceptions must also be considered due to their central role in diagnosis of dementia. One study used workshops to identify professionals (such as GPs, practice nurses, mental health nurses) own thoughts and experiences of diagnosing dementia. A number of consequences were identified, including labelling and stigma which were thought to be factors that may alter the relationship between the patient and others, and concern that doctors would overlook other pathologies. The workshops also suggested that relatives could also experience shame, stigma, anxiety and isolation, and that the relative's apprehension at the perceived tasks ahead of them might alter their relationship with the patient (Iliffe, Manthorpe & Eden, 2003).

A number of themes have emerged through the narrative accounts of people diagnosed with MCI. This has included contextual factors, such as the process of normal aging and individual experiences of those with dementia, alongside media coverage of dementia. People diagnosed with MCI have also reacted to the diagnosis with a range of emotional responses. Studying the discourses of those who have been given a MCI diagnosis will contribute to the understanding of how the language used reflects views in society about MCI and how this has impacted on how this group of people react and interpret the diagnosis, alongside the individual and social factors that may play an important role.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Participant Recruitment

This study will aim to recruit 6-8 participants who have been given a diagnosis of MCI in the past 6 months. The participants will be recruited from memory clinics across BCUHB, where a diagnosis of MCI is confirmed by a multi-disciplinary team. Clinical staff working in the memory clinics will be asked to identify potential participants who may be willing to take part in, and can consent to, research and who have received a diagnosis of MCI based on the Petersen et al. (2001) criteria. Information packs will be either given or sent to the potential participants, by the memory clinic clinician to maintain confidentiality. The information packs cover confidentiality and consent, and include a reply slip to be sent back to the Chief Investigator if they are interested in taking part in the study or would like further information.

Inclusion will be dependent on a diagnosis of MCI given by the Memory Clinic multi-disciplinary team, the ability to fluently communicate verbally in English, the ability to give informed consent to take part in the study, no co-morbid diagnosis (either mental health or physical health), and aged 55 or over.

Exclusion criteria will be no diagnosis of MCI or diagnosis given by someone other than the Memory Clinic multi-disciplinary team, participants not being verbally fluent in English, deemed to not have capacity to consent, a co-morbid diagnosis (including a mental health diagnosis or physical health diagnosis), language difficulties (such as aphasia), and aged under 55.

Design and Procedures

This study will qualitatively analyse interview transcripts. The study will use discourse analysis, as described by Potter and Wetherell (1987), to analyse the transcripts from the interviews. Themes from previous qualitative studies will be used to form the basis of the interview and the interview schedule will be devised in conjunction with the research supervisors.

The participants will be given the option of having the interview conducted at the local memory clinic or at their home. The interview will last up to one hour, and there will be a loose interview structure to enable free conversation, as this is the best way of identifying discourses. If the participant chooses to have the interview at the home, then the BCUHB lone worker policy will be adhered to.

Measures

No measures will be used during the interviews, however demographic data will be collected. This will specifically include the participant's gender, age, ethnicity, 1st language, marital status, education, and months living with diagnosis of MCI.

Data Management and Analysis

The interviews will be recorded onto a Dictaphone which will be kept in a locked drawer in Dr Katie Salisbury's Office (Flintshire Mental Health Services for Older People, Wepre House, Connah's Quay). When the data is transcribed, it will be anonymised and password protected on the computer, and will be kept on an encrypted memory stick. Paper data will be anonymised and kept in a locked drawer. The data collected will comply with Data Protection legislation. This will be ensured by:

•Only collecting necessary data for the study.
•Only using the data collected for the specified purpose of the study.
•Keeping the data safe and secure. Paper data and the Dictaphone will be kept in a locked drawer, and computerised data will be anonymised and password protected.
•Keeping the data for no longer than necessary.
•Explaining to the participant's what data will be collected and why.

The paper and transcribed data will be destroyed and deleted after the period of time specified by Bangor University policy and Data Protection legislation.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- [x] Design of the research
- [ ] Management of the research

☐ Undertaking the research
☐ Analysis of results
☐ Dissemination of findings
☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.
A service user from the North Wales Clinical Psychology Programme participant panel has read through and amended the participant information sheet and consent form. The service user has experience of using Memory Clinic services.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

A diagnosis of Mild Cognitive Impairment, which has been confirmed by the Memory Clinic multi-disciplinary team,
The ability to fluently communicate verbally in English,
The ability to give informed consent to take part in the study,
No co-morbid diagnosis,
Aged 55 or over.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

No diagnosis of Mild Cognitive Impairment, or diagnosis not confirmed by Memory Clinic multi-disciplinary team,
Not able to fluently communicate verbally in English,
Deemed to not have capacity to consent,
A co-morbid diagnosis (including a mental health diagnosis or physical health diagnosis),
Language difficulties (such as aphasia),
Aged under 55.

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Approached regarding the research.	1	0	15 minutes	Healthcare professional in Memory Clinic involved in older person's care will give details about the research.
Receive information sheet.	1	0	1 day	To be given to potential participants by healthcare professional, or sent to their home, to be read at home. Potential participants may take up to 1 day to read the information sheets, contact the Chief Investigator with any further questions, and make a decision about whether to take part in the study.
Request to participate.	1	0	5 minutes	Complete reply slip and returned in stamped, addressed envelope to the Chief Investigator.

Gain informed consent.	1	0	15 minutes	Chief Investigator to discuss the nature of the study, including withdrawal and consent, and then gain written informed consent from participant.
Demographic questionnaire.	1	1	15 minutes	Chief Investigator to ask participant questions relating to gender, age, ethnicity, 1st language, marital status, education, and months living with diagnosis of MCI.
Research interview.	1	0	60 minutes	Participant to talk about living with a diagnosis of MCI.

A21. How long do you expect each participant to be in the study in total?

It is expected that participants will be involved with the study for up to 18 months, from the point of receiving the information pack until receiving a summary of the findings. However participants will only be involved directly in the study for the 1 hour interview.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Discussing a recent diagnosis of MCI may be an emotive topic for participants and the research interview may be demanding for the participant in relation to concentration and emotive content.

The Chief Investigator is a Trainee Clinical Psychologist and, therefore, has the clinical skills to manage distress during the interview and has skills and competences as learnt from placements across the lifespan in a range of settings. The Chief Investigator will address the demanding nature of the interview and by regularly asking the participant if they would like a break. The Chief Investigator will receive supervision from the research supervisor and clinical supervisor, who are both qualified Clinical Psychologists and work regularly with this client group.

All participants will be given details of other sources of support on an information sheet that they can take away with them. Should the participant appear distressed, with consent, the Chief Investigator will liaise with the person who referred the participant to the study, regarding further support. The normal limits of confidentiality will be adhered to, in that information will only be disclosed if the participant is at risk from themselves or others, in the Chief Investigators clinical judgement.

If participants have travelled to the memory clinic for the interview they will be reimbursed for travel expenses.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

(●) Yes ( ) No

If Yes, please give details of procedures in place to deal with these issues:

The interview may include topics that the participant may find sensitive or upsetting. The Chief Investigator will allow the participants to take their time and come back to topics if necessary.

The normal limits of confidentiality will be adhered to, in that information will only be disclosed if the participant is at risk from themselves or others, in the Chief Investigators clinical judgement. It is not envisaged that any disclosures will occur.

A24. What is the potential for benefit to research participants?

there will be no direct benefit to the research participants, however participants may find it beneficial to be listened to and share their story.

Participants may find the experience of taking part in and being part of research beneficial as they are contributing to the scientific understanding of the diagnosis of MCI.

Participants may find the summary of findings helpful in understanding what their story has contributed towards, together with hearing the views of other people with a diagnosis of MCI.

A26. What are the potential risks for the researchers themselves? *(if any)*

Interviews may take place at the participants home, if this is more suitable for the participant. The BCUHB lone worker policy will therefore be adhered to. If a home visit takes place then the Chief Investigator will inform one of the study supervisors. The supervisor will be informed of the time of the interview and when the Chief Investigator is expected to return or make contact with the supervisor. In order to protect confidentiality as long as is required, an envelope with the details of the participant (name, address and telephone number) will be left at the supervisor's clinic, and will only be opened by the supervisor if the Chief Investigator does not return to the clinic or make contact with the supervisor by a specified time. The envelope will be destroyed upon the Chief Investigator's return.

Supervision of the Chief Investigator will be provided for by Dr Katie Salisbury (Clinical Supervisor) and Dr Carolien Lamers (Research Supervisor), both of whom are qualified Clinical Psychologists working in Older Adults Community Mental Health Teams. They are both HCPC registered, and members of the Division of Clinical Psychology and Associate Fellows of the British Psychological Society.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Clinical staff working in the memory clinics will be asked to identify potential participants who may be willing to take part in research. Clinical staff will be aware of the inclusion and exclusion criteria, and will be asked identify potential participants who have received a diagnosis of MCI based on the Petersen et al. (2001) criteria.

The clinical staff will alert the potential participants to the study, and if they are interested or would like further information, then the information packs will either be given or sent to them. The information packs will include an outline of the study and cover confidentiality and consent.

The Chief Investigator will not know who has been given information packs, in order to maintain confidentiality and anonymity. No further action will be taken once the information packs have been given to potential participants.

If the potential participant would like to take part in the study, there will be a reply slip and stamped addressed envelope included in the information pack for them to complete and send back to the Chief Investigator. The Chief Investigator will then use the information on the reply slip (e.g. name, address and telephone number) to contact the potential participant to arrange the interview and answer any further questions.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

○ Yes ◉ No

Please give details below:
Clinical staff working in the memory clinics will be asked to identify potential participants who may be willing to take part in research. Clinical staff will be aware of the inclusion and exclusion criteria, and will be asked identify potential participants who have received a diagnosis of MCI based on the Petersen et al. (2001) criteria. The Chief Investigator will not know who have been given information packs, in order to maintain confidentiality and anonymity. No further action will be taken once the information packs have been given to potential participants.

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

○ Yes ◉ No

A29. How and by whom will potential participants first be approached?

Clinical staff working in the memory clinics will be asked to identify potential participants who may be willing to take part in research. Clinical staff will be aware of the inclusion and exclusion criteria, and will be asked identify potential participants who have received a diagnosis of MCI based on the Petersen et al. (2001) criteria.

The clinical staff will alert the potential participants to the study, and if they are interested or would like further information, then the information packs will either be given or sent to them. The information packs will include an outline of the study and cover confidentiality and consent.

The Chief Investigator will not know who have been given information packs, in order to maintain confidentiality and anonymity. No further action will be taken once the information packs have been given to potential participants.

A30-1. Will you obtain informed consent from or on behalf of research participants?

(●) Yes ( ) No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Capacity will be assessed by the clinical team in the memory clinic. Capacity will therefore be assumed and a diagnosis of Mild Cognitive Impairment does not necessarily affect this. Not having capacity to consent is part of the exclusion criteria for taking part in the study.

The study will be explained to all participants and they will be informed that they are able to withdraw from the study at any point, via an information sheet which they will receive prior to taking part in the study, and will be reiterated at the start of the interview. They will be given the opportunity to contact the Chief Investigator prior to the interview if they have further questions. Written consent will be gained prior to the interview commencing. Participants will also be aware that should they withdraw during the study, that the recording will be deleted in front of the them.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

(●) Yes ( ) No

A31. How long will you allow potential participants to decide whether or not to take part?

Potential participants will be given or sent an information pack from the clinical staff in the Memory Clinic. The Chief Investigator will not know who has been given information packs, and therefore will not contact potential participants unless they have sent back the reply slip in the information pack. Therefore there is no time limit on how long potential participants have to decide whether or not to take part.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?*(e.g. translation, use of interpreters)*

All information sheets, consent forms and debrief information will be provided in both English and Welsh. However, as the interviewer is unable to speak Welsh, all interviews will be conducted in English.

Due to the detailed nature of the research question and related methodology, participants must be able to fluently speak English and must not have language problems, such as aphasia. This forms part of the inclusion and exclusion criteria.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

All information sheets, consent forms and debrief information will be provided in both English and Welsh. However, as

the interviewer is unable to speak Welsh, all interviews will be conducted in English.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

- ○ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ○ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ○ The participant would continue to be included in the study.
- ○ Not applicable – informed consent will not be sought from any participants in this research.
- ◉ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

Informed consent will be gained at the start of the one hour interview. It is highly unlikely that informed consent will be lost during the one hour interview.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? *(Tick as appropriate)*

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☑ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☑ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals
- ☑ Use of audio/visual recording devices
- ☑ Storage of personal data on any of the following:
  - ☑ Manual files including X–rays
  - ☐ NHS computers
  - ☐ Home or other personal computers
  - ☐ University computers
  - ☐ Private company computers
  - ☑ Laptop computers

Further details:

Clinical staff at the Memory Clinics will send the information pack to potential participants without the Chief Investigator accessing their addresses. If the potential participant's participate, they will send back the reply slip in the information pack to the Chief Investigator. The reply slip will ask for potential participants name, address and telephone number.

Direct quotations may be published in the write up of the study. This will explained clearly on the information sheet and there will be a tick box on the consent form for the participant to consent to this. Any identifiable information will be removed or replaced, and pseudonyms will be used.

A digital audio recording of the interview will need to be made for the purposes of the research. This will be transcribed by the Chief Investigator onto a password protected laptop upon completion of the interview.

The Chief Investigator's personal laptop computer will be used to transcribe the data, however no files will be stored on the laptop. The transcriptions will be stored on an encrypted memory stick, which will be kept in a locked drawer in Dr Katie Salisbury's Office (Flintshire Mental Health Services for Older People, Wepre House, Connah's Quay).

Paper data (e.g. consent forms, demographic data) will be anonymised and kept in a locked drawer. The data collected will comply with Data Protection legislation. This will be ensured by:
•Only collecting necessary data for the study.
•Only using the data collected for the specified purpose of the study.
•Keeping the data safe and secure. Paper data and the Dictaphone will be kept in a locked drawer, and computerised data will be anonymised and password protected and stored on an encrypted memory stick.
•Keeping the data for no longer than necessary.
•Explaining to the participant's what data will be collected and why.

The paper and transcribed data will be destroyed and deleted after the period of time specified by Bangor University policy and Data Protection legislation.

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

All names, places and specific information related to the participants will be either changed or generalised to avoid identification. Once the clinical staff in the Memory Clinic have spoken to the potential participant about the research, they will have no knowledge of who consented to participate, or what individual participants discussed or disclosed to the Chief Investigator.

However, discussing a recent diagnosis of MCI may be an emotive topic for participants. Should the participant appear distressed, with consent, the Chief Investigator will liaise with the person who referred the participant to the study, regarding further support. The normal limits of confidentiality will be adhered to, in that information will only be disclosed if the participant is at risk from themselves or others, in the Chief Investigators clinical judgement.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

The Chief Investigator will not access the participant's personal data during the study. Potential participants will be required to complete a reply slip and send back to the Chief Investigator with their details on (name, address and telephone number).

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- (●) Less than 3 months
- ( ) 3 – 6 months
- ( ) 6 – 12 months
- ( ) 12 months – 3 years
- ( ) Over 3 years

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives

for taking part in this research?

◉ Yes ○ No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
If participants have travelled to the memory clinic for the interview they will be reimbursed for their travel expenses.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

○ Yes ◉ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes ◉ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

○ Yes ◉ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

○ Yes ◉ No

Please give details, or justify if not registering the research.
This research is not publicly funded and therefore will not be registered on a public database. It will be registered on the Betsi Cadwaladr University Health Board database for the duration of the study, and a paper copy of the completed Doctoral Thesis will be stored at the Bangor University library.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

- ☑ Peer reviewed scientific journals
- ☐ Internal report
- ☑ Conference presentation
- ☐ Publication on website
- ☐ Other publication
- ☐ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators

☐ No plans to report or disseminate the results

☐ Other (please specify)

A53. Will you inform participants of the results?

◉ Yes ○ No

Please give details of how you will inform participants or justify if not doing so.
When the study is completed participants will be given a written summary of the findings of the study, if they have ticked the box on the consent form stating they would like to receive the information.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

☐ Independent external review

☐ Review within a company

☐ Review within a multi−centre research group

☑ Review within the Chief Investigator's institution or host organisation

☑ Review within the research team

☑ Review by educational supervisor

☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
A proposal of the research has been submitted and approved by the research department on the North Wales Clinical Psychology Programme at Bangor University. The project has also been approved by the Bangor School of Psychology Ethics.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size:	6
Total international sample size (including UK):	6
Total in European Economic Area:	0

Further details:
A minimum of 6 participants will be interviewed.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

Sample size is not usually a main issue in discourse analysis as the interest is in the variety of ways the language is used (Potter & Wetherell, 1987). Large variations in linguistic patterns can emerge from a small number of people. 6 - 8 participants will be interviewed as a result.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

This study will qualitatively analyse interview transcripts. The study will use discourse analysis (Potter & Wetherell,

1987) to analyse the transcripts from the interviews. Themes from previous qualitative studies will be used to form the basis of the interview and the interview schedule will be devised in conjunction with the research supervisors.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co−applicants, protocol co−authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
	Dr	Carolien	Lamers
Post	Clinical Psychologist		
Qualifications	BSc, DClinPsy, CPsychol		
Employer	Betsi Cadwaladr University Health Board		
Work Address	North Wales Clinical Psychology Programme,		
	Department of Psychology, 43 College Road		
	Bangor, Gwynedd		
Post Code	LL57 2DG		
Telephone	01248388068		
Fax			
Mobile			
Work Email	c.lamers@bangor.ac.uk		

	Title	Forename/Initials	Surname
	Dr	Katie	Salisbury
Post	Clinical Psychologist		
Qualifications	BSc, DClinPsy, CPsychol		
Employer	Betsi Cadwaladr University Health Board		
Work Address	Flintshire Mental Health Services for Older People		
	Wepre House, Wepre Drive,		
	Civic Centre, Connah's Quay		
Post Code	CH5 4HA		
Telephone	01978726932		
Fax	01244819571		
Mobile			
Work Email	katie.salisbury@wales.nhs.uk		

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status:
- ○ NHS or HSC care organisation
- ◉ Academic
- ○ Pharmaceutical industry
- ○ Medical device industry
- ○ Local Authority
- ○ Other social care provider (including voluntary sector or

Commercial status: Non-Commercial

private organisation)

◯ Other

If Other, please specify:

Contact person

Name of organisation	Bangor University School of Psychology
Given name	Hefin
Family name	Francis
Address	School of Psychology
Town/city	Bangor
Post code	LL57 2AS
Country	UNITED KINGDOM
Telephone	01248388339
Fax	
E-mail	H.Francis@bangor.ac.uk

Is the sponsor based outside the UK?

◯ Yes ◉ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

☐ Funding secured from one or more funders

☐ External funding application to one or more funders in progress

☑ No application for external funding will be made

What type of research project is this?

◉ Standalone project

◯ Project that is part of a programme grant

◯ Project that is part of a Centre grant

◯ Project that is part of a fellowship/ personal award/ research training award

◯ Other

Other – please state:

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

◯ Yes ◉ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title	Forename/Initials	Surname
	Mr	Sion	Lewis
Organisation	Betsi Cadwaladr University Health Board		
Address	Research and Development		
	Ysbyty Gwynedd		
	Bangor, Gwynedd		
Post Code	LL57 2PW		
Work Email	Sion.Lewis@wales.nhs.uk		
Telephone	01248384877		
Fax			
Mobile			

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/05/2014
Planned end date: 31/07/2015
Total duration:
Years: 1 Months: 2 Days: 31

A71-2. Where will the research take place? *(Tick as appropriate)*

- ☐ England
- ☐ Scotland
- ☑ Wales
- ☐ Northern Ireland
- ☐ Other countries in European Economic Area

Total UK sites in study 5

Does this trial involve countries outside the EU?
○ Yes ◉ No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? *Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:*

- ☐ NHS organisations in England
- ☑ NHS organisations in Wales 5
- ☐ NHS organisations in Scotland
- ☐ HSC organisations in Northern Ireland
- ☐ GP practices in England
- ☐ GP practices in Wales
- ☐ GP practices in Scotland
- ☐ GP practices in Northern Ireland
- ☐ Social care organisations
- ☐ Phase 1 trial units
- ☐ Prison establishments
- ☐ Probation areas
- ☐ Independent hospitals

☐ Educational establishments
☐ Independent research units
☐ Other (give details)

Total UK sites in study: 5

A76. Insurance/ indemnity to meet potential legal liabilities

***Note:* in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland**

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)
☑ Other insurance or indemnity arrangements will apply (give details below)

Bangor University will meet the potential legal liability of the sponsor for harm to participants arising from the management of the research. Please see attached sponsorship letter.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)
☑ Other insurance or indemnity arrangements will apply (give details below)

Bangor University will meet the potential legal liability of the sponsor for harm to participants arising from the management of the research. Please see attached sponsorship letter.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

NHS Indemnity scheme applies as participants will be NHS patients.

Please enclose a copy of relevant documents.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.*

Research site		Investigator/ Collaborator/ Contact	
Institution name	Cefni Memory Clinic/Clinic Cof	Title	Dr
Department name		First name/ Initials	Cara
Street address	Llangefni	Surname	Rogowski
Town/city	Ynys Mon		
Post Code	LL77 7PP		
Institution name	Hergest Unit	Title	Dr
Department name	Ysbyty Gwynedd	First name/ Initials	Joanne
Street address	Bangor	Surname	Kelly-Rhind
Town/city	Gwynedd		
Post Code	LL57 2PW		
Institution name	Older Adults Psychology Services	Title	Dr
Department name	Bodnant Unit	First name/ Initials	Louise
Street address	Maesdu Road	Surname	Cunliffe
Town/city	Llandudno		
Post Code	LL30 1QY		
Institution name	Glan Traeth Community Team	Title	Dr
Department name	Royal Alexandra Hospital	First name/ Initials	Fiona
Street address	Marine Drive	Surname	Sanders
Town/city	Rhyl		
Post Code	LL18 3EA		
Institution name	Older Adult Community Mental Health Team	Title	Dr
Department name	Heddfan	First name/ Initials	Nicola
Street address	Croesnewydd Road	Surname	Weatherall
Town/city	Wrexham		
Post Code	LL13 7TD		
Institution name	Flintshire Mental Health Services for Older People	Title	Dr
Department name	Wepre House	First name/ Initials	Katie
Street address	Wepre Drive	Surname	Salisbury
Town/city	Connah's Quay		
Post Code	CH5 4HA		

Institution name	Title
Department name	First name/ Initials
Street address	Surname
Town/city	
Post Code	

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
    - May be sent by email to REC members.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication*(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

(●) Chief Investigator

( ) Sponsor

- ○ Study co-ordinator
- ○ Student
- ○ Other – please give details
- ○ None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

☑ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Miss Sian Pierce on 04/07/2014 09:52.

Job Title/Post:

Organisation:

Email:

Signature: .....

Print Name: Sian Pierce

Date: 03/07/2014 *(dd/mm/yyyy)*

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co–sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

This section was signed electronically by Mr Hefin Francis on 04/07/2014 10:01.

Job Title/Post:	School Manager for Psychology
Organisation:	Bangor University
Email:	h.francis@bangor.ac.uk

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by carolien Lamers on 04/07/2014 10:52.

Job Title/Post:	clinical psychologist
Organisation:	Betsi Cadwaladr Universtity Health Board
Email:	c.lamers@bangor.ac.uk

Academic supervisor 2

This section was signed electronically by Dr Katie Salisbury on 04/07/2014 10:31.

Job Title/Post:	Clinical Psychologist
Organisation:	Betsi Cadwaladr NHS Trust
Email:	Katiesiansalisbury@yahoo.co.uk

Research Ethics Committee Favourable opinion with additional conditions

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

Pwyllgor Moeseg Ymchwil Cymru 5
Wales Research Ethics Committee 5
Bangor

Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk
Website : www.nres.nhs.uk

Miss Sian Pierce
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
School of Psychology, Bangor University
43 College Road
Bangor, Gwynedd
LL57 2DG psp0d8@bangor.ac.uk

18 July 2014

Dear Miss Pierce,

Study title:	**How do people with a diagnosis of Mild Cognitive Impairment use discourses to interpret the diagnosis?**
REC reference:	**14/WA/1072**
IRAS project ID:	**140596**

The Research Ethics Committee reviewed the above application at the meeting held on 17 July 2014. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Dr Rossela Roberts, rossela.roberts@wales.nhs.uk

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

1. The Committee requested that the Participant information Sheet is revised to address the following points:

a) Use Bangor University letter headed paper.

b) Written in the first of third person consistently

c) Define or explain the term 'discourse' in this context.

d) Clarify the purpose of the study: in paragraph 4, the sentence "this study will help us to understand this diagnosis and what it means to people" needs to be rephrased

e) Clarify the duration of the interview appointment to take into account the time required to obtain consent and explain the interview process

2. The Committee requested that the Consent Form is revised to seek explicit consent to inform the GP/clinical team of any incidental findings (as described in the Information Sheet)

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers.

The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study.

Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on question 2 of the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Summary of discussion at the meeting

Ethical issues raised by the Committee in private discussion, together with responses given by you when invited to join the meeting

Recruitment arrangements and access to health information; fair participant selection
The Committee was satisfied that the participant selection has taken into account the patients' clinical care and sufficient details are provided in the protocol regarding the inclusion and exclusion criteria.
The Committee queried whether potential participants to be approached would be aware of their diagnosis of MCI.
You clarified that the clinical team will only approach potential participants who would have received the diagnosis as they attended the memory clinic.
You clarified that this was set with a view to enable a larger pool of potential participants.
A further query was raised in relation to the process in place to address potential poor response rate.
You clarified that memory clinical staff will ask participants whether they have responded / decided to take part in the study.

Care and protection of research participants; respect for participants' welfare and dignity; data protection and confidentiality
The Committee discussed the arrangements made to protect privacy through confidentiality as well as the information governance aspects of the study, where and for how long will data be stored, and clarified who will have access to the data.
A clarification was requested in relation to the storage/destruction of research data in accordance to Bangor University Policy: the Committee queried what exactly the policy provisions are.
You stated that you are unable to clarify this but will check with the University and make arrangements for the data to be stored / destroyed in accordance to the Policy.

Informed Consent process and the adequacy and completeness of participant information
The Committee noted that written informed consent is taken as part of a process - with participants having adequate time to consider the information, and opportunity to ask questions. The information is clear as to what the participant consents and there is no inducement or coercion. The Committee agreed that the procedures described in the protocol have been adequately addressed in the Information Sheet, but felt that minor amendments should be made to ensure that individuals understand the information and can make a voluntary informed decision to enrol and continue to participate.
The information Sheet needs to clarify what 'discourse' is, it has to be written either in the first or third person, clarify the purpose of the study, the duration of the interviews, and explicit consent needs to be sought to inform the GP of incidental findings.
You agreed to make the required changes.

The Chairman thanked you for your availability to speak to this submission and gave you an opportunity to ask questions. You did not raise any issues.
The Chairman confirmed that the Committee will deliberate and will be in touch shortly.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

Based on the information provided, the Committee was satisfied with the following aspects of the research:

- Social or scientific value; scientific design and conduct of the study
- Recruitment arrangements and access to health information, and fair participant selection
- Favourable risk benefit ratio; anticipated benefit/risks for research participants
- Care and protection of research participants; respect for participants' welfare and dignity
- Informed consent process
- Suitability of the applicant and supporting staff
- Independent review
- Suitability of supporting information
- Other general issues
- Suitability of the summary of the research

The Committee identified issues with the following aspects of the research:

- Adequacy and completeness of participant information

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
REC Application Form		04 July 2014
Project Proposal	1	23 July 2013
Information Sheet for Memory Clinic Clinicians	1	04 July 2014
Participant Information Sheet and Reply Slip	1	04 July 2014
Participant consent form	1	04 July 2014
Interview schedule	1	04 July 2014
Summary CV for Chief Investigator	1	04 July 2014
Summary CV for Academic Supervisor CV - Dr Carolien Lamers		04 July 2014
Summary CV for Academic Supervisor CV - Dr Katie Salisbury		04 July 2014
Evidence of Sponsor insurance or indemnity [Bangor University Insurance Certificate]	1	04 July 2014

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.
No declarations of interest were made in relation to this application

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

14/WA/1072	**Please quote this number on all correspondence**

Yours sincerely

Rossela Roberts

Mr Derek James Crawford, MBChB, FRCS
Chair
E-mail: rossela.roberts@wales.nhs.uk

Enclosure: *List of names and professions of members who were present at the meeting and those who submitted written comments*

"After ethical review – guidance for researchers"

Copy: Sponsor: Mr Hefin Francis
School Manager
School of Psychology, Bangor University
Brigantia Building, Penrallt Rd
Bangor, Gwynedd, LL57 2AS h.francis@bangor.ac.uk

Academic Supervisor: Dr Katie Salisbury
Flintshire Mental Health Services for Older People
Wepre House, Wepre Drive
Civic Centre, Connah's Quay
Flintshire, CH5 4HA katie.salisbury@wales.nhs.uk

Academic Supervisor: Dr Carolien Lamers
North Wales Clinical Psychology Programme
School of Psychology, Bangor University
43 College Road
Bangor, Gwynedd, LL57 2DG c.lamers@bangor.ac.uk

R&D Office: Mr Sion Lewis
Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd, LL57 2PW sion.lewis@wales.nhs.uk

Wales Research Ethics Committee 5

Attendance at Committee meeting on 17 July 2014

Committee Members

Name	*Profession*	*Capacity*	*Present*
Dr. Karen Addy	Clinical Psychologist	Expert	Yes
Dr. Swapna Alexander	Consultant Physician	Expert	Yes
Mrs. Kathryn Chester	Research Nurse	Expert	No
Dr. Christine Clark	Consultant Obstetrician & Gynaecologist	Expert	No
Dr. Michael Cronin	Consultant Paediatrician (deputy to Dr. Clark)	Expert	No
Mr. Derek James Crawford	Retired Consultant Surgeon (Chair)	Expert	No
Mrs. Gwen Dale-Jones	Retired Personal Assistant	Lay +	Yes
Mr. Eliezer Lichtenstein	Student	Lay +	No
Dr. Mark Lord	Consultant Pathologist	Expert	No
Dr. Paul Mullins	Senior Lecturer, MRI Physicist	Lay +	Yes
Mr. Vishwanath Puranik	Associate Specialist ENT Surgeon	Expert	No
Mrs. Lynn Roberts	Matron, Emergency Department	Expert	Yes
Mr. David Alwyn Rowlands	Retired Development & Monitoring Officer	Lay +	Yes
Dr. Jason Walker	Consultant Anaesthetist	Expert	Yes
Dr. Philip Wayman White	General Practitioner (Vice-Chairman, in the Chair)	Expert	Yes
Ms. Sydna Ann Williams	Lecturer	Lay +	Yes

In attendance

Name	*Position (or reason for attending)*
Dr. Rossela Roberts	Clinical Governance Officer / RES Manager

Research Ethics Committee Details of amendments

Miss Sian Pierce
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
School of Psychology
Bangor University
43 College Road Bangor
Gwynedd
LL57 2DG
5th August 2014

Dear Mr Derek Crawford,

REC reference: 14/WA/1072

I am writing to inform you that I have made the changes agreed in the Research Ethics Committee meeting on the 17th July 2014.

In relation to the changes made to the Participant Information Sheet, I have:

a) Removed the Bangor University logo from the word document, and will print off the documents on Bangor University headed paper.
b) Written consistently in the first person.
c) Briefly explained the meaning of the use of the word 'discourse', under the heading 'Purpose of the Study'.
d) Rephrased "this study will help us to understand the diagnosis and what it means to people" under the heading of 'Purpose of the Study', to "By understanding the language people use to talk about a diagnosis of Mild Cognitive Impairment, it is hoped that this will help clinicians who use the diagnosis to understand what it means to people."
e) Clarified that talking through the interview process and gaining consent may take 15 to 20 minutes, followed by an interview of no longer than one hour.

In relation to the changes to the Consent form, I have added a tick box for the participants to agree to their GP being informed that they have taken part in the study. This information has also been updated on the Participant Information Sheet.

Further to our discussion around how long Bangor University will keep the data after the study has been completed, I have been informed that this is 5 years. The Participant Information Sheet has been updated to include this.

I enclose the updated versions of the Participant Information Sheet and Consent Form, with the changes highlighted.

If you would like any further information then please contact me.

Yours sincerely,

Sian Pierce

Research Ethics Committee Acknowledgement of document in compliance with additional conditions

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

Pwyllgor Moeseg Ymchwil Cymru 5
Wales Research Ethics Committee 5
Bangor

Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk
Website : www.nres.nhs.uk

Miss Sian Pierce
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
School of Psychology, Bangor University
43 College Road
Bangor, Gwynedd
LL57 2DG psp0d8@bangor.ac.uk

05 August 2014

Dear Miss Pierce,

Study title:	**How do people with a diagnosis of Mild Cognitive Impairment use discourses to interpret the diagnosis?**
REC reference:	**14/WA/1072**
IRAS project ID:	**140596**

Thank you for your letter of 05 August 2014.

I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 18 July 2014

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Covering letter [Documents in compliance with approval conditions]		05 August 2014
Participant Information Sheet and Reply Slip	2	01 August 2014
Participant Consent Form	2	01 August 2014

(end of list)

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
REC Application Form		04 July 2014
Project Proposal	1	23 July 2013
Information Sheet for Memory Clinic Clinicians	1	04 July 2014
Participant Information Sheet and Reply Slip	2	01 August 2014
Participant Consent Form	2	01 August 2014
Interview schedule	1	04 July 2014
Summary CV for Chief Investigator	1	04 July 2014
Summary CV for Academic Supervisor CV - Dr Carolien Lamers		04 July 2014
Summary CV for Academic Supervisor CV - Dr Katie Salisbury		04 July 2014
Evidence of Sponsor insurance or indemnity [Bangor University Insurance Certificate]	1	04 July 2014
Covering letter [Documents in compliance with approval conditions]		05 August 2014

You should ensure that the sponsor has a copy of the final documentation for the study.

It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

14/WA/1072	**Please quote this number on all correspondence**

Yours sincerely

Rossela Roberts

Dr Rossela Roberts
Research Ethics Service Manager

E-mail: rossela.roberts@wales.nhs.uk

Copy: Sponsor: Mr Hefin Francis
School Manager
School of Psychology, Bangor University
Brigantia Building, Penrallt Rd
Bangor, Gwynedd, LL57 2AS h.francis@bangor.ac.uk

Academic Supervisor: Dr Katie Salisbury
Flintshire Mental Health Services for Older People
Wepre House, Wepre Drive
Civic Centre, Connah's Quay
Flintshire, CH5 4HA katie.salisbury@wales.nhs.uk

Academic Supervisor: Dr Carolien Lamers
North Wales Clinical Psychology Programme
School of Psychology, Bangor University
43 College Road
Bangor, Gwynedd, LL57 2DG c.lamers@bangor.ac.uk

R&D Office: Miss Debra Slater
Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd, LL57 2PW
debra.slater@wales.nhs.uk

Research and Development Application

NHS R&D Form IRAS Version 3.5

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)
Discourses around a diagnosis of Mild Cognitive Impairment

1. Is your project research?

(●) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product
( ) Clinical investigation or other study of a medical device
( ) Combined trial of an investigational medicinal product and an investigational medical device
( ) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
( ) Basic science study involving procedures with human participants
( ) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
(●) Study involving qualitative methods only
( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
( ) Study limited to working with data (specific project only)
( ) Research tissue bank
( ) Research database

If your work does not fit any of these categories, select the option below:

( ) Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?	( ) Yes	(●) No
b) Will you be taking new human tissue samples (or other human biological samples)?	( ) Yes	(●) No
c) Will you be using existing human tissue samples (or other human biological samples)?	( ) Yes	(●) No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

[ ] England
[ ] Scotland
[x] Wales
[ ] Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- ○ England
- ○ Scotland
- ◉ Wales
- ○ Northern Ireland
- ○ This study does not involve the NHS

4. Which review bodies are you applying to?

- ☑ NHS/HSC Research and Development offices
- ☐ Social Care Research Ethics Committee
- ☑ Research Ethics Committee
- ☐ National Information Governance Board for Health and Social Care (NIGB)
- ☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

◉ Yes ○ No

6. Do you plan to include any participants who are children?

○ Yes ◉ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes ◉ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes ○ No

Please describe briefly the involvement of the student(s):
The student is the Chief Investigator, who will carry out recruitment, interviews, transcription, analysis and write up.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ◉ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ◉ No

Integrated Research Application System
Application Form for Research involving qualitative methods only

NHS/HSC R&D Form (project information)

Please refer to the Submission and Checklist tabs for instructions on submitting R&D applications.

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Discourses around a diagnosis of Mild Cognitive Impairment

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

How do people with a diagnosis of Mild Cognitive Impairment use discourses to interpret the diagnosis?

A2-1. Educational projects

Name and contact details of student(s):

Student 1

Title	Forename/Initials	Surname
Miss	Sian	Pierce

Address	North Wales Clinical Psychology Programme, Department of Psychology, 43 College Road Bangor, Gwynedd
Post Code	LL57 2DG
E-mail	psp0d8@bangor.ac.uk
Telephone	01248382205
Fax	

Give details of the educational course or degree for which this research is being undertaken:
Name and level of course/ degree:
Doctorate in Clinical Psychology

Name of educational establishment:
North Wales Clinical Psychology Programme, Bangor University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Katie	Salisbury
Address	Flintshire Mental Health Services for Older People Wepre House, Wepre Drive, Civic Centre, Connah's Quay		
Post Code	CH5 4HA		
E-mail	katie.salisbury@wales.nhs.uk		
Telephone	01978726932		
Fax	01244819571		

Academic supervisor 2

	Title	Forename/Initials	Surname
	Dr	Carolien	Lamers
Address	North Wales Clinical Psychology Programme, Department of Psychology, 43 College Road Bangor, Gwynedd		
Post Code	LL57 2DG		
E-mail	c.lamers@bangor.ac.uk		
Telephone	01248388068		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	**Academic supervisor(s)**
Student 1 Miss Sian Pierce	☑ Dr Katie Salisbury ☑ Dr Carolien Lamers

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- ◉ Student
- ○ Academic supervisor
- ○ Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Miss	Sian	Pierce
Post	Trainee Clinical Psychologist		
Qualifications	Bsc. (hons) Psychology		
Employer	Betsi Cadwaladr University Health Board		
Work Address	North Wales Clinical Psychology Programme Department of Psychology, 43 College Road Bangor, Gwynedd		

Post Code	LL57 2DG
Work E-mail	psp0d8@bangor.ac.uk
* Personal E-mail	
Work Telephone	01248382205
* Personal Telephone/Mobile	
Fax	

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title	Forename/Initials	Surname
	Mr	Hefin	Francis
Address	School of Psychology		
	Bangor University		
	Bangor, Gwynedd		
Post Code	LL57 2AS		
E-mail	h.francis@bangor.ac.uk		
Telephone	01248388339		
Fax			

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):
Sponsor's/protocol number:
Protocol Version:
Protocol Date:
Funder's reference number:
Project website:

Additional reference number(s):

Ref.Number Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

○ Yes ◉ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and

members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

Mild Cognitive Impairment (MCI) is a mild decline in either single or multiple cognitive domains, such as memory, attention, visuospatial or executive functioning abilities. However, unlike a diagnosis of dementia, global cognitive abilities remain intact alongside the person's ability to undertake basic activities of daily living (Gauthier, Reisberg, Zaudig, Peterson, Ritchie, Broich et al., 2006). MCI is used to describe a heterogeneous clinical state that over time may progress into dementia, remain stable or revert back to normal.

The majority of research into MCI has focussed on characterising the rates, predictors and potential modifiers of progression to specific dementia types (Petersen, Doody, Kurz, Mohs, Morris, Rabins, et al, 2001).

A number of themes have emerged through the narrative accounts of people diagnosed with MCI. This has included contextual factors, such as the process of normal aging and individual experiences of those with dementia, alongside media coverage of dementia. People diagnosed with MCI have also reacted to the diagnosis with a range of emotional responses. Studying the discourses of those who have been given a MCI diagnosis will contribute to the understanding of how the language used reflects views in society about people with MCI and how this has impacted on how this group of people react and make sense of the diagnosis, alongside the individual and social factors that may play an important role.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Staff from memory clinics, where the person was diagnosed with MCI, will identify participants who are deemed to have capacity to consent to take part in the study. Only participants who have capacity can take part in the study. At the time of the interview, the interviewer will explain consent to the participant. They will be informed that they are able to withdraw from the study at any point. If at the time of interview, the interviewer cannot be satisfied that informed consent can be given, the interview will be ended.Participants will only be able to take part in the project if they are able to give informed consent, and this is part of the inclusion criteria.

Discussing a recent diagnosis of MCI may be an emotive topic for participants. The normal limits of confidentiality will be adhered to, in that information will only be disclosed if the participant is at risk from themselves or others, in the Chief Investigators clinical judgement. This will be explained to the participant at the time of the interview. All participants will also be given details of other sources of support on an information sheet that they can take away with them.

Interviews may take place at the participants home, if this is more suitable for the participant. The BCUHB lone worker policy will therefore be adhered to. If a home visit takes place then the Chief Investigator will inform one of the study supervisors. The supervisor will be informed of the time of the interview and when the Chief Investigator is expected to return or make contact with the supervisor. In order to protect confidentiality as long as required, an envelope with the details of the participant (name, address and telephone number) will be left at the supervisor's clinic, and will only be opened by the supervisor if the Chief Investigator does not return to the clinic or make contact with the supervisor by a specified time.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply:*

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation

- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☑ Qualitative research
- ☐ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

How do people with a diagnosis of Mild Cognitive Impairment use discourses to interpret the diagnosis?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

- What discourses do people draw on around aging, physical and cognitive abilities, cognitive decline, MCI and dementia, and how does this position people in society?
- How is this reflected in sense of self identity/representations of self?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Mild Cognitive Impairment (MCI) is a mild decline in either single or multiple cognitive areas, such as memory, attention, visuospatial or executive functioning abilities. However, unlike a diagnosis of dementia, global cognitive abilities remain intact alongside the person's ability to undertake basic activities of daily living (Gauthier, Reisberg, Zaudig, Peterson, Ritchie, Broich et al., 2006). MCI is used to describe a heterogeneous clinical state that over time may progress into dementia, remain stable or revert back to normal. Conversion rates from MCI to dementia vary from 2% to 31% (Bruscoli & Lovestone, 2004).

The term itself was originally created for research purposes, and is relatively unknown to the general public which may impact on its meaning to those given the diagnosis (Dale, Hougham, Hill & Sachs, 2006). A lack of understanding can cause uncertainty around the meaning of a diagnosis of MCI, and people given this diagnosis are at risk of both over and under estimating the significance of the diagnosis (Lingler, Nightingale, Erlen, Kane, Reynolds, Schulz & DeKosky, 2006).

It has however been suggested that caution should be used in terms of using MCI as a clinical diagnosis. It has been argued that an MCI diagnosis has poor predictive ability in the general population, and that the ineffectiveness of the diagnosis in fact clouds efforts to reliably identify emerging dementia (Ritchie, Artero & Touchon, 2001).

The majority of research into MCI has focussed on characterising the rates, predictors and potential modifiers of progression to specific dementia types (Petersen, Doody, Kurz, Mohs, Morris, Rabins, et al, 2001).

A number of qualitative studies have been completed in order to understand the experiential implications of being diagnosed with MCI. Lingler et al (2006) found that a fundamental aspect of living with the diagnosis was understanding and coming to terms with MCI, which included both cognitive and emotional dimensions. Factors that influenced their interpretations included expectations of normal aging, personal exposure to individuals with dementia and concurrent health problems. Similarly, Joosten-Weyn Banningh, Vernooij-Dassen, Rikkert & Teunisse (2008) found four common themes were identified when interviewing people with MCI; changes, attributions, consequence and coping strategies. Coping strategies have been further studied, and it has been found that problem focussed and emotion focussed coping strategies are used more often than dysfunctional coping strategies (McIlvane, Popa, Robinson, Houseweart & Haley, 2008) by both people with MCI and their carer's.

Roberts & Clare (2013) studied awareness in MCI, specifically the psychological impact of living MCI and particularly on the psychological impact of living with memory difficulties and how these impact on daily life. They identified four higher order themes; 'interdependence', 'life goes on as normal', 'disavowal of difficulty' and 'fear and uncertainty'.

Interestingly, although the diagnosis of MCI was disclosed following assessment at the memory clinic, no participant used the term MCI which may suggest that the term had no meaning for them.

Berg, Wallin, Nordlund & Johansson (2013) looked more specifically at living with MCI, interviewing individuals who had been diagnosed with MCI over a seven month period. Thematic analysis revealed themes around the life situation and events related to the first visit to the memory clinic, coping with lower cognitive capacity with the aim of enhancing quality of life, and worries about dementia and further cognitive deteriorations.

To increase understanding of the impact of diagnosing people with MCI, the societal and media views must also be considered. There has been a lack of research in this area of MCI diagnosis and therefore the views of dementia may be considered as an alternative, as it is possible that similar discourses will be prevalent.

The language of the media has been shown to have a considerable influence over how dementia is portrayed. The terms used to describe people with dementia include phrases such as 'there's nobody there', which is becoming a pervasive view, reflected in novels, films and media reports of people with dementia (Sweeting & Gilhooly, 1997). Negative media coverage is commonly associated with representations that stereotype people with dementia, and whilst these stereotypes relate to dementia they are also associated more generally with aging (Dant & Johnson, 1991). Kirkman (2006) studied items from newspapers in New Zealand over a 5 year period which contained the word 'Alzheimer's'. Three main discourses were found; biomedicine, aging and gender. These contribute to the ways people with Alzheimer's disease continue to be stereotyped in media representations.

Alongside the media views, health care workers perceptions must also be considered due to their central role in diagnosis of dementia. One study used workshops to identify professionals (such as GPs, practice nurses, mental health nurses) own thoughts and experiences of diagnosing dementia. A number of consequences were identified, including labelling and stigma which were thought to be factors that may alter the relationship between the patient and others, and concern that doctors would overlook other pathologies. The workshops also suggested that relatives could also experience shame, stigma, anxiety and isolation, and that the relative's apprehension at the perceived tasks ahead of them might alter their relationship with the patient (Iliffe, Manthorpe & Eden, 2003).

A number of themes have emerged through the narrative accounts of people diagnosed with MCI. This has included contextual factors, such as the process of normal aging and individual experiences of those with dementia, alongside media coverage of dementia. People diagnosed with MCI have also reacted to the diagnosis with a range of emotional responses. Studying the discourses of those who have been given a MCI diagnosis will contribute to the understanding of how the language used reflects views in society about MCI and how this has impacted on how this group of people react and interpret the diagnosis, alongside the individual and social factors that may play an important role.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Participant Recruitment

This study will aim to recruit 6-8 participants who have been given a diagnosis of MCI in the past 6 months. The participants will be recruited from memory clinics across BCUHB, where a diagnosis of MCI is confirmed by a multi-disciplinary team. Clinical staff working in the memory clinics will be asked to identify potential participants who may be willing to take part in, and can consent to, research and who have received a diagnosis of MCI based on the Petersen et al. (2001) criteria. Information packs will be either given or sent to the potential participants, by the memory clinic clinician to maintain confidentiality. The information packs cover confidentiality and consent, and include a reply slip to be sent back to the Chief Investigator if they are interested in taking part in the study or would like further information.

Inclusion will be dependent on a diagnosis of MCI given by the Memory Clinic multi-disciplinary team, the ability to fluently communicate verbally in English, the ability to give informed consent to take part in the study, no co-morbid diagnosis (either mental health or physical health), and aged 55 or over.

Exclusion criteria will be no diagnosis of MCI or diagnosis given by someone other than the Memory Clinic multi-disciplinary team, participants not being verbally fluent in English, deemed to not have capacity to consent, a co-morbid diagnosis (including a mental health diagnosis or physical health diagnosis), language difficulties (such as aphasia), and aged under 55.

Design and Procedures

This study will qualitatively analyse interview transcripts. The study will use discourse analysis, as described by Potter

and Wetherell (1987), to analyse the transcripts from the interviews. Themes from previous qualitative studies will be used to form the basis of the interview and the interview schedule will be devised in conjunction with the research supervisors.

The participants will be given the option of having the interview conducted at the local memory clinic or at their home. The interview will last up to one hour, and there will be a loose interview structure to enable free conversation, as this is the best way of identifying discourses. If the participant chooses to have the interview at the home, then the BCUHB lone worker policy will be adhered to.

Measures

No measures will be used during the interviews, however demographic data will be collected. This will specifically include the participant's gender, age, ethnicity, 1st language, marital status, education, and months living with diagnosis of MCI.

Data Management and Analysis

The interviews will be recorded onto a Dictaphone which will be kept in a locked drawer in Dr Katie Salisbury's Office (Flintshire Mental Health Services for Older People, Wepre House, Connah's Quay). When the data is transcribed, it will be anonymised and password protected on the computer, and will be kept on an encrypted memory stick. Paper data will be anonymised and kept in a locked drawer. The data collected will comply with Data Protection legislation. This will be ensured by:

•Only collecting necessary data for the study.
•Only using the data collected for the specified purpose of the study.
•Keeping the data safe and secure. Paper data and the Dictaphone will be kept in a locked drawer, and computerised data will be anonymised and password protected.
•Keeping the data for no longer than necessary.
•Explaining to the participant's what data will be collected and why.

The paper and transcribed data will be destroyed and deleted after the period of time specified by Bangor University policy and Data Protection legislation.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- [x] Design of the research
- [ ] Management of the research
- [ ] Undertaking the research
- [ ] Analysis of results
- [ ] Dissemination of findings
- [ ] None of the above

Give details of involvement, or if none please justify the absence of involvement.
A service user from the North Wales Clinical Psychology Programme participant panel has read through and amended the participant information sheet and consent form. The service user has experience of using Memory Clinic services.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

- [ ] Blood
- [ ] Cancer
- [ ] Cardiovascular
- [ ] Congenital Disorders
- [x] Dementias and Neurodegenerative Diseases
- [ ] Diabetes
- [ ] Ear
- [ ] Eye
- [ ] Generic Health Relevance
- [ ] Infection
- [ ] Inflammatory and Immune System
- [ ] Injuries and Accidents
- [ ] Mental Health
- [ ] Metabolic and Endocrine
- [ ] Musculoskeletal
- [ ] Neurological
- [ ] Oral and Gastrointestinal
- [ ] Paediatrics
- [ ] Renal and Urogenital
- [ ] Reproductive Health and Childbirth
- [ ] Respiratory
- [ ] Skin
- [ ] Stroke

Gender:	Male and female participants
Lower age limit: 55	Years
Upper age limit:	No upper age limit

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

A diagnosis of Mild Cognitive Impairment, which has been confirmed by the Memory Clinic multi-disciplinary team,
The ability to fluently communicate verbally in English,
The ability to give informed consent to take part in the study,
No co-morbid diagnosis,
Aged 55 or over.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

No diagnosis of Mild Cognitive Impairment, or diagnosis not confirmed by Memory Clinic multi-disciplinary team,
Not able to fluently communicate verbally in English,
Deemed to not have capacity to consent,
A co-morbid diagnosis (including a mental health diagnosis or physical health diagnosis),
Language difficulties (such as aphasia),
Aged under 55.

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Approached regarding the research.	1	0	15 minutes	Healthcare professional in Memory Clinic involved in older person's care will give details about the research.
Receive information sheet.	1	0	1 day	To be given to potential participants by healthcare professional, or sent to their home, to be read at home. Potential participants may take up to 1 day to read the information sheets, contact the Chief Investigator with any further questions, and make a decision about whether to take part in the study.
Request to participate.	1	0	5 minutes	Complete reply slip and returned in stamped, addressed envelope to the Chief Investigator.
Gain informed consent.	1	0	15 minutes	Chief Investigator to discuss the nature of the study, including withdrawal and consent, and then gain written informed consent from participant.
Demographic questionnaire.	1	1	15 minutes	Chief Investigator to ask participant questions relating to gender, age, ethnicity, 1st language, marital status, education, and months living with diagnosis of MCI.
Research interview.	1	0	60 minutes	Participant to talk about living with a diagnosis of MCI.

A21. How long do you expect each participant to be in the study in total?

It is expected that participants will be involved with the study for up to 18 months, from the point of receiving the information pack until receiving a summary of the findings. However participants will only be involved directly in the study for the 1 hour interview.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Discussing a recent diagnosis of MCI may be an emotive topic for participants and the research interview may be demanding for the participant in relation to concentration and emotive content.

The Chief Investigator is a Trainee Clinical Psychologist and, therefore, has the clinical skills to manage distress during the interview and has skills and competences as learnt from placements across the lifespan in a range of settings. The Chief Investigator will address the demanding nature of the interview and by regularly asking the participant if they would like a break. The Chief Investigator will receive supervision from the research supervisor and clinical supervisor, who are both qualified Clinical Psychologists and work regularly with this client group.

All participants will be given details of other sources of support on an information sheet that they can take away with them. Should the participant appear distressed, with consent, the Chief Investigator will liaise with the person who referred the participant to the study, regarding further support. The normal limits of confidentiality will be adhered to, in that information will only be disclosed if the participant is at risk from themselves or others, in the Chief Investigators clinical judgement.

If participants have travelled to the memory clinic for the interview they will be reimbursed for travel expenses.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

◉ Yes ○ No

If Yes, please give details of procedures in place to deal with these issues:

The interview may include topics that the participant may find sensitive or upsetting. The Chief Investigator will allow the participants to take their time and come back to topics if necessary.

The normal limits of confidentiality will be adhered to, in that information will only be disclosed if the participant is at risk from themselves or others, in the Chief Investigators clinical judgement. It is not envisaged that any disclosures will occur.

A24. What is the potential for benefit to research participants?

there will be no direct benefit to the research participants, however participants may find it beneficial to be listened to and share their story.

Participants may find the experience of taking part in and being part of research beneficial as they are contributing to the scientific understanding of the diagnosis of MCI.

Participants may find the summary of findings helpful in understanding what their story has contributed towards, together with hearing the views of other people with a diagnosis of MCI.

A26. What are the potential risks for the researchers themselves? *(if any)*

Interviews may take place at the participants home, if this is more suitable for the participant. The BCUHB lone worker policy will therefore be adhered to. If a home visit takes place then the Chief Investigator will inform one of the study supervisors. The supervisor will be informed of the time of the interview and when the Chief Investigator is expected to return or make contact with the supervisor. In order to protect confidentiality as long as is required, an envelope with the details of the participant (name, address and telephone number) will be left at the supervisor's clinic, and will only be opened by the supervisor if the Chief Investigator does not return to the clinic or make contact with the supervisor by a specified time. The envelope will be destroyed upon the Chief Investigator's return.

Supervision of the Chief Investigator will be provided for by Dr Katie Salisbury (Clinical Supervisor) and Dr Carolien Lamers (Research Supervisor), both of whom are qualified Clinical Psychologists working in Older Adults Community Mental Health Teams. They are both HCPC registered, and members of the Division of Clinical Psychology and Associate Fellows of the British Psychological Society.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used?*For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Clinical staff working in the memory clinics will be asked to identify potential participants who may be willing to take part in research. Clinical staff will be aware of the inclusion and exclusion criteria, and will be asked identify potential participants who have received a diagnosis of MCI based on the Petersen et al. (2001) criteria.

The clinical staff will alert the potential participants to the study, and if they are interested or would like further information, then the information packs will either be given or sent to them. The information packs will include an outline of the study and cover confidentiality and consent.

The Chief Investigator will not know who has been given information packs, in order to maintain confidentiality and anonymity. No further action will be taken once the information packs have been given to potential participants.

If the potential participant would like to take part in the study, there will be a reply slip and stamped addressed envelope included in the information pack for them to complete and send back to the Chief Investigator. The Chief Investigator will then use the information on the reply slip (e.g. name, address and telephone number) to contact the potential participant to arrange the interview and answer any further questions.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

○ Yes ◉ No

Please give details below:
Clinical staff working in the memory clinics will be asked to identify potential participants who may be willing to take part in research. Clinical staff will be aware of the inclusion and exclusion criteria, and will be asked identify potential participants who have received a diagnosis of MCI based on the Petersen et al. (2001) criteria. The Chief Investigator will not know who have been given information packs, in order to maintain confidentiality and anonymity. No further action will be taken once the information packs have been given to potential participants.

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

○ Yes ◉ No

A29. How and by whom will potential participants first be approached?

Clinical staff working in the memory clinics will be asked to identify potential participants who may be willing to take part in research. Clinical staff will be aware of the inclusion and exclusion criteria, and will be asked identify potential participants who have received a diagnosis of MCI based on the Petersen et al. (2001) criteria.

The clinical staff will alert the potential participants to the study, and if they are interested or would like further information, then the information packs will either be given or sent to them. The information packs will include an outline of the study and cover confidentiality and consent.

The Chief Investigator will not know who have been given information packs, in order to maintain confidentiality and anonymity. No further action will be taken once the information packs have been given to potential participants.

A30-1. Will you obtain informed consent from or on behalf of research participants?

◉ Yes ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Capacity will be assessed by the clinical team in the memory clinic. Capacity will therefore be assumed and a diagnosis of Mild Cognitive Impairment does not necessarily affect this. Not having capacity to consent is part of the exclusion criteria for taking part in the study.

The study will be explained to all participants and they will be informed that they are able to withdraw from the study at any point, via an information sheet which they will receive prior to taking part in the study, and will be reiterated at the start of the interview. They will be given the opportunity to contact the Chief Investigator prior to the interview if they have further questions. Written consent will be gained prior to the interview commencing. Participants will also be aware that should they withdraw during the study, that the recording will be deleted in front of the them.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

◉ Yes ○ No

A31. How long will you allow potential participants to decide whether or not to take part?

Potential participants will be given or sent an information pack from the clinical staff in the Memory Clinic. The Chief Investigator will not know who has been given information packs, and therefore will not contact potential participants unless they have sent back the reply slip in the information pack. Therefore there is no time limit on how long potential participants have to decide whether or not to take part.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? *(e.g. translation, use of interpreters)*

All information sheets, consent forms and debrief information will be provided in both English and Welsh. However, as the interviewer is unable to speak Welsh, all interviews will be conducted in English.

Due to the detailed nature of the research question and related methodology, participants must be able to fluently speak English and must not have language problems, such as aphasia. This forms part of the inclusion and exclusion criteria.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

All information sheets, consent forms and debrief information will be provided in both English and Welsh. However, as the interviewer is unable to speak Welsh, all interviews will be conducted in English.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

- ○ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ○ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ○ The participant would continue to be included in the study.
- ○ Not applicable – informed consent will not be sought from any participants in this research.
- ◉ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

Informed consent will be gained at the start of the one hour interview. It is highly unlikely that informed consent will be lost during the one hour interview.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? *(Tick as appropriate)*

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☑ Use of personal addresses, postcodes, faxes, emails or telephone numbers

- [x] Publication of direct quotations from respondents
- [ ] Publication of data that might allow identification of individuals
- [x] Use of audio/visual recording devices
- [x] Storage of personal data on any of the following:
  - [x] Manual files including X-rays
  - [ ] NHS computers
  - [ ] Home or other personal computers
  - [ ] University computers
  - [ ] Private company computers
  - [x] Laptop computers

Further details:
Clinical staff at the Memory Clinics will send the information pack to potential participants without the Chief Investigator accessing their addresses. If the potential participant's participate, they will send back the reply slip in the information pack to the Chief Investigator. The reply slip will ask for potential participants name, address and telephone number.

Direct quotations may be published in the write up of the study. This will explained clearly on the information sheet and there will be a tick box on the consent form for the participant to consent to this. Any identifiable information will be removed or replaced, and pseudonyms will be used.

A digital audio recording of the interview will need to be made for the purposes of the research. This will be transcribed by the Chief Investigator onto a password protected laptop upon completion of the interview.

The Chief Investigator's personal laptop computer will be used to transcribe the data, however no files will be stored on the laptop. The transcriptions will be stored on an encrypted memory stick, which will be kept in a locked drawer in Dr Katie Salisbury's Office (Flintshire Mental Health Services for Older People, Wepre House, Connah's Quay).

Paper data (e.g. consent forms, demographic data) will be anonymised and kept in a locked drawer. The data collected will comply with Data Protection legislation. This will be ensured by:
•Only collecting necessary data for the study.
•Only using the data collected for the specified purpose of the study.
•Keeping the data safe and secure. Paper data and the Dictaphone will be kept in a locked drawer, and computerised data will be anonymised and password protected and stored on an encrypted memory stick.
•Keeping the data for no longer than necessary.
•Explaining to the participant's what data will be collected and why.

The paper and transcribed data will be destroyed and deleted after the period of time specified by Bangor University policy and Data Protection legislation.

A37. Please describe the physical security arrangements for storage of personal data during the study?

Paper information regarding participants will be stored in a locked cupboard in Dr Katie Salisbury's Office (Flintshire Mental Health Services for Older People, Wepre House, Connah's Quay). The Chief Investigator's personal laptop computer will be used to transcribe the data, however no files will be stored on the laptop. The transcriptions will be stored on an encrypted memory stick, which will be kept in a locked drawer in Dr Katie Salisbury's Office (Flintshire Mental Health Services for Older People, Wepre House, Connah's Quay).

Participants personal information, which is stored on the laptop, will be identified by a number. This number will be linked to the participants name in a document stored in a locked filing cabinet in Dr Katie Salisbury's Office (Flintshire Mental Health Services for Older People, Wepre House, Connah's Quay).

A38. How will you ensure the confidentiality of personal data?*Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

All names, places and specific information related to the participants will be either changed or generalised to avoid identification. Once the clinical staff in the Memory Clinic have spoken to the potential participant about the research, they will have no knowledge of who consented to participate, or what individual participants discussed or disclosed to the Chief Investigator.

However, discussing a recent diagnosis of MCI may be an emotive topic for participants. Should the participant appear distressed, with consent, the Chief Investigator will liaise with the person who referred the participant to the study, regarding further support. The normal limits of confidentiality will be adhered to, in that information will only be disclosed if the participant is at risk from themselves or others, in the Chief Investigators clinical judgement.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

The Chief Investigator will not access the participant's personal data during the study. Potential participants will be required to complete a reply slip and send back to the Chief Investigator with their details on (name, address and telephone number).

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

The data will be generated at the participants homes or in their local outpatient clinic. Audio files will be transcribed to a password protected file on the Chief Investigator's password protected personal laptop, following the end of the interview.

A digital audio recording of the interview will need to be made for the purposes of the research. This will be transcribed by the Chief Investigator onto a password protected laptop upon completion of the interview and stored on an encrypted memory stick.

The Chief Investigator's personal laptop computer will be used to transcribe the data, however no files will be stored on the laptop. The transcriptions will be stored on an encrypted memory stick, which will be kept in a locked drawer.

Transcription and analysis of the data will take place at either an NHS clinic or at the Chief Investigator's home. Supervision will be required for this process, which will be conducted by Dr Carolien Lamers, Clinical Psychologist, and Dr Katie Salisbury, Clinical Psychologist, both of whom are qualified Clinical Psychologists working in Older Adults Community Mental Health Teams. They are both HCPC registered, and members of the Division of Clinical Psychology and Associate Fellows of the British Psychological Society.

A42. Who will have control of and act as the custodian for the data generated by the study?

	Title	Forename/Initials	Surname
	Dr	Katie	Salisbury
Post Qualifications			
Work Address	Flintshire Mental Health Services for Older People Wepre House, Wepre Drive, Civic Centre, Connah's Quay		
Post Code	CH5 4HA		
Work Email	katie.salisbury@wales.nhs.uk		
Work Telephone	01978726932		
Fax	01244819571		

A43. How long will personal data be stored or accessed after the study has ended?

- (●) Less than 3 months
- ( ) 3 – 6 months
- ( ) 6 – 12 months
- ( ) 12 months – 3 years

○ Over 3 years

A44. For how long will you store research data generated by the study?

Years: 2
Months: 0

A45. Please give details of the long term arrangements for storage of research data after the study has ended. *Say where data will be stored, who will have access and the arrangements to ensure security.*

Anonymised paper copies of transcribed data will be stored in a locked filing cabinet in Dr Katie Salisbury's office (Flintshire Mental Health Services for Older People, Wepre House, Connah's Quay).

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

◉ Yes ○ No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
If participants have travelled to the memory clinic for the interview they will be reimbursed for their travel expenses.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

○ Yes ◉ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes ◉ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

○ Yes ◉ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

○ Yes ◉ No

Please give details, or justify if not registering the research.
This research is not publicly funded and therefore will not be registered on a public database. It will be registered on the Betsi Cadwaladr University Health Board database for the duration of the study, and a paper copy of the completed

Doctoral Thesis will be stored at the Bangor University library.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

- [x] Peer reviewed scientific journals
- [ ] Internal report
- [x] Conference presentation
- [ ] Publication on website
- [ ] Other publication
- [ ] Submission to regulatory authorities
- [ ] Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- [ ] No plans to report or disseminate the results
- [ ] Other (please specify)

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

Any quotes or examples used in disseminating findings will be checked for anonymity, ensuring no personally identifiable information is disseminated. This process will begin with the transcription and anonymisation of the audio recordings.

A53. Will you inform participants of the results?

(●) Yes ( ) No

Please give details of how you will inform participants or justify if not doing so.
When the study is completed participants will be given a written summary of the findings of the study, if they have ticked the box on the consent form stating they would like to receive the information.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

- [ ] Independent external review
- [ ] Review within a company
- [ ] Review within a multi–centre research group
- [x] Review within the Chief Investigator's institution or host organisation
- [x] Review within the research team
- [x] Review by educational supervisor
- [ ] Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
A proposal of the research has been submitted and approved by the research department on the North Wales Clinical Psychology Programme at Bangor University. The project has also been approved by the Bangor School of Psychology Ethics.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size:	6
Total international sample size (including UK):	6
Total in European Economic Area:	0

Further details:
A minimum of 6 participants will be interviewed.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

Sample size is not usually a main issue in discourse analysis as the interest is in the variety of ways the language is used (Potter & Wetherell, 1987). Large variations in linguistic patterns can emerge from a small number of people. 6 - 8 participants will be interviewed as a result.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

This study will qualitatively analyse interview transcripts. The study will use discourse analysis (Potter & Wetherell, 1987) to analyse the transcripts from the interviews. Themes from previous qualitative studies will be used to form the basis of the interview and the interview schedule will be devised in conjunction with the research supervisors.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co–applicants, protocol co–authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
	Dr	Carolien	Lamers
Post	Clinical Psychologist		
Qualifications	BSc, DClinPsy, CPsychol		
Employer	Betsi Cadwaladr University Health Board		
Work Address	North Wales Clinical Psychology Programme, Department of Psychology, 43 College Road Bangor, Gwynedd		
Post Code	LL57 2DG		
Telephone	01248388068		
Fax			
Mobile			
Work Email	c.lamers@bangor.ac.uk		

	Title	Forename/Initials	Surname
	Dr	Katie	Salisbury
Post	Clinical Psychologist		
Qualifications	BSc, DClinPsy, CPsychol		

Employer	Betsi Cadwaladr University Health Board
Work Address	Flintshire Mental Health Services for Older People Wepre House, Wepre Drive, Civic Centre, Connah's Quay
Post Code	CH5 4HA
Telephone	01978726932
Fax	01244819571
Mobile	
Work Email	katie.salisbury@wales.nhs.uk

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status:
- ○ NHS or HSC care organisation
- ◉ Academic
- ○ Pharmaceutical industry
- ○ Medical device industry
- ○ Local Authority
- ○ Other social care provider (including voluntary sector or private organisation)
- ○ Other

Commercial status: Non-Commercial

If Other, please specify:

Contact person

Name of organisation	Bangor University School of Psychology
Given name	Hefin
Family name	Francis
Address	School of Psychology
Town/city	Bangor
Post code	LL57 2AS
Country	UNITED KINGDOM
Telephone	01248388339
Fax	
E-mail	H.Francis@bangor.ac.uk

Is the sponsor based outside the UK?

○ Yes ◉ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

☐ Funding secured from one or more funders

☐ External funding application to one or more funders in progress
☑ No application for external funding will be made

What type of research project is this?

◉ Standalone project
○ Project that is part of a programme grant
○ Project that is part of a Centre grant
○ Project that is part of a fellowship/ personal award/ research training award
○ Other

Other – please state:

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? *Please give details of subcontractors if applicable.*

○ Yes ◉ No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○ Yes ◉ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title	Forename/Initials	Surname
	Mr	Sion	Lewis
Organisation	Betsi Cadwaladr University Health Board		
Address	Research and Development		
	Ysbyty Gwynedd		
	Bangor, Gwynedd		
Post Code	LL57 2PW		
Work Email	Sion.Lewis@wales.nhs.uk		
Telephone	01248384877		
Fax			
Mobile			

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/05/2014
Planned end date: 31/07/2015
Total duration:
Years: 1 Months: 2 Days: 31

A71-1. Is this study?

○ Single centre
◉ Multicentre

A71-2. Where will the research take place? *(Tick as appropriate)*

☐ England
☐ Scotland
☑ Wales
☐ Northern Ireland
☐ Other countries in European Economic Area

Total UK sites in study 5

Does this trial involve countries outside the EU?
○ Yes ◉ No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? *Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:*

☐ NHS organisations in England	
☑ NHS organisations in Wales	5
☐ NHS organisations in Scotland	
☐ HSC organisations in Northern Ireland	
☐ GP practices in England	
☐ GP practices in Wales	
☐ GP practices in Scotland	
☐ GP practices in Northern Ireland	
☐ Social care organisations	
☐ Phase 1 trial units	
☐ Prison establishments	
☐ Probation areas	
☐ Independent hospitals	
☐ Educational establishments	
☐ Independent research units	
☐ Other (give details)	

Total UK sites in study: 5

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

○ Yes ◉ No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

The supervisory team, the North Wales Clinical Psychology Programme, and the Bangor University School of Psychology Ethics Department will take responsibility for the conduct of the research.

Research Governance Frameworks will be adhered to and monitored, if necessary, by the Betsi Cadwaladr University Health Board NHS Research and Development department.

A76. Insurance/ indemnity to meet potential legal liabilities

***Note:* in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland**

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)

☑ Other insurance or indemnity arrangements will apply (give details below)

Bangor University will meet the potential legal liability of the sponsor for harm to participants arising from the management of the research. Please see attached sponsorship letter.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)

☑ Other insurance or indemnity arrangements will apply (give details below)

Bangor University will meet the potential legal liability of the sponsor for harm to participants arising from the management of the research. Please see attached sponsorship letter.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

NHS Indemnity scheme applies as participants will be NHS patients.

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

○ Yes ◉ No ○ Not sure

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.*

Research site		Investigator/ Collaborator/ Contact	
Institution name	Cefni Memory Clinic/Clinic Cof	Title	Dr
Department name		First name/ Initials	Cara
Street address	Llangefni	Surname	Rogowski
Town/city	Ynys Mon		
Post Code	LL77 7PP		
Institution name	Hergest Unit	Title	Dr
Department name	Ysbyty Gwynedd	First name/ Initials	Joanne
Street address	Bangor	Surname	Kelly-Rhind
Town/city	Gwynedd		
Post Code	LL57 2PW		
Institution name	Older Adults Psychology Services	Title	Dr
Department name	Bodnant Unit	First name/ Initials	Louise
Street address	Maesdu Road	Surname	Cunliffe
Town/city	Llandudno		
Post Code	LL30 1QY		
Institution name	Glan Traeth Community Team	Title	Dr
Department name	Royal Alexandra Hospital	First name/ Initials	Fiona
Street address	Marine Drive	Surname	Sanders
Town/city	Rhyl		
Post Code	LL18 3EA		
Institution name	Older Adult Community Mental Health Team	Title	Dr
Department name	Heddfan	First name/ Initials	Nicola
Street address	Croesnewydd Road	Surname	Weatherall
Town/city	Wrexham		
Post Code	LL13 7TD		
Institution name	Flintshire Mental Health Services for Older People	Title	Dr
Department name	Wepre House	First name/ Initials	Katie
Street address	Wepre Drive	Surname	Salisbury
Town/city	Connah's Quay		
Post Code	CH5 4HA		

Institution name	Title
Department name	First name/ Initials
Street address	Surname
Town/city	
Post Code	

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
    - May be sent by email to REC members.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication*(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

(•) Chief Investigator

( ) Sponsor

- ○ Study co-ordinator
- ○ Student
- ○ Other – please give details
- ○ None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

☑ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Miss Sian Pierce on 16/07/2014 08:33.

Job Title/Post:	Trainee Clinical Psychologist	
Organisation:	North Wales Clinical Psychology Programme	
Email:		
Signature:	.....	
Print Name:	Sian Pierce	
Date:	03/07/2014	*(dd/mm/yyyy)*

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co–sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

This section was signed electronically by Mr Hefin Francis on 17/07/2014 08:33.

Job Title/Post:	School Manager for Psychology
Organisation:	Bangor University
Email:	h.francis@bangor.ac.uk

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by carolien Lamers on 16/07/2014 11:16.

Job Title/Post:	Clinical lecturer/ clinical psychologist
Organisation:	North Wales Clinical Psychology Programme
Email:	c.lamers@bangor.ac.uk

Academic supervisor 2

This section was signed electronically by Dr Katie Salisbury on 16/07/2014 09:56.

Job Title/Post:	Clinical Psychologist
Organisation:	Betsi Cadwaldr NHS Trust
Email:	katiesiansalisbury@yahoo.co.uk

Research and Development Notification that governance checks are not satisfied

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol Y&D - Y Dwyrain
R&D Internal Review Panel - East

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Chairman/Cadeirydd - Dr Nefyn Williams PhD, FRCGP
Email: wendy.scrase2@wales.nhs.uk
sion.lewis@wales.nhs.uk
Tel/Fax: 01248 384 877

Miss Sian Pierce
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme,
Department of Psychology,
43 College Road
Bangor
LL57 2PW
psp0d8@bangor.ac.uk

15th August 2014

Dear Miss Sian Pierce

Re: Notification that governance checks are not satisfied

Study Title	Discourses around a diagnosis of Mild Cognitive Impairment
IRAS reference	140596

Thank you for submitting your R&D application and supporting documents.
The above study was reviewed by the BCUHB R&D Internal Review Panel in its meeting of the 14th August 2014

Below, please find a list of documents you have submitted for review:

Document:	Version	Date
Cover Letter to Research Ethics		05.08.2014
Proposal	1.0	23.07.2013
Consent Form	2.0	01.08.2014
Information Sheet for Memory Clinic Clinicians	1.0	04.07.2014
Interview Schedule	1.0	04.07.2014
Participant Information Sheet	2.0	01.08.2014
SSI Form	3.5	15.07.2014
R&D Form	3.5	16.07.2014
SL44 Acknowledgement of documents in compliance with additional conditions 14-WA-1072 (Pierce)		05.08.2014
SL05 Favourable opinion with additional conditions 14-WA-1072 (Pierce)		18.07.2014
Sources of Support	1.0	04.07.2014
School of Psychology Approval (email)		01.07.2014
CV Miss Sian Pierce		No date
CV Dr Carolien Lamers		Dated 2014
CV Dr Katie Salisbury		No date
Risk assessment form completed by researcher		08.08.2014
Bangor University Insurance Certificate		01.08.2013

Unfortunately, we have been unable to satisfy all the governance checks for your study.
Below are the details of the governance check(s) that we have been unable to satisfy:

The IRP discussed the research governance issues arising under the following checks:

Implications for internal departments assessed
The Panel discussed the additional work to support a study, ensuring that each department has assessed the impact of any additional procedures on their routine work.
As the study requires memory clinic staff to identify suitable patients and perform some of the recruitment procedures, the Panel requested to have sight of the departmental authorisation.

Research and Development Notification the governance checks are not satisfied

Compliance with Data protection and data security issues assessed
The Panel discussed the information governance aspects of the study, specifically relating to adherence with UK law and Health Board policies. A query was raised in relation to the arrangements for recording and storage of data. There is insufficient information in the protocol and application form to determine whether the recording device is encrypted to ensure that no participant identifiable information is at risk of inappropriate disclosure. Similarly, the Panel requested a clarification of whether the researcher's own laptop (where the data is to be stored) is encrypted It was also noted that the sound files and transcripts will be stored on University computers for a period of 5 years; the Panel requested a clarification of the custody mechanism for this data.

Risks to NHS organisation assessed
The Panel considered the potential risks generated by the study, the consequences of those risks and the arrangements for mitigation. This is a low risk hosted study and there would be no requirement for site monitoring unless there are concerns identified from central monitoring that cannot be addressed by any other means; the audit plan will request the submission of progress reports; the study may be included in other audits.

Before confirming its final opinion the Panel asked for a complete response to the issues identified in the following governance checks:

Implications for internal departments assessed
The Panel requested that the study is discussed with the Chief of Staff or the Academic Lead for the Mental Health and Learning Disabilities CPG and approval is sought;
The R&D office will provide the applicant with the relevant form for the CoS to sign, as a confirmation that the implications for internal departments have been assessed - as the study requires memory clinic staff to identify suitable patients and perform some of the recruitment procedures.

Compliance with Data protection and data security issues assessed
The Panel requested reassurance that the recording device and the researchers' personal laptop are encrypted to ensure that no participant identifiable information is at risk of inappropriate disclosure.
As it is proposed to store data for a period of 5 years on a university computer the Panel also requested a clarification of the custody mechanism (who has custody of the data, who will ensure that the data is destroyed after the retention period has elapsed, etc)

If you are able to provide additional information or further clarification to resolve these issues, we will review the relevant local governance checks again.

Authority to consider your response and to confirm the Panel's final opinion has been delegated to the Chairman.

The Panel will issue a final opinion on the application within a maximum of 60 days from the initial receipt of application, excluding the time taken by you to respond fully to the above points.

The Panel expects to receive a response from you by no later than 03rd September 2014 otherwise we shall consider the application to have been withdrawn.

Should you decide not to proceed with this study, please inform us as soon as possible.

Please do not hesitate to contact us if you require any further information or assistance.

Yours sincerely,

Dr Nefyn Williams PhD, FRCGP
Associate Director of R&D
Chairman Internal Review Panel

Copy to:

Sponsor:
Hefin Francis
School of Psychology
Bangor University
Bangor
LL57 2AS
h.francis@bangor.ac.uk

Academic Supervisors:
Dr Katie Salisbury
Clinical Psychologist
Flintshire Mental Health Services for Older People
Wepre House, Wepre Drive,
Civic Centre,
Connah's Quay
CH5 4HA
katie.salisbury@wales.nhs.uk

Dr Carolien Lamers
Clinical Psychologist
North Wales Clinical Psychology Programme,
Department of Psychology,
43 College Road
Bangor,
LL57 2DG
c.lamers@bangor.ac.uk

Research and Development Details of amendments

Miss Sian Pierce
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
School of Psychology
Bangor University
43 College Road Bangor
Gwynedd
LL57 2DG
5th September 2014

Dear Dr Nefyn Williams,

IRAS Reference: 140596

I am writing to inform you that I am able to provide additional information and resolve the issues identified in the Research and Development Internal Review Panel in its meeting on the 14th August 2014.

Implications for internal departments assessed
The study has been discussed with Dr Giles Harborne, Chief of Staff. I have attached the relevant form with Dr Giles Harborne's signature to confirm that he is in agreement with the study.

Compliance with Data protection and data security issues assessed
The data will be stored on an encrypted memory stick, and not saved on the researcher's personal laptop or on the recording device.

The data will be stored for a period of 5 years by Dr Katie Salisbury, who is a Research Supervisor on this project. She will ensure that the data is destroyed after the period of 5 years. Data will be stored in a locked cabinet in her office at Flintshire Mental Health Services for Older People, Wepre House, Wepre Drive, Civic Centre, Connah's Quay, CH5 4HA.

If you would like any further information then please contact me.

Yours sincerely,

Sian Pierce

Research and Development Approval granted

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol Y&D - Y Dwyrain
R&D Internal Review Panel - East

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Chairman/Cadeirydd - Dr Nefyn Williams PhD, FRCGP
Email: debra.slater@wales.nhs.uk
sion.lewis@wales.nhs.uk
Tel/Fax: 01248 384 877

Miss Sian Pierce
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme,
Department of Psychology,
43 College Road
Bangor
LL57 2PW psp0d8@bangor.ac.uk

05th September 2104

Dear Miss Sian Pierce

Re: Confirmation that R&D governance checks are complete / R&D approval granted

Study Title	Discourses around a diagnosis of Mild Cognitive Impairment
IRAS reference	140596

The above research project was reviewed at the meeting of the BCUHB R&D Internal Review Panel

The Panel is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

Thank you for responding to the Panel's request for further information. The R&D office considered the response on behalf of the Panel and is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

The Internal Review Panel is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board sites as described in the application.

The Documents received were as follows:

Documents reviewed	*Version*	*dated*
Cover Letter to Research Ethics		05.08.2014
Proposal	1.0	23.07.2013
Consent Form	2.0	01.08.2014
Information Sheet for Memory Clinic Clinicians	1.0	04.07.2014
Interview Schedule	1.0	04.07.2014
Participant Information Sheet	2.0	01.08.2014
SSI Form	3.5	15.07.2014
R&D Form	3.5	16.07.2014
SL44 Acknowledgement of documents in compliance with additional conditions 14-WA-1072 (Pierce)		05.08.2014
SL05 Favourable opinion with additional conditions 14-WA-1072 (Pierce)		18.07.2014
Sources of Support	1.0	04.07.2014
School of Psychology Approval (email)		01.07.2014
CV Miss Sian Pierce		No date
CV Dr Carolien Lamers		Dated 2014
CV Dr Katie Salisbury		No date
Risk assessment form completed by researcher		08.08.2014
Bangor University Insurance Certificate		01.08.2013

The study should not commence until the Ethics Committee reviewing the research has confirmed final ethical approval ('favourable opinion').

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (2009). An electronic link to this document is provided on the BCUHB R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the Betsi Cadwaladr University Health Board.

If your study is adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that the Chief Investigator will be required to regularly upload recruitment data onto the portfolio database. To apply for adoption onto the NISCHR CRP, please go to: http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=31979.

Once adopted, NISCHR CRP studies may be eligible for additional support through the NISCHR Clinical Research Centre. Further information can be found at: http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=28571 and/or from your NHS R&D office colleagues.

To upload recruitment data, please follow this link: http://www.crncc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment. Uploading recruitment data will enable NISCHR to monitor research activity within NHS organizations, leading to NHS R&D allocations which are activity driven. Uploading of recruitment data will be monitored by your colleagues in the R&D office.

If you need any support in uploading this data, please contact debra.slater@wales.nhs.uk or sion.lewis@wales.nhs.uk

If you would like further information on any other points covered by this letter please do not hesitate to contact me.

On behalf of the Panel, may I take this opportunity to wish you every success with your research.

Yours sincerely,

Dr Nefyn Williams PhD, FRCGP
Associate Director of R&D
Chairman Internal Review Panel

Copy to:

Sponsor:
Hefin Francis
School of Psychology
Bangor University
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Academic Supervisors:
Dr Katie Salisbury
Clinical Psychologist
Flintshire Mental Health Services for Older People
Wepre House, Wepre Drive,
Civic Centre,
Connah's Quay
CH5 4HA
katie.salisbury@wales.nhs.uk

Dr Carolien Lamers
Clinical Psychologist
North Wales Clinical Psychology Programme,
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43 College Road
Bangor,
LL57 2DG

c.lamers@bangor.ac.uk

General Appendix

Appendix 1.1: Mixed Methods Appraisal Tool Quality Rating

Table 1: ***Mixed Methods Appraisal Tool Quality Rating***

Study designs	Methodological quality criteria
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)? 1.2. Is the process for analysing qualitative data relevant to address the research question (objective)? 1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected? 1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?
2. Quantitative randomised control (trial)	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)? 2.2. Is there a clear description of the allocation concealment (or blinding when applicable)? 2.3. Are there complete outcome data (80% or above)? 2.4. Is there low withdrawal/dropout (below 20%)?
3. Quantitative non-randomised	3.1. Are participants (organizations) recruited in a way that minimizes selection bias? 3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes? 3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups? 3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)? 4.2. Is the sample representative of the population understudy?

	4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)? 4.4. Is there an acceptable response rate (60% or above)?
5. Mixed methods *	

*Not included as there were no mixed methods studies included in this review.

Appendix 2.1: Demographic Information

Demographic Questions

Participant Number:

Gender:

Age:

Ethnicity:

Married:

Education:

Informed consent gained:

Appendix 2.2: Information Sheet for Memory Clinic Clinicians

4/7/2014 Version 1

RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME

PRIFYSGOL BANGOR UNIVERSITY

Information Sheet for Memory Clinic Clinicians

Study Title: How do people with a diagnosis of Mild Cognitive Impairment use discourses to interpret the diagnosis?

Research Team: Sian Pierce (Trainee Clinical Psychologist), Dr Katie Salisbury (Older Adults Clinical Psychologist), and Dr Carolien Lamers (Older Adults Clinical Psychologist). North Wales Clinical Psychology Programme, Bangor University.

You are invited to assist in the recruitment for this study. This information sheet contains information about the study, but please contact me if you have any further questions.

This study will be looking at how people with a diagnosis of Mild Cognitive Impairment (MCI) talk about this condition and how they understand it. It is hoped that the findings will further help clinicians understand the impact of this diagnosis, and what it means to people and their position in society to have MCI. This study is being completed as part of a thesis at the North Wales Clinical Psychology Programme, Bangor University, by Sian Pierce (Trainee Clinical Psychologist) and has been reviewed and approved by the ethics committee of the School of Psychology, Bangor University, and NHS Research and Development, Betsi Cadwaladr University Health Board.

The study will involve an interview which will be recorded, of no longer than one hour, which will be completed by Sian Pierce (Trainee Clinical Psychologist). The interview will take place at the participant's home or at a local NHS facility.

In order to protect confidentiality, potential participants will be identified by yourselves, as staff who are working with people with MCI and who know the person who may be interested in taking part.

Appendix 2.2

The study has a few inclusion and exclusion criteria for potential participants.

Inclusion criteria:

A diagnosis of MCI which has been confirmed by the Memory Clinic multi-disciplinary team,

The ability to fluently communicate verbally in English,

The ability to give informed consent to take part in the study,

Aged 55 or over.

Exclusion criteria:

A co-morbid diagnosis (including a mental health diagnosis or physical health diagnosis),

Language difficulties (such as aphasia).

If you have identified someone who fits these criteria, and who you think may be interested in taking part in the study, could you please initially inform them (either face to face or telephone call) about the study and give them the included information pack, which contains further information about the study, including consent and confidentiality. There is a reply slip included in the information pack, with a stamped addressed envelope, for the potential participant to send back if they are willing to be contacted about the study. In order to protect confidentiality, I will not be able to contact the potential participants unless they return the reply slip with their contact details on to me. Of course there is no obligation for the person to take part in the study.

If someone you have identified agrees to take part in the study, the usual limits of confidentiality apply. You will only be contacted if I am concerned that the participant is at risk of harm from themselves or others. Their GP will not know they have taken part in the study.

If you have any further questions or would like further information please contact:

Sian Pierce
North Wales Clinical Psychology Programme,
Department of Psychology,
43 College Road,
Bangor,

Appendix 2.2

Gwynedd,
LL57 2DG
psp0d8@bangor.ac.uk
01978 726932 (please leave a message and I will get back to you)

If you have any complaints about how this study is conducted, please address these too:

For an NHS complaint:	Concerns Team Betsi Cadwaladr University Health Board Ysbyty Gwynedd Bangor Gwynedd LL57 2PW Email: ConcernsTeam.bcu@wales.nhs.uk Tel: 01248 384194
For a University complaint:	Hefin Francis (School Manager) School of Psychology Adeilad Brigantia Penrallt Road Gwynedd LL57 2AS Email: h.francis@bangor.ac.uk Tel: 01248 388339

Thank you very much for taking the time to read this information and assisting in the recruitment of this study.

Appendix 2.3: Information Pack for Potential Participants

1/8/14 Version 2

RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME

PRIFYSGOL BANGOR UNIVERSITY

Information Sheet

Study Title: How do people with a diagnosis of Mild Cognitive Impairment use discourses to interpret the diagnosis?

Research Team: Sian Pierce (Trainee Clinical Psychologist), Dr Katie Salisbury (Older Adults Clinical Psychologist), and Dr Carolien Lamers (Older Adults Clinical Psychologist). North Wales Clinical Psychology Programme, Bangor University.

Invitation to Participation

You are invited to read this information sheet to help you decide whether you would like to take part in this study. Please contact me (Sian Pierce) if you would like any further information, and take your time to make your decision. My contact details are at the end of this information sheet.

Purpose of the Study

The study will be looking at how people with a diagnosis of Mild Cognitive Impairment talk about it and understand it. This study will look at the use of 'discourses', which is the language that people use to talk about a particular topic. By understanding the language people use to talk about a diagnosis of Mild Cognitive Impairment, it is hoped that this will help clinicians who use the diagnosis to understand what it means to people. This study is being completed as part of a thesis at Bangor University.

What will the study involve?

The study will involve a recorded interview with me (Sian Pierce). Initially I will talk you through the interview process and then ask you to sign the consent form, which may take 15 to 20 minutes. The interview itself will take no longer than one hour. The interview can take place at your home or at a NHS facility near you. If you travel to take part in the study, your travel expenses will be reimbursed.

Why have you been invited to take part?

You have been invited because you have been given a diagnosis of Mild Cognitive Impairment by the Memory Clinic.

Do you have to take part?

No, your participation is voluntary. A member of the memory clinic team, who knows you, has identified you as somebody who might be interested in taking part in this study. The memory clinic team will not be able to give me your information, so if you are interested in taking part, please send the attached reply slip back, in the stamped addressed envelope.

When we meet, I will explain the nature of the study to you and answer any further questions you may have. If you are happy to proceed, you will be asked to sign a consent form. However, you can withdraw from the study at any point and any information you have provided will be destroyed or removed. This means that you can withdraw part-way through or at the end of the interview.

Will your participation in the study be kept confidential?

Yes, only your GP will be informed that you have participated in the study. The usual limits of confidentiality will apply, in that I will only discuss your participation in the study with a member of the Memory Clinic if I am concerned that you or other people are at risk of harm. I will always discuss any concerns I may have with you before I speak to colleagues.

The study will be written up as part of a doctoral thesis. However, all information will be anonymised and any clues as to your identity will be removed. Any quotes from you used in the thesis will be entirely anonymous. Disguised extracts from the interview may be quoted in the thesis and any subsequent publications.

What will happen if you are interested in taking part in the study?

If you are interested in taking part in the study, or have any further questions, please complete the reply slip included in this information pack and post it in the attached freepost envelope. When I have received the reply slip, I will contact you to arrange a time to meet. This might be at your house or at a NHS facility near you.

When we meet we will further discuss consent, confidentiality and your right with withdraw

at any point. Should you wish to continue, you will be asked to complete a consent form and some demographic questions (such as age, and when you were initially diagnosed with Mild Cognitive Impairment). The interview will then take place and be recorded.

What will happen to the information you give?

The information you have provided and the interview itself, will be kept confidential for the duration of the study. On completion of the thesis, the information will be retained for a further five years and then destroyed and the recording removed.

What will happen to the results?

The results will be presented in the thesis. They will be seen by the research supervisors, a second marker and the external examiner. The thesis may be read by future students on the course. The study may be published in a research journal.

If you are interested in the results of the study, I will send you a summary once the study has been completed.

What are the possible disadvantages of taking part?

I do not envisage any negative consequences for you in taking part, however it is possible that talking about your experience in this way may cause some distress. At the end of the interview, I will discuss with you how you found the experience and how you are feeling. I will give you an information sheet at the end of the interview with contact numbers for support, should you feel distressed, or you could contact your GP. You can also withdraw from the study at any point.

Who has reviewed this study?

This research has been reviewed and approved by the ethics committee of the School of Psychology, Bangor University, and the NHS Research and Development, Betsi Cadwaladr University Health Board.

Appendix 2.3

If you would like any further information, please contact:

Sian Pierce
North Wales Clinical Psychology Programme
Department of Psychology
43 College Road
Bangor
Gwynedd
LL57 2DG
psp0d8@bangor.ac.uk
01978 726932 (please leave a message and I will get back to you)

If you have any complaints about how this study is conducted, please address these too:

For an NHS complaint:	Concerns Team Betsi Cadwaladr University Health Board Ysbyty Gwynedd Bangor Gwynedd LL57 2PW Email: ConcernsTeam.bcu@wales.nhs.uk Tel: 01248 384194
For a University complaint:	Hefin Francis (School Manager) School of Psychology Adeilad Brigantia Penrallt Road Gwynedd LL57 2AS Email: h.francis@bangor.ac.uk Tel: 01248 388339

Thank you very much for taking the time to read this information and considering taking part in this study.

Reply Slip

If you are interested in taking part in the research, please fill in this reply slip and post it in the envelope provided. You do not need to put a stamp on the envelope.

☐ I am interested in taking part in this research. I would like the researcher to contact me.

My name:

My telephone number:

My email address:

My address:

Appendix 2.4: Consent Form

1/8/14 Version 2

RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU

NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME

PRIFYSGOL BANGOR UNIVERSITY

CONSENT FORM

Study Title: How do people with a diagnosis of Mild Cognitive Impairment use discourses to interpret the diagnosis?

Research Team: Sian Pierce (Trainee Clinical Psychologist), Dr Katie Salisbury (Older Adults Clinical Psychologist), Dr Carolien Lamers (Older Adults Clinical Psychologist).

Please initial all boxes

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I agree for my GP to be informed that I have taken part in this study. ☐

4. I give permission for my interview to be recorded. ☐

5. I understand that anonymity will be ensured in the write-up by disguising my identity. ☐

6. I understand that disguised extracts from my interview may be quoted in the thesis and any subsequent publications. ☐

7. I would like to receive a summary of the findings of the study, when the study is completed. ☐

8. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Chief Investigator	Date	Signature

Appendix 2.5: Interview Schedule

4/7/2014 Version 1

Interview Schedule

When using discourse analysis, as much natural conversation as possible should be allowed, in order to elicit and identify discourses. Therefore a semi-structured interview will be used.

Introduction

I would like to talk to you about when you were told that you have Mild Cognitive Impairment.

Externalizing

It was decided that the interviewer should refrain from presenting the definitions, and let the participants create the reality.

1. Can you say what you think Mild Cognitive Impairment is?
    a. Possible follow up if the participant mentions dementia: How is it the same/different?
2. Had you heard about Mild Cognitive Impairment before?

Personalizing

1. How has being told you have Mild Cognitive Impairment influenced your life?
2. How do you describe/think about yourself now, compared to before?
3. What do your family and friends say about this?

Specifying

1. Can you say what the advantages are of knowing you have Mild Cognitive Impairment?
2. What are the disadvantages?

Closing questions

1. Is there anything you feel we have not discussed that you feel is relevant?
2. Are there any areas you feel are too difficult to discuss?

Appendix 2.6: Sources of Support

4/7/2014 Version 1

RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME

PRIFYSGOL BANGOR UNIVERSITY

Sources of Support Information Sheet

Should you wish to talk to someone regarding what we've discussed today, there are a number of people you can contact.

You can talk to your GP, who may be able to refer you to a counsellor within the clinic should you wish. You could also speak to the clinician who informed you about the study.

There are also a number of organizations that provide confidential support and information:

Samaritans
08457 909090 – 24hours a day
http://www.samaritans.org/

Age UK Information & Advice
0800 169 6565 – 8am to 7pm
http://www.ageuk.org.uk/

Alzheimer's Society
01248 671137
http://www.alzheimers.org.uk/

MIND – a mental health charity
0845 766 0163 – 9am to 5pm
http://www.mind.org.uk/

Appendix 2.7: Sample Interview Transcript and Analysis

Bold: said with emphasis/louder voice. *Italics*: said softer/quieter/under breath. !: vocal intonation became higher.
(.) noticeable breathing space, (..) 3-5 second pause, (…) more than 5 second pause.
Underscore: indicating text referred to in findings.

Sections have been removed for readability.

Coding	Transcript interview with Margaret	Findings
	Interviewer: Okay. Urm so I'd like to talk to you today about your experience of your diagnosis of mild cognitive impairment. Urm and I was just wondering if you could tell me, to start off with, what you think mild cognitive impairment is?	
MCI	Margaret: (.) *I think* (.) it's ur (.) the way it's affected me is that (.) I'm not remembering, facts from (.) from the present. There's a lot I can remember from the past, and so I'm forgetting names, even though I know the person that I'm talking to so well. And I can start a conversation and **forget** (.) just where the things going, sometimes. [Okay] And um it's very funny because my husband suffers from the same so we tell each other long stories but we can usually fill each other's gaps up! [Oh right ok] But	Hesitant, uncertain, does not know what to say. "me", "I'm" – Personalising. Emphasis – surprise? "funny" implying humorous or strange? – minimising? "suffers" – it is a problem. Something is missing? Part of something bigger?

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	it's very funny when there's somebody else there. [Yeah] So uh it's it's an impairment of of ones previously (.) reasonably bright intellect, it's as simple as that it it's. I used to be able to (.) go off into all sorts of detail (.) even sit exams, and yet here I am now and I'm fumbling about trying to remember words and names.	"funny" – repetition. Externalising. No other words. Contrast to previously "reasonable bright intellect".
Expertise	[Yeah] So that's how it works for me. Interviewer: Yeah. You urm just said a moment ago about impairment of your intellect, so is it affecting more than just your memory, are there other parts that you think it's affecting?	Active.
Ageing	Margaret: Well it causes me to feel quite unhappy sometimes (.) that I've lost that edge that I think I had. You know, that I just feel that I'm a silly old woman sometimes, that I just can't, be as bright and forthcoming as I was. I've got three daughters (.) and, we used to have such lovely conversations, and we still do because they know they can fill in the bits and pieces but (.) I just think sometimes that life's got a bit less (.) urr (.) enjoyable in that sense. [Right, okay] Although they tend to talk about fashion and that things, which I joi don't join in with anyway (Interviewer laughs). They're three lovely girls.	Something/a part of her is lost. Will not be taken seriously – societal view of old people? Hesitation – uncertainty vs emotive.

	Interviewer: Yeah. Yeah. Urm, so in what ways has it affected you on a day to day basis?	
Ageing	Margaret: On a day to day basis? (.) It hasn't, it hasn't really, no. [Okay] No the days come and go, there's (.) no it hasn't really affected me at all, not that side of things it hasn't. No. [Yeah] (..)	Repeating, clarifying. Does not finish sentence. Repetition "no" – emphasis vs unsure. Two sides?
Death/dying	And there's a constant feeling of being at the end of my life now, I'm very aware that I'm 77, and that (.) ur I've got to really enjoy every single moment of what's left, cos I'm, ha, happily married and I've got a lovely family, just keep thinking I'm going to have to leave them all one of these days, sooner rather than later. **That** comes into my everyday feelings. [Okay] A lot. [Yeah] Quite a lot.	Implying impending death – unspoken? "got to" – not a choice? Imposed/expected of her by others. Euphemism – Impending death. Ageing and death – more important, given more space to think about than MCI.
	Interviewer: Yeah. So has having this diagnosis of mild cognitive impairment almost emphasised that a little bit or?	
Expertise Dementia	Margaret: Well in a sense it was a bit of a relief cos I I already knew that it was that I was suffering from it. [Okay] I'd read a bit about it and I already felt that's where it was going. [Okay] But um (.) so many of my friends (.) and people that I talk to, they're suffering in the same ways so it's become a bit of a joke really	"already knew" – she is the expert on her own wellbeing. "it" – nameless – what is it? "suffering" – illness discourse. Repetition of "it" – emphasis. Repetition of "suffering".

	(laughs). [Right] *Yeah it has*. So I just tend to accept it, what can you do? [Yeah] I do lots of puzzles and read a lot and that helps. Interviewer: Yeah (.) so had you heard about mild cognitive impairment. [Yes] before you went to the memory service?	Quiet – resigned? Rhetorical or wants answer from an expert? Powerless.
Expertise	Margaret: Oh yes. Interviewer: Oh right okay.	Certainty.
	Margaret: Yes I have, yes I had heard about it. Interviewer: Where had you heard about it?	Repeating – certain, but no other words.
MCI Expertise	Margaret: Well (.) I suppose (.) from way back in my work and all the rest of it. You know as a (PROFESSION) I knew a lot about, when I visited the elderly I was aware of of what it was and what was going on with them. [Yeah] (.) Yeah so yes I had heard about it, I knew what it *involved*. [Yeah] Just a, just a bit, anxious about how quickly it, it proceeds. [Yeah] And how much	Pauses, vague, unsure. Contrast to above – becomes less certain. Vague, unsure. Expert – knew from her work vs uncertain – repetition, not finishing sentences. Repetition – emotive and uncertain about whether to say, whether to name?
Dementia	worse it can get. (.) And that awful word Alzheimer's *looming up.* [Yeah] *All the time*. Because I had a, my grandmother on my	Description of medical diagnosis. Labels are powerful and evoke powerful connotations. "looming up" – growing, getting bigger.

	father's side and his sister suffered from Alzheimer's, and I remember how they were and how it affected them. Interviewer: Yeah. So is that something that's playing on your mind at the moment?	"suffered" – word linked to dementia/illness. Used several times before.
Dementia	Margaret: Urm (.) <u>from time to time</u> I remember it and think about it. But I <u>try to avoid</u> thinking about it. Interviewer: Okay. Yeah (.) how do you manage to avoid thinking about it?	Tentative. Avoid – active effort. Does think about but does not want to.
Dementia Ageing	Margaret: Well (.) those sort of thoughts can make you feel quite miserable and so (.) I'm still <u>looking at it</u>, <u>we</u> go out a lot and <u>we</u>, <u>we</u> run a club for old people. [Oh right] A weekly club. [Yeah] And that <u>takes up a lot of the interest in our lives</u>. Urm and several of those ladies, <u>they</u> tend to be all ladies because it's a whist club. Interviewer: A?	Cannot hide from it, getting closer. Outsider looking in. Repetition of "we" – not alone, positioned self within a group. No space for MCI, dementia, illness. "they" – separating herself – does not identify herself as an old lady?
Expertise	Margaret: A whist, whist drive, sort of a whist drive? <u>You know,</u>	She's the expert – has the interviewer not heard of a whist drive?

	haven't you heard of? Interviewer: No I haven't. Margaret: The card game whist. Interviewer: Oh yes, yes I know what you mean now. Yeah. Okay.	
Death/dying	Margaret: So we run it as a little whist group, we've been running it for 12 years. [Yeah] And we've seen a lot of our (.) urm members declining over those years and we've lost a few, through death and um (.) but the ones that go are very happy to be there. [Yeah] And enjoy it (.) and we enjoy it too. [Yes] So I	"little" – no space. Hesitant about what to say, how to say it. "declining" "lost" – in number or cognitively? No words. Separating herself from others in the group.
Ageing	suppose that's one way that you're aware that as people get older, they lose that edge, you know that (.) but it doesn't seem to worry them too much we've got two 90 year old. [Oh yeah] Bright 90 year olds (.) [Yeah] So it seems to take people in	"you're" "they" – not her – separating herself again. "that (.) but" – does not finish sentence. "them" – separating when talking about decline vs "we've" – including herself when talking about "bright 90 year olds".
Expertise	different ways. I think mines the very gradual way, perhaps, I don't know.	"it seems to take people" – nameless – lose people? Own perception of prognosis reduces in certainty.
Dementia	Interviewer: Do you mean the way to d dementia?	Hesitation – unsure whether to name "it"? Dementia unspoken/

		not spoken about/hidden away?
Dementia Expertise	Margaret: Yes. Yes. I think so. You can stave it off if you, you know if you keep active and all the rest of it. The newspapers are full of how to avoid it anyway, aren't they? We get lots of urm (.) advice how to avoid dementia. Interviewer: Yeah. Do you do any of those things that you've read in the papers?	"You" – externalising. "stave" – fight against. Vague, lots of ways to "stave" it off? Who is the expert? Margaret, newspaper or interviewer? "advice" – not definitive, opinions.
Expertise Dementia	Margaret: Well yes, you know it's all about diet and exercise, and getting out and about and meeting people and having lots of interests. Yes we do, we do do all those things. Interviewer: Is that in an active effort to, as you said, stave off dementia or are those things that you would just do anyway?	"we" – inclusive, who? Do those things but does not seem to work? Do those things already?
Expertise Dementia	Margaret: I think they're things we would do anyway aren't they. [Yeah] So yes (.) but you know we were talking about, see this whole (.) what's it called again? Interviewer: Mild cognitive impairment?	She has the expertise – already doing those things. Unsure, has not got the words.

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Expertise	Margaret: Yeah it's not that so much, but what (NAME)'s been doing, this mindfulness. [Oh right] Yes well I try to use that when I start getting these urm feelings and unhappy thoughts. [Yeah] Urr but I don't find that it helps all that much sometimes. You know I try to concentrate on my breathing and all the rest of it, but it works for a few minutes and then it all comes back. Best thing for me is to get in my in my car and go to (PLACE) or somewhere. [Yeah] And talk to everybody. And that gets rid of it. Interviewer: Yeah. Yeah. So getting out and about?	Expert does not know/have the answer. Cannot be stopped. She is the expert, she knows what she needs. Something unwanted. "it" – nameless.
Expertise	Margaret: Definitely is is it's the best policy for me. [Yeah] And that's why it's so hard for people who are housebound, it must be dreadful. Interviewer: Yeah (.) so what prompted you to go to the, was it the memory clinic or was it your GP to start with?	Definite, decisive, followed by repetition – knows what she needs but is difficult to do? Does not always work? Unspoken.
MCI	Margaret: Yes it was the memory clinic. Because (.) I'd noticed that my memory was getting worse and worse (.) so I asked Dr (NAME), about it and she referred me. [Right] So I've been	She knew, she had the knowledge.

	going for a while. Section removed. Interviewer: (.) Yeah okay. Urm do you, has having mild cognitive impairment affected your ability to do mindfulness do you think or to do meditation, has it impacted on that?	
Expertise	Margaret: Oh no. [No] No it hasn't at all. [Yeah] No *that doesn't work that way at all*. [Okay] I think we tend, I think sometimes we meditate more often than we realise, you can you can perhaps just sit down and look out at the garden and perhaps just drift off into a meditative state you know, (.) so I think we do more of it than we realise. [Yeah] But (.) the anxiety thing, it doesn't seem to work. [Yeah, *okay*] (.) As we're doing this chatting thing (laughs) I'll, I might as well just say that one of the worst things for me is animal cruelty, I can't bear it. And often when you're out and you see a dog perhaps being (.) badly treated and (.) it absolutely gets me (.) and then I try to use the mindfulness thing. If I can't intervene, and usually you can't, (.) cos it's across the road from you or something, that's one of the worst things for me.	Repetition of "no" – insistent that MCI has not affected her ability. Not got the right words to describe what she means – vague. Implied expectation that it should work. "As" – as an aside, something that's related? Frequent pauses but fluent content – emotive. Helpless/lack of control/lack of power.

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	Interviewer: Yeah. Yeah. So if some things really get to you. Margaret: Yes very badly. Interviewer: And you try to use mindfulness and sometimes it helps and sometimes it doesn't. Margaret: Yeah that's right. Yes. It does. Interviewer: Yeah (.) okay. So do you remember being told about your diagnosis of mild cognitive impairment?	
Expertise	Margaret: Yes, it was (NAME) that told me. [Okay] Yeah (NAME) told me, <u>the doctor didn't</u>. Interviewer: No. So you had the assessments at the memory clinic? Margaret: Yes. Interviewer: So you had some tests to do.	Expected the doctor to tell her? Doctor viewed as more of an expert then who did tell her?

Expertise MCI	Margaret: Yes I did. [Yeah] <u>She (.) I</u> was quite amazed at what it showed, because one the major things was that there were four pictures. And you to, look at those pictures and then explain (.) what the people in the picture were doing. <u>I **couldn't** **do it**</u>! <u>I **just couldn't** **do it**</u>! <u>I **couldn't** **even remember who was in the pictures**</u>! [Yeah] Except that I ur I recognised was a family and a dog there. [Yeah] So that **amazed** me, that I couldn't do that (.) but <u>I can</u> remember ur lists of words, and <u>I can</u>, <u>I can</u> do that. [Yeah] So that was a **real shock**. Interviewer: Okay, so did you find out that different parts of your memory were affected or weren't affected?	Change of perspective. Repetition "I couldn't" – emphasis, shock, unexpected. Repetition "I can" – contrast to above. Moves from past to present – focus on the here and now? Distancing self from diagnostic process.
MCI	Margaret: Yes. That's right. Yes definitely, there were <u>bits</u> that *were* and <u>bits</u> that *weren't*. Interviewer: Yeah. Urm what was it like being told that you had this diagnosis? Margaret: (.) Urm.	"bits" – not part of her, detached. Implies small, minimising?

	Interviewer: If you can remember?	
Hierarchy of illness Ageing	Margaret: It was a little bit, shocking I suppose in a way (.) but just a month ago I was told that I had cancer, so. [Oh gosh] You just think to yourself, which is worse you know. It's all part of old age. It's the old vehicle, you know (.) having problems in its different parts I suppose. [Yeah] So (.) compared with **that** diagnosis, the mild cognitive impairment one, ur wasn't quite in that league.	Conflict – minimising the amount of shock? She already knew? "but" – something else more shocking, in contrast. "all part" – making sense through normal ageing, expected. Machine metaphor – more familiar discourse to make sense. "**that**" – cancer emphasised but nameless. League of illnesses.
	Interviewer: (.) What do you think the differences are between the two diagnoses, why whys it changed your opinion?	
Hierarchy of illness Death/dying	Margaret: Well its urm (.) well its whether it involves lots of treatment and constant visits to the hospital, and feeling that you know (.) definitely on the way to the end now. I suppose with mild cognitive impairment, there were things that you can do,	Repetition – time to think, unsure. "constant" – enduring, taking over identity/life. Death implied, not said.
Dementia	you can read, which I love reading an, and watch (.) dramas on television. (.) It doesn't feel as severe, as Alzheimer's yes it would be. We've got a friend, younger than us, and his wife got it and he's lost her completely. She doesn't know who he is and they were such a happy married, couple. [Yeah] And, terrible	"you" vs "I" – moves from detachment to personalising. Alzheimer's is viewed as severe. Less expected in younger people? She has gone, her identity has gone. No longer happily married.

	grief that has affected him. He's lost her, he feels completely (.) whereas with the diagnosis of cancer then, the chances are that you still retain a lot of your memories you know an (.) and you recognise your family and that stuff, I suppose. Interviewer: Yeah. I guess it doesn't affect you as a person, what your personality is, [That's right] it doesn't affect you intellect? Margaret: Yes that's what it is. Interviewer: You still stay the same person.	Repetition. Comparing with other illnesses – making sense of what factors affect severity? "recognise" – still known. "I suppose" – weighing up.
Dementia Hierarchy of illness Ageing Death/dying	Margaret: You do. [Yeah] Well I think you do, I haven't been there yet quite but I think you do. [Yeah. Yeah] It's just this awful long haul down to (.) old age isn't it and death (.) you sort of think how nice it would be if you could just sort of press a button and say right that's it I'm going, and there's a lot of that of course in, in the press isn't there. [Yeah] When I was, a lot younger I didn't think along these lines. But now I've reached (.) this age (.) I suppose (.) *I think about it quite a lot*. Interviewer: Mmm (.) yeah. Do you ever speak to your family	Reduces in certainty. "yet quite" – aware positioning is close, trying to distance self. Negative imagery – long hard journey, like ageing? "death" – explicitly stated. "you" – detachment. Implied assisted dying. "press" – media influences. Repetition "I" – contrast to "you"/detachment above – taking ownership of what she had said before. Pauses, but fluent content – well-formed discourse, emotive.

	about this?	
Death/dying Expertise	Margaret: Urm (.) a <u>little bit</u> but (.) *no* <u>I'm far too busy listening to what they're telling me</u>. But a <u>little bit</u> *I suppose*. My youngest daughters a (<u>PROFESSION</u>) and she and I talk about these things quite a bit. Interviewer: Okay. Yeah. (.) Urm with your youngest daughter being a (PROFESSION), did she suggest that you should go to your GP about the memory problems?	Repetition "little bit" – can only tolerate a little? No space to talk, cannot be tolerated, younger generation discourse is louder. Her daughter is the expert?
Expertise MCI	Margaret: <u>No. No</u>. [No okay] <u>No</u>, she didn't. Interviewer: Do does your family, so your daughter's, do they know about your memory problems?	Repetition "No" – definitive. Her choice.
MCI	Margaret: Yes they do. Interviewer: Your diagnosis? Margaret: Yeah. [Yeah, okay] It doesn't seem to make any difference to them at all.	Short clipped sentences when asking about family's views. No shared discourse built – if do not share then no discourse?

	Interviewer: No?	
MCI	Margaret: Because we we don't dwell on things like that. You know. [Yeah] (.) *We have lots of other interesting things to talk about*.	Repetition "we" – emphasis – her as part of her family. Hierarchy of discourses – what is more prominent? Younger generation discourse?
	Interviewer: Yeah, okay. So were they not surprised when you got this diagnosis? Or was it just I've got this diagnosis and that's that and moved on from there?	
Hierarchy of illness MCI	Margaret: Well the diagnosis of this, its minor isn't it. Its its, you know, I mean the chances are that it's not going to get any worse because (NAME) did a, when I first met her she did a uh the test and then a year later she did the test, and she said if anything it's	"minor" – comparisons. "isn't it – rhetorical, seeking agreement. "Its its" "a," "a uh" – repetition, stop start sentences – uncertain?
Expertise	got slightly better in parts. [Okay] So that was reassuring. So I don't see that diagnosis as really being anything to **worry** about.	She's the expert. "that" – in comparison to other diagnoses.
Ageing	[Yeah] It's just, it's just something that happens as you get older. [Yeah] And lots and lots of people live with it, and there are all sorts of ways of dealing with it. So no, I don't see it as a, as a major problem.	Justifying, inevitable. Positioned within normal ageing. Emphasis, MCI is common. "major" – contrast to "minor" above.

	Interviewer: No, no. Do you know what the urm prognosis is for mild cognitive impairment, so what the outcomes might be in the future?	
MCI Expertise	Margaret: Well no because I haven't had that conversation so I don't know. I'd be quite glad if you'd tell me actually (laughs).	Conversation with an expert. Putting researcher in expert position.
	Interviewer: Yeah, I'll tell you what, I'll tell you towards the end [Towards the end] of the interview. [Okay] Yes I will go through. [Yes] I will go through that with you.	
MCI Expertise	Margaret: And how to spot when things are going worse, because I don't think I know that really.	Tentatively putting interviewer in expert position – not sure if she does not know?
	Interviewer: Yeah. So have you been tested twice then by the memory service?	
Expertise	Margaret: Yes. [Okay] Yes and I think they're going to test me again, a year from the last time. [Yeah] I'm hoping they will anyhow.	"they're" the experts, the memory clinic.
	Interviewer: Yeah. My guess is that you probably are on that	

	waiting list to be reassessed in a year's time.	
Expertise	Margaret: Yes I think so, yes I will be. [Yeah] That's common is it to be tested every year sort of thing?	Unsure, becomes more certain. Putting interviewer in expert position.
	Interviewer: *Yeah*. So how do you feel about being just put on this waiting list to just be tested every year?	
Expertise	Margaret: It's reassuring to know that somebody's keeping an eye on you. [Yeah] It means that you know, at some point you're going to be shown (.) whether you're just as you were or you've you've got worse. [Yeah] So it's sort of an official recognition of where you are.	Surveillance. Somebody else is the expert. Repetition "you" – distancing/externalising. Power? Makes diagnosis official and legitimate.
	Interviewer: Yeah. So you don't feel worried about the testing coming up, you know when you get the appointment letter through?	
	Margaret: No, absolutely not. I quite enjoy it (laughs)! (Interviewer laughs) [Oh okay!] *Yes I do*.	Certain, definite.
	Interviewer: Yeah. And have you spoken to people outside your	

	family, so friends, about this diagnosis of mild cognitive impairment?	
MCI	Margaret: I've <u>not actually</u> mentioned the diagnosis, <u>just simply, just simply chatted (.)</u> generally about what a pain it is when you can't remember names and <u>(.)</u> especially in our little club, we're always talking about <u>it</u>, <u>but</u> they can all play a good game of whist! (laughs) So you know that are a few there that sort of say oh I can't remember what I was talking about and I'll say well	Would normally share with friends? Repetition, pauses – unsure what to say. What is "it"? "but" – minimising previously mentioned difficulties, can still play whist.
Ageing	that's just how I am, **<u>we're all the same</u>** you know! And that <u>gets over that</u>, that's fine. It's like a sort of urm supportive little group in that sense. [Yeah] While they're busily playing cards they're telling you all these things that affect them, so that by <u>sharing it it helps a lot</u>. [Oh okay. Yeah] So <u>sharing worries</u>. But <u>we don't use words like mild cognitive impairment</u>. [No] No. We don't use those words.	She's no different to them, included, part of social group. Implied that there is something to get over? Something difficult implied in the conversation/discourse of forgetting – dementia? Sharing helps – but does not share MCI. These words hold no meaning.
	Interviewer: What words do you use?	
MCI	Margaret: <u>(.)</u> Just <u>we, I</u> can't remember so and so's name when I meet them, and you know (.) I I went to the shops and I couldn't remember what I'd come for and I go upstairs and I get to the top	Pauses – unsure of what to say, how to answer question. Moves from "we" (group) to "I" (self) – uses herself as an example because MCI is not spoken about.

	of the stairs and I can't remember what **on earth it was I came upstairs for**, things like that. Interviewer: Yeah. So you talk about how it practically affects you. [Yes] In your day to day lives. [Yes] So you know, the things that you forget.	Said with emphasis – surprise, emphasis on effects on MCI.
MCI Expertise	Margaret: And it so doesn't matter. You make lists more than you used to. Lists are very useful aren't they? Interviewer: Yeah. So is that something that you do then to help you with your memory problems?	"so" – emphasises. Uses list example to minimise problems. Pull in, include the interviewer – Margaret already knows the answer, she is the expert.
MCI	Margaret: Yes, we've got a notice board in the kitchen which tends to have all the bits and pieces on it that we need to remember, an. [Yeah] You know, although I've just been to see what the doctors su (.) what practice my doctor is in and I can't even find that on the board so that must've been thrown away at some point. Interviewer: *Yeah*. So is there anything else that you do to help with your memory problems?	"we've" – her and her husband, part of a group, included. Exception, notice board does not always work. "even" – surprised, should be able to find it.

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MCI Expert	Margaret: Urm (.) yes I do crosswords. [Yeah] And urm (.) I don't do them because of <u>that</u>, I do them because I enjoy doing them so (.) I don't think I've got <u>too much</u> to worry *about at the moment*, its it is very mild *<u>whatever it is</u>*. [Yeah] I know it's probably going to get worse, but *<u>so what</u>*, you know. There is, there are various things <u>they</u> can do aren't there, aren't there medications, medication <u>that you can take?</u> [Urm] <u>That might help?</u> Interviewer: Yeah there is for Alzheimer's, yes. [Yes] *Yeah* (.) Urm (.) it won't nes it won't make it better but it can stop it deteriorating as quickly.	"that" – MCI/memory problems not named. Implied there is something to worry about. Unknown, no words – MCI does not mean anything. Said quietly – difficult to say, does not mean what she says? "they" – who? Who are the experts? Interviewer as expert. Asking for reassurance.
MCI Ageing Dementia	Margaret: Yes. And <u>you</u> sort of wonder, at what point, <u>you</u> know <u>you've</u> got <u>Alzheimer's rather than you know a bit of senile dementia,</u> what where is the cut-off *point*. Interviewer: Yeah, what do you think the cut-off point is?	"you" – detaching . "bit" – can just have a small amount? Which story to tell – ageing vs dementia.
Dementia	Margaret: *Well <u>I don't know</u>, <u>I don't know</u>* really. (.) Now that would worry <u>me</u>, that would worry <u>me</u> very much. (.) <u>I'm</u> not	Repetition, said quietly, pause – time to think, uncertain. "me" "I'm" – personalising.

	sure (.) perhaps there isn't a cut of point, perhaps there's a	Offering an alternative answer.
Expertise	gradual deterioration, *I don't know*. (.) I'll ask you at the end (laughs).	Putting interviewer in expert position.
	Interviewer: Urm and what do you think has caused the mild cognitive impairment, do you have an idea of what you think might've caused it?	
Ageing	Margaret: I think it's just part of of getting older. [Yeah] We're	Minimising – normal.
Dementia	all living a lot longer now aren't we? But also the fact that it's in the family as well. [Right] It seems to be in the female side of my father's family I think. [Yeah] Because he was as bright as a button when he went and so was my mum. But it might be the female side, so I'm in direct line aren't I from Granny to Auntie to me. And so I start thinking along those lines. There's a lot	Inescapable. Genetics – cannot change prognosis, inescapable.
Expertise	being written about it, and I tend to read it if I see it in the, particularly in the newspapers you see, articles about it, I read those (.) but I try not to think about it too much.	Written word is powerful. Media influences. Contradiction – does vs does not want to know.
	Interviewer: Yeah. *Yeah*. (.) *Okay*, and how did you think about yourself before the diagnosis of mild cognitive impairment? How would you have described yourself?	

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MCI	Margaret: Well (.) just quite capable of (.) of remembering facts and (.) holding a decent conversation without having to think now where did I see that or whose name was *that or*. It's harder now to chat with people, especially when you don't know them too well (.) although I'm not doing too badly with you, am I? (laughs). Interviewer: No, not at all (laughs).	Now not as capable? Pauses – difficult to articulate? Past vs present – changes. Bringing interviewer into conversation, seeking reassurance.
Hierarchy of illness	Margaret: No, so it hasn't really made that much difference. (.) *There's so many other things* to worry about. Interviewer: Yeah. Do you think of yourself any differently now, compared to before you had the diagnosis?	Changes perspective to above – does vs does not affect her. "other things" – other more concerning illnesses.
Ageing Hierarchy of illness	Margaret: (.) Yes I think do. I used to be able to whizz through my life, you know whizz through the housework and go to work, and see the family and now everything slowed down very much. [Yeah] But that might because there's an underlying depression there too I think. Which, I've got tablets for that, (.) I but think everything's slowed down *so much and* (.) arthritic pain doesn't	"whizz" – speech is fluent, continuous, paced. Talks about slowing down – speech begins to slow down – frequent pauses, contrast to above. "slowed down" – reflected in speech.

	help either (.) it's the tendon (.) *um*. (.) You're much less efficient at things, even (.) cooking, you know, becomes an absolute (.) burden sometimes, you know, but I've got a husband who enjoys cooking and he's just made 18 pans of marmalade (laughs). Interviewer: Gosh! (laughs) That will keep you going for a while!	"even" – the changes are unexpected.
Ageing	Margaret: (laughs) Yes well we give a lot of it away. But he loves doing things like that, that's a great blessing. He's out walking at the moment, he's the same age as me, 77 and he's got a walking friend and he's got a friend he goes to air shows with and, he's very positive, and (.) [Yeah] he makes everything a lot easier. [Okay] Yeah he does. Interviewer: Yes, so he's quite supportive?	Minimising how long it will keep them going for – will not be around for that long? Alternative ageing discourse – not slowed down like her. Everything is now harder.
Ageing	Margaret: **Very** supportive. Yes, he's fantastic. [Yeah] So lucky. And *how long have we been married now* (.) urm, *I think its* 35 years now we've been married. [Yeah, wow] And urm I'm just so lucky to have him. [Yeah] (.) His ears'll be burning!	Implied others not so lucky. Putting husband in position of responsibility – she is dependent on his support.

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	Interviewer: (laughs) Yeah. Urm, so, do you talk to him about the mild cognitive impairment?	
MCI	Margaret: Yes, yes, sometimes. But his his way of looking at it is, <u>don't worry about it, it's fine</u>. [Yeah] You know, we'll deal with it, its fine, and that's his way of looking at everything really. [Yeah] He does worry about things like the garden. See I <u>used to</u>	No space to talk about/husband does not want to talk about it either – no space to talk about MCI. Past tense – no longer? Things are changing.
Ageing	love the garden, when we moved here 25 years ago, I <u>had</u> greenhouses full of tomatoes and I <u>had</u> a lovely vegetable garden, and , and now it's it's really hard work to do it, so I've filled it up with shrubs and lawns and trees. [Yeah] There's half an acre out there you haven't seen have you?	
	Interviewer: No. Gosh.	
	Margaret: And it's a big garden. We had hens when we came	
Ageing	here. [Yeah] And we thought of having a goat (.) and <u>it's all gone</u> now, you know. And you see <u>now our children have those sort of</u>	Discourse of loss. Younger generation taking over.
Death/dying	<u>ideas</u>. And *you think to yourself* <u>life goes so quickly so get on with yourself, go do it. Do it while you can</u>. One of them's just, she's got two horses now. [Yeah] And (.) she's filling her life up	Advice to younger generation – wisdom.

	with animals, she's like me. Interviewer: Yeah, very much taking after you then on the animal front? Margaret: Well. Yeah, I think with all three of them they're all very different personalities but (.) I can see me in lots of things that they do. [Yeah] (..) I think that's, <u>I think somebody who was perhaps alone and didn't have family and friends</u>, they would	Positioning herself in terms of others.
MCI	suffer terribly as they began to lose (.) names and (.) places, but (.) it's it's <u>so</u> different when <u>you've</u> got a fairly full life. [Yeah] They're all coming next Saturday (.) we've got **10** coming for dinner. [Yeah] In this little bungalow! (Interviewer laughs) So we're going to make it easier, cook a few chickens and do a load of oven chips, that'll sort them out (laughs)! [Okay, yeah!] A few trifles, and that will do won't it. [Yeah] But it's lovely that	"so" – contrast between her life and others. "you've" – distancing herself – concerned about how she might be viewed by the interviewer?
Ageing	they're all coming , it's it's for (NAME)'s birthday. So (.) see my daughters are in their 50s and I think oh <u>*goodness*</u>! [Yeah] *Can't believe it*. [Yeah] So I'm looking forward to that. Interviewer: Yeah. Urm so its sounds like being busy and having lots of things to do, keeps you going?	Surprise – does not fit with how she sees herself?

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	Margaret: It does, [Yeah] it does. And you can switch off as well in other ways, is if you've got a really good book on the go you know you can get into that and stop worrying so much. I'm trying to wade through Wolf Hall at the moment. [Oh right, yeah] Because of the, because it's on the television. [Yeah] And	Being busy allows her to "switch off". "you" – appears to be giving advice.
MCI	urm it's fairly hard going but I like the way she writes, Hilary Mantel. [Mmm] (.) See I'm remembering things aren't I? There you are you see. Bring up the Bodies is the next one, I've got that as well to read. (.) I suppose really you know when you look at how your children's lives are, and how busy they are and	More capable than others (like the interviewer?) may think? Looking for reassurance – proving to interviewer that she can remember?
Ageing	stressed they get (.) we're very lucky at this end of our lives because we can (.) we can enjoy a lot of things that there isn't the time for earlier. I remember being so **rushed** all the time, [Yeah] and you don't have to be **rushed** anymore.	"we're" – who? Her and husband, her and whist group, her as part of older generation/population? Wisdom. "I" vs "you".
	Interviewer: No. Is it quite difficult though adjusting to [It **was**] not being quite so rushed?	
Ageing	Margaret: Ahh when I first retired (.) I I went from somebody who, you know, I felt, was important in life, well not important that's the wrong word (.) capable and (.) and then all of a sudden	Viewed socially as important, useful.

Ageing	you wake up one morning and you're just plain old Mrs so and so, OAP. [Yeah] That's I think why we started this group because it was a chance to give back a bit of that. Because in work I I used to be involved with groups. [Yeah] So it was a nice way of giving that back. And there are so many, very lonely old people out there (.) but it's sometimes difficult to get them to join a group, you know. [Yeah] They tend to be (.) you have to really find them, or someone else finds them for you. Interviewer: Yeah, yeah I guess if they're quite isolated. [Yes] They won't know what's going on, [No] they won't have the [And they're] the *social contacts*. Margaret: And they're a bit suspicious about things, not sure they want to be involved with a group. [Yeah] But we've got 18 members, which is quite a lot really. Interviewer: Yeah. *Yeah*. So it sounds like in the past you, kind of defined yourself by this job, you had responsibilities. [Yes] You had, you had a role, you know, there was meaning wasn't there.	"I" vs "you" – distancing from ageing. Nameless, categorised. "that" – what does she want to give back? How old people are viewed by others. Old age is hidden away. Group is getting bigger – previously referred to as "little".

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Expertise	Margaret: Yes and I <u>had</u> the opportunity to go and <u>really</u> help somebody sometimes you know. <u>Just like you're doing now</u>, sitting talking, I used to do a lot of that. Because after a while they'd start to tell you about the things that were really worrying them. [Yeah] And um sometimes you could help a bit, or even just listen, that was the important part of it. [Yeah] And I always felt, you're there to do a (PROFESSION) and (.) and they'd finish up telling you what a, you know, a sad life they were having with their marriages or whatever. (.) <u>*Sometimes you could do something and sometimes you couldn't but you could listen.*</u> I enjoyed that part of the job, I really did. [Yeah] Really enjoyed	She used to have opportunity to be meaningful. She used to be like the interviewer – she is the expert. Said quietly – wants the interviewer to listen closely. Wisdom.
Ageing	that. <u>I did miss it</u>, in a way <u>I did miss it</u>. [Yeah] Not as much *now*. (.) The job has changed a lot anyway. [Right] <u>I don't think they go out visiting as much as we did.</u> We used to try and get in about 5 or 6 visits a day. [Yeah] And (.) I suppose all the check, (PROFESSION), the clinics, and the (.) and the paperwork. So it was very busy. [Yeah] (..) [*Yeah*] So. Interviewer: (.) Yeah, so it sounds like things changed quite significantly then when you retired. Margaret: They did, yes.	Repetition – emphasis. Discourse of loss. Younger generation do not do as good a job as her generation.

	Interviewer: Um, almost a bit of shock, not to be working anymore. Margaret: That's right. Yeah. Interviewer: And then did that change again when you had this diagnosis that, of mild cognitive impairment or did things just stay the same?	
MCI Hierarchy of illness	Margaret: Just stayed the same. [Yeah] I can't honestly say that I think about it very much. [No] You know, I don't see it as a problem. But then again I haven't gone into what its likely to become in the future, I don't know enough about that part of it (.) urm (.) so I (.) I think the other diagnosis has probably given me more [Yeah] cause for worry, you know. Although they've been very reassuring about that as well so (.) (laughs). [Yeah] (.) No, I'm not worried about not worried about this other thing at all. Interviewer: No. Okay. So do you think there are any advantages to knowing that you have mild cognitive impairment?	Emphasising that she does not think about it, it has not changed her life. Changing her position/justifying why she does not think it is a problem. Reassuring about MCI diagnosis too. MCI is nameless.

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MCI Ageing	Margaret: (.) Urm. In a way yes. In a way it sort of **helps** to have a diagnosis doesn't it. When things aren't going (.) quite right and you're thinking why on earth can't I remember like used to be able to, it's it's good to have a diagnosis you know where you're going, you know what's happening to you. [Yeah] And, it's a common thing isn't it, so many people, *of my age* have got (.) a bit of it, or a lot of it. [Yeah] So it's not something I'm worried about really. Interviewer: No. No (.) urm you said earlier that your husband also has some memory difficulties. Margaret: Yes he does. Interviewer: Occasionally and you end up finishing each other's stories. Margaret: (laughs) Yes yes. Interviewer: Um, does he have a diagnosis? Margaret: No he hasn't.	Biomedical discourse – diagnoses are helpful. Tentative phrasing. Benefit of having a diagnosis is for prognosis – however does not know/have clear prognosis around MCI. MCI is normal ageing. Is MCI a bit of ageing? Not worried when MCI is positioned alongside normal ageing.

	Interviewer: No. Okay.	
Ageing	Margaret: (laughs) The chances of him having one are remote because <u>he's the sort</u> that would say oh no I'm fine.	Different "sort[s]" of older people?
	Interviewer: Yeah. So he wouldn't go to the GP and talk about having memory problems, no.	
Hierarchy of illness MCI	Margaret: No I don't think he would. And urm <u>I don't know where he is in relation to mine, but I'd say that perhaps mines worse than his</u>. [Right] You know. (.) I tend to put things in <u>strange</u> places sometimes you know. Because I'm thinking about other things, I'll just put something down, I **loose** things constantly, that's <u>one of the biggest things about it</u>. I can't find things, I spend hours looking for things. [Yeah] And ur so I try to get really tidy. <u>But</u> (.) the trouble with that is I put things away very carefully (laughs). And then I can't remember where I've put. [Yeah] So I've chucked out all my boxes that you can't see into and I've got these plastic boxes now so that I can see right away what's in them. [Yeah] I do a lot of craft. [Right] And urm (.) so I've got wool (.) I could open a shop the amount of wool	Positioning her cognitive difficulties in relation to her husbands – hierarchy of cognitive difficulties. Unusual for her, MCI is "strange"? "it" nameless – but big impact – MCI is an annoyance? Her strategies do not seem to work.

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	I've got. And material an. [Yeah] And I make things and that's another lovely part of the week. We have a little sewing club on a Wednesday morning, and, just a very small group but I really enjoy that little group. [Yeah] I think that's one of the answers, just to get out there and join little groups. [Yeah] And I'm, just,	"small" "little" repetition – she is small – ageing? Contrast to MCI "biggest" – above.
Expertise	get involved *with things*. [Yeah] You know.	She's the expert, has wisdom.
	Interviewer: Urm (.) are you ever self-conscious that you can't do things as well as maybe you used to be able to do maybe 20 or 30 years ago?	
	Margaret: Yes, I can't I can't thread needles like I could. And	Repetition – emphasis.
Hierarchy of illness	there's a lot of arthritis in my hands that when I knit, I can only knit for so long then I have to give up. So I'm aware of that (.) but (.) not to any great extent. [No] You sort of, you adapt to what you can do. [Yeah] You know I paint as well, I love watercolours so I do those. [Yeah] And urm (.) that's not too difficult, you can hold a paintbrush and you can get on with that.	Arthritis positioned as having more of an affect than MCI. "give up" – choice, forced – by ageing. (.) but (.) – hesitant, fluent content, emotive. Repetition "you" – externalising, what has to be done, choice less.
Ageing	[Yeah] So no, I just find that time is going so quickly, the weeks are just hurtling by. [Yeah] And you feel you want to really cherish every moment really. That's the feeling. [Yeah] (.) And	Contrast to previous statement "I've got to" (p.2) – alternative discourse, however "you" detaches, something she ought to say?
Death/dying	the thought of having to leave family one day, that's fairly	Death/dying implied, not said.

	horrific as well. Interviewer: (.) Yeah, so it sounds like there are more pressing things on your mind, other than this [Yeah] diagnosis [Yes] this is only a very small part of your life.	Emotive language. Mirroring Margaret's language – "small" "little"
Hierarchy of illness MCI	Margaret: Yes it's a very minor part. It, because it's not at the level yet. If it got worse, and (.) say I couldn't drive my car that would be a, that would be a big problem because I just love that independence. [Yeah] So ur yes. I jus. As things are, if they would stay as they are, that would be just fine. [Yeah] That would be lovely, I can deal with that, I can live with that. Interviewer: Yeah, yeah. (.) Urm are there any disadvantages to having this diagnosis of mild cognitive impairment?	"very minor" – emphasising how small. "level" – what level? Like a clear cut off point. "If" – tentatively considering possibility MCI worsening. Stumbles over phrasing – difficult to say. Making compromises
MCI	Margaret: Well (.) not if you try to put it out of your mind. You just try not to think about it. [Yeah] You just um get on with it. I can do just about everything I want to do and need to do. [Yeah] And (.) so I can't really see any massive disadvantages. [No] You, you can't tell stories about things like you used to be able to, but I mean it's, you know, you go somewhere enjoy a film or	Considering answer. Goes on to try to justify why no disadvantages. "you", then moves to "I". "massive" – in comparison to? Implies still big disadvantages.

	you enjoy a play (clock chimes) and you try to recoup back to somebody else and you **<u>can't</u>** because you <u>can't</u> remember the <u>blummin</u> details you know (laughs). [Yeah] Can't remember who was in it and urm, bits of the story aren't always there and (.) so	Emphasis and repetition – emphasising what she cannot do. No other words.
Expertise	(.) that's how it works. [Yeah] (.) <u>I think really I'm probably</u>, <u>only a very mild</u> case of it you know. The only thing that worries me is what's going to happen (.) down the line, in a years' time.	She's the expert, justifying. In contrast to "massive" above – shift in description, many problems but "only" a mild case– minimising, emphasising.
Dementia	[Yeah] In two years' time, <u>is it going to be very much worse?</u> (.) *I* wonder.	Wanting interviewer to take expert role and answer question? "worse" – implied dementia?
	Section removed.	
Dementia	Margaret: Yes. And then <u>going onto</u> Alzheimer's, <u>that's?</u>	Gradual decline. "that's?" – interviewer as expert, looking for answers.
	Interviewer: Well Alzheimer's is a type of dementia.	
Dementia	Margaret: Oh I see <u>of course it is, yes</u>. So you get to the point that you don't recognise people <u>and</u>.	Margaret knew the answer? Taking back expert role. Does not/cannot continue sentence.
Dementia	Interviewer: Yeah, <u>some people</u> get to that point, yeah. Urm I think with everybody it's slightly different, you know, the, the, what exactly happens.	Trying to make distinct between stages of dementia.

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Dementia Hierarchy of illness	Margaret: Yes. Okay. It's such a cruel thing to happen *isn't it.* You sort of feel that, that, mind you my brothers got Motor Neurone Disease, and (.) he's paralysed, he's got to be fed by a tube, he can't speak. But his intellect is fine. [Yeah] You know like Stephen Hawking, he's a typical example. [Yeah] (.) I I think that must be torture when (.) *everybody else.* The longer I live the longer I realise, the more I realise that most of us have got nightmare-ish things going on at some point in the future. It's	"cruel" – used word before in context of animal cruelty. "*isn't it*" - bring interviewer in. "mind you" – minimising, hierarchy of illnesses. Does not finish sentence – cannot be spoken about. Wisdom. "nightmare-ish" – not real, like being in a dream/asleep.
Ageing	just part of it. Although some people seem to live, golden lives don't they. [Yeah] Although do you know I think it's all down to attitude as well, if you can sort of say oh right that's happening, so what and go and do something else, you can avoid it. It's	MCI is part of life, part of ageing. Bringing interviewer into conversation, looking for assurance. "avoid it" – like with dementia.
Expertise	**dwelling** on it that's the problem. [Yeah] And that's why I don't dwell on it, I try to, you know (.) avoid it if I can but take any advice. [Yeah] *Is it still switched on?*	She is the expert. Knows what she needs to do to avoid worrying about dementia.
	Interviewer: *It's still on yes*. Urm, so (laughs)	
	Margaret: That's the elephant into the room! (laughs).	Like MCI? Like dementia?
	Interviewer: The voice recorder, yeah (laughs).	

	Margaret: Oh, dear! Interviewer: Urm so, we, we're coming towards the end of the interview urm I was wondering whether there's anything else that you think might be relevant but that we haven't discussed?	
MCI Dementia	Margaret: Urm (..) well you know you were talking about forgetting where you're going (.) all my life I've found that problem! [Okay] (Interviewer laughs). That I can get lost in a town quite easily (laughs). [Yeah] So (.) I think that's happening now. I can't I can't visualise ur a route and I just wondered if that's something that's part of you anyway?	Tentative – worry. "you" – distancing due to fear of dementia?
	Interviewer: Have you ever been able to do that very well? Margaret: Urm no (laughs). Interviewer: No, well.	
Expertise	Margaret: So there you are that's that isn't it.	Question has not explicitly been answered – answers it herself.

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	Interviewer: Yeah, it needs to be a **change** in your abilities.	
Expertise	Margaret: A **change**, that's right.	"**change**" – using same language emphasis as interviewer. "that's right" – taking back expert role?
	Interviewer: Yeah, so if that, if that was totally normal for you and it has been for most of your life then.	Margaret finishes sentence.
	Margaret: I don't need to worry about that too much. [No] No and one of, and one of the girls has got exactly the same problem (laughs). [Yeah] (Interviewer laughs). So when she and I go out together it's (.) **who** knows where we'll finish up (laughs)! [Yeah] (Interviewer laughs) (.) Oh that's good that was a thing I	Emphasising how little she needs to worry about dementia. Minimising general difficulties. "it's (.)" – does not finish sentence, changes route. "thing" – nameless, not specified.
Expertise	wondered about. But I don't think it's getting any worse. He tends to do the driving which is a pity really, my cars only done seven thousand miles. [Yeah] And I some, he likes to drive and that's part of him so that's why I've been beetled off sometimes when he's on one of his treks, like today. [Yeah] Or later on I've got a friend lives round the corner and I'll ring her up, come on (NAME), we're going for a wander. [Yeah] Don't know where we'll finish up! [Yeah] But you know all those things you can do them so long as you can still do those things. [Yeah] *I think* that's the answer isn't it. [Yeah] But thank you, you've made	She is the expert in her own condition, monitoring her own changes. "part of him" – like forgetting route is part of her. Like with MCI? She is the expert – wisdom.

	things a lot clearer. [Okay] I'm delighted to know that one in three of <u>us</u> actually gets over this, I can't see it happening, but if, <u>I think I've had mild cognitive impairment all my life</u> (laughs)! (Interviewer laughs) I can memorise facts pretty well, or I used to be able to but. [Yeah] It's <u>part of my</u> personality (laughs) (.) <u>it</u> makes for quite an interesting life. [Yeah, yeah] (.) And also <u>it</u> makes you very compassionate for people who are clearly going through something, you know, I often go to (PLACE) ur (PLACE) market, have a <u>wander</u> round there and I go in that little tea room that's there and, sometimes, the people in there you can tell that <u>they're</u> struggling an. Desperately sorry for them, *you know*. [Yeah] (.) All <u>we</u> can do is just (.) well, kindness is the big thing I think. [Yeah] I love my little group, and even, you know even on Boxing Day they wanted to meet because so many of them are so lonely (.) <u>all I've done is talk about my group haven't I, instead of talking about what this means!</u> Interviewer: No no that's okay! Margaret: (laughs) Oh good.	"us" – now part of a MCI group? Minimising. "part of" – repetition. Is MCI part of her or not? Repetition "it" – what is she referring to? MCI? "wander" – used term earlier – like people with dementia? "they're" – detaching herself – making comparisons. "we" – who? Her and interviewer? Unsure about MCI – spoken about group instead.

Appendix 2.7

Expertise	Interviewer: Okay (.) so is there anything else? Margaret: No [No] there isn't. [Okay] I've found this really helpful. [Okay] Very helpful. Interviewer: Okay so I'll turn this off now then.	Giving interviewer expert position.

Appendix 2.8: Further transcript examples illustrating discourses

Below are further sections of other interviews, not referred to in the text, illustrating the presented main discourses. Longer extracts are presented where appropriate to give a flavour of the conversations. Some sections can illustrate more than one discourse, but are quoted under the most prominent discourse. Texts are not repeated here if they have been presented in the text.

Bold: said with emphasis/louder voice. *Italics*: said softer/quieter/under breath.
!: vocal intonation became higher.
(.) noticeable breathing space, (..) 3-5 second pause, (…) more than 5 second pause.
Underscore: indicating text referred to in findings.

Not Knowing – Mild Cognitive Impairment

Name	**Extract of Transcription**	**Findings**
Gwen	Well it's a bit (.) ah, to me it sounds as though, how much I understand now, you know has it affected my brain (laughs), well you know affected me [Yeah] me ur stroke. [Yeah] That's the only thing I can think of.	Stop, start, pause – uncertainty about what to say, how to say it – does vs does not know. Repetition "you know" – she does not know? Stops conversation.
Gwen	I don't notice much difference you know, I mean if it had affected me bodily I would notice it more I suppose. [Yeah] But ur, I think my daughter (NAME) says I do forget (.) which **I do forget** you know, I tend to have to write things down I forget a lot. [Yeah] Even **easily** you know I'll (.) and then I'll think, and I don't at all (laughs). [Yeah] And then (NAME) will ask me something and oh I dunno (laughs).	MCI not affecting her. Affected her mind, not her body. Body vs mind – hierarchy of illness. MCI is affecting her – contrast to above – shift in positioning. "**I do forget**" – emphasis – she does forget – surprise? Disjointed, pauses – what to say. Laughs – masking thoughts/feelings, minimising impact.
Gwen	Yeah, *I suppose*. (..) But ur (..) I'm not too bad, I don't, it doesn't really bother	Quiet – does not want to agree. Pauses, disjointed – does not know

	me that much <u>but</u> I have to write things down or (.) my daughter reminds me you know (laughs).	what to say. "but" – implies MCI does affect her, moving position.
Clive	… cognitive ur impairment, **mild** cognitive impairment …	Trying to say phrase right – does not say it very often.
Clive	I think I am coping with it now, yes. **<u>But</u>,** as I said <u>(.)</u> from when I finished with (NAME) <u>(.)</u> <u>I think</u> it's gone worse. [Right] Because <u>I'm</u> <u>(.)</u> <u>I'm</u> <u>I'm</u> forgetting things that I did two minutes ago, you know.	Despite coping, something is still not right. He is the expert. Pauses, repetition "I'm" – difficult to say?
Clive	I just think about it *occasionally and that I don't know what it is*. I've just <u>got to live with it</u>.	Quiet – drawing interviewer in vs does not want to say out loud. No choice.
Andrew	If <u>you</u> could speak <u>plain English</u> we'd get on better!	Words do not make sense – jargon. Medicalising causing exclusion?
Andrew	Interviewer: And before you were given the diagnosis had you heard of it before? Andrew: <u>(.) T to</u> be honest I don't think so. [No. Okay] Not this <u>short term mem,</u> (laughs) being a, being a person I had to go short term, <u>it's still bloody memory loss</u>, you know! [Yeah] This <u>term short-term seems to disguise it</u> in some way you know!	Pause, repetition – time to think. Phrase is unfamiliar. The term 'short term' hides what the problem is? The language covers it up.
Jack	Interviewer: …So I was wondering if you could tell me what you think mild cognitive impairment is. Jack: Urm, <u>minor</u> loss of memory function.	"minor" – minimising. Short answer, cuts off conversation – no words.

Appendix 2.8

Jack	Interviewer: And do you ever use that name (MCI)? Jack: No. Interviewer: No, ju so when you. Jack: Just forgetfulness. Interviewer: You just call it forgetfulness? Jack: Yeah cos it's too complicated that name (laughs)!	 Short, definite answer. MCI language not accessible – does not make sense. Clarifying Language not accessible.
Margaret	Margaret: …So sharing worries. But we don't use words like mild cognitive impairment. [No] No. We don't use those words. Interviewer: What words do you use? Margaret: (.) Just we, I can't remember so and so's name when I meet them, and you know (.) I I went to the shops and I couldn't remember what I'd come for and I go upstairs and I get to the top of the stairs and I can't remember what **on earth it was I came upstairs for**, things like that.	The words do not make sense. Pause – unsure what to say? Moves from "we" (group) to "I" (self) – uses herself as example because it is not spoken about? Emphasis – surprise?
Margaret	… I don't think I've got too much to worry *about at the moment*, its it is very mild *whatever it is*…	 Does not use term MCI, does not know what "it" is.
Simon	(.) Well, I'm not really sure, but I think it's to do with urm (.) memory (.) not remembering things. [Yeah] And (.) but you do remember things but (.) not entirely, if a if you understand what I mean. [Right okay] Urm (.) some thing's I forget altogether. [Right] Urm. I don't know how they can come up	Frequent pauses – hesitant, no words, unsure. Do not remember vs do remember – confusing discourse. Seeking reassurance. "they" – who?

	with **mild** when its, what's the difference? [Yeah] You know mild dose of it or (.) fully blown I don't know.	Emphasis – the word does not fit with the experience. "mild dose" – like the flue, using illness terminology, more familiar.
Simon	Interviewer: How did you feel when she told you that you had mild cognitive impairment? Simon: (.) I thought I hadn't. [Okay] I thought I'm alright like, nothing wrong like. [Yeah] Urm, I still sometimes think that. [Yeah] But when, when I (.) look back on things I do (.) I don't do silly things, but, I don't finish anything off. [Right ok] Urm (.) I lose interest in things which I've never done that before. I've always started a job and finished it. [Yeah] (.) And it's just them sort of things you know, it's (.) it's just strange in a way. [Yeah] I can't seem to concentrate.	"I thought" – repetition. "I'm alright like, nothing wrong like" – rephrasing answer, same meaning – emphasis? Observing/monitoring himself. "I don't do silly things" – caveat, justification. "just strange" – no other way to describe.
William	Interviewer: … can say what you think mild cognitive impairment is. William: Well, urm (.) it's loss of memory (.) and I suppose loss of concentration levels. [Right] Tha tha that's how I understand it.	Pauses, disjointed – needs time. Repetition "loss" – emphasis. Repetition "tha" – unsure what to say.
William	Interviewer: … Yeah, do you, your friends still go to the pub quizzes? William: Yes. [Right] Yeah they're all asking me to go but no. *I'm not, I'm not going*. [No] (.) Ask me a simple a question and you don't know, you look, feel like a fool don't you. [Right, okay] Well I do *anyway so*.	Quiet, repetition – emphasis. "me" vs "you" – changes subject. Emotive language, unwanted description of himself – how others

		may view him?

Knowing – Ageing and Dying

Name	Extract of Transcription	Findings
Gwen	Well I think of (NAME) getting old but I don't think of myself as getting older. [Yeah] You know you think oh I'm just me.	Comparing, putting herself in a different position.
Gwen	*It's one of those* things you can't help, you're getting older, you're getting old.	Blame should not be attributed to her. "older" vs "old" – becomes more definite.
Gwen	… You know so I, I don't want to leave any hassle, if I go…	Repetition – how to say it. "hassle" – burden. "if I go" – death implied, not explicitly stated.
Clive	Like they say, the older you get the more cells in the brain that die. [Yeah] Well (.) is it cells dying that do the memory thing? Are they dying?	"they" – who? Who is the expert? Cells dying as cause of memory loss – due to ageing. Interviewer put in expert position.
Clive	You know it's those sort of problems, they aggravate you to death.	Emotions cause death? Emphasising the effect of the problems reported.
Jack	I think they (family) worry to the extent that you do with any (laughs) elderly relative. You know, I mean, my son (.) still talks to me like I'm an idiot (laughs), you know! And has done since he was a teenager! And my daughters 37 and she she's the youngest and she um, she just talks over me sometimes and I just think, will you shut up (laughs)! You know. But that's typical of your own kids, but I don't think they actively think of me of of	"elderly relative" – older people create worry. "still" – always has done. Views of older generations. No space for him – younger generation takes over. Tentatively fighting against ageing discourse.

	urm going into lunacy or anything like that. *You know*.	"lunacy" – emotive word. What else? Dementia?
Jack	(.) Well I think it's just, (.) the synapse in your brain sort of break down after a while, it's (.) they say it's in your teens that your brains the best, and after that it sort of starts to wear away a bit. And I think, I just think it's that, you know, you get sort of, nibbles out of the edges (laughs). [Right!] Urm and it it just, you find that you're just not quite up to the mark you were before, thinking wise and remembering. *Ur* and apart from that it doesn't affect you physically, well *not to my mind*. [No, no] *What mind* I've got left (laughs)!	Pause – time to think. "synapse" – technical language. "they" – who? Viewed as an expert. Imagery – making sense using his own language. "mark" – like at school? "you" – externalising. Quiet – difficult to say, turns to humour.
Margaret	It was a little bit, shocking I suppose in a way (.) but just a month ago I was told that I had cancer, so. [Oh gosh] You just think to yourself, which is worse you know. It's all part of old age. It's the old vehicle, you know (.) having problems in its different parts I suppose. [Yeah] So (.) compared with **that** diagnosis, the mild cognitive impairment one, ur wasn't quite in that league.	Conflict – minimising the amount of shock? She already knew? "but" – something else more shocking, in contrast. "all part" – making sense through normal ageing, expected. Machine metaphor – more familiar discourse to make sense. "**that**" – cancer emphasised but nameless. League of illnesses.
Margaret	Ahh when I first retired (.) I I went from somebody who, you know, I felt, was important in life, well not important that's the wrong word (.) capable and (.) and then all of a sudden you wake up one morning and you're just plain old Mrs so and so, OAP.	Viewed socially as important, useful. "I" vs "you" – distancing from ageing. Nameless, categorised.

	[Yeah] That's I think why we started this group because it was a chance to give back a bit of <u>that</u>. Because in work I I used to be involved with groups. [Yeah] So it was a nice way of giving that back. And there are so many, <u>very lonely old people</u> out there (.) but it's sometimes difficult to get them to join a group, you know. [Yeah] They tend to be (.) <u>you have to really find them, or someone else finds them for you</u>.	"that" – what does she want to give back? How old people are viewed by others. Old age is hidden away.
Margaret	… And <u>you feel you want to</u> really cherish every moment really. That's the feeling. [Yeah] (.) And the thought of having to <u>leave family one day</u>, that's fairly <u>horrific</u> as well.	you" detaches, something she ought to say? Death/dying implied, not said. Emotive language.
Simon	<u>(.)</u> I just look at it as if it's <u>(.)</u> there's <u>other people worse off</u> <u>(.)</u> you know. <u>(.)</u> Try not to complain really. [Yeah] Cos <u>obviously</u> get things the older you get.	Pauses – reflection, time to think. Hierarchy of illness. Inevitable, expected with ageing.
William	Interviewer: … And how, what was their reaction? (referring to his friends) William: Oh the <u>usual thing</u>, <u>it's your age</u>, things like that you know <u>(.)</u> nothing <u>(.)</u> derogatory or nothing, they all understood. [Yeah] <u>They're</u> a very good bunch. [Yeah] *So yeah,* (.) yeah <u>I've</u> had a lot of support from them.	"usual thing" "it's your age" – well known discourse – ageing. Pauses – unsure, difficult to talk about. "They're" vs "I've" – no longer positioned within the group, detached.
William	I was 62, so I'm <u>not **old**</u>. [No] I still act like a <u>fool</u> (laughs) when I go out I still have a good laugh. [Yeah] Well I, <u>when you say old people you think of people with Zimmer frames</u> and things like that, you know. [Yeah] I suppose I am	Fighting against societal views of old age. "fool" – associated with younger generation, stated in context of being viewed as young. Societal views of old age.

	an old person to some people. (.) [Yeah] If you're 15, I'm an old person, *you know*. (.) It's all relative really.	Perceptions based on context.

Not Wanting to Know – Dementia

Name	**Extract of Transcription**	**Findings**
Clive	Well I have a dread about having to go into an old people's home, suffering from dementia. [Right] Or that sort of thing *you know*.	"dread" – fear. "having to go" – no choice. "suffering" – illness/disability reference?
Clive	I know a lot of people suffer with dementia, and it's an awful affliction. (..) Alright they're starting to get (.) to be able to work out what's causing it and what the (.) best way to treat it is. They've got drugs now I think haven't they? Or they're experimenting with drugs to try and ur reduce it. They said they will never cure it. But they'll slow it down so it's (.) you're not living like a cabbage like for like 10 years, or them last years of your life.	"suffer" repetitive word – associated with dementia? "awful" – emotive. Repetitive "they" – who? Who is the expert? Pauses, fluent content – difficult to talk about, say the words. Emotive language.
Andrew	Just cos you've got slight memory loss, doesn't say you're an idiot or not responsible for what you're saying like.	"just" "slight" – justifying, minimising. Not viewed as being able to contribute to society/discourse. Memory loss viewed as under umbrella of dementia?
Andrew	This all, this all comes back to the mechanical self you know, this a mechanical reaction, you know. Oh aye. I I don't know, I don't know if I think they'll ever cure it, but if I can reduce it.	Repetition – what to say. Machine metaphor/reference. Repetition – uncertain. "they" vs "I" – they cannot make it better but he can reduce it – he is the expert.
Jack	Interviewer: How how do you compare	

	yourself, the problems you have with the problems that your father had with? (previously stated father had dementia) Jack: Oh well that was much more severe because I mean he'd lost all idea of who he was, who anybody else was, where he was, you know, he was just, he'd gone into senility really, *you know*. Urr (.) of course you say to yourself I don't want to be like that (.) and I still don't (laughs)!	"Oh well that" – distancing. "much more" – emphasis, distancing. Old age vs dementia. Distancing self from dementia Humour masks difficult, emotive topic.
Jack	Interviewer: So a lot more than just short term memory loss. (talking about father's problems) Jack: Oh complete loss. Yeah.	"complete" – physical, mental and identity.
Margaret	… It doesn't feel as severe, as Alzheimer's yes it would be. We've got a friend, younger than us, and his wife got it and he's lost her completely. She doesn't know who he is and they were such a happy married, couple. [Yeah] And, terrible grief that has affected him. He's lost her, he feels completely	Alzheimer's is viewed as severe. Less expected in younger people? She has gone, her identity has gone. No longer happily married. Repetition.
Margaret	Margaret: … So it seems to take people in different ways. I think mines the very gradual way, perhaps, I don't know. Interviewer: Do you mean the way to d dementia? Margaret: Yes. Yes. I think so. You can stave it off if you, you know if you keep active and all the rest of it. The newspapers are full of how to avoid it	"it" – nameless, lose people? Own perception of prognosis reduces in certainty. Hesitation – unsure whether to name "it"? Dementia unspoken/ not spoken about/hidden away? "You" – externalising. "stave" – fight against. Vague, lots of ways to "stave" it off? Who is the expert? Margaret,

	anyway, aren't they? We get lots of urm (.) advice how to avoid dementia.	newspaper or interviewer? "advice" – not definitive, opinions.
Simon	… I suppose there's different levels of it (.) *like*, it's mild what I've got. (.) I mean what's someone look like or sound like that's got, a severe case of it. Are they urrr, (.) would they be hospitalised or? *I don't know*. [Yeah. Yeah (.) Urm] Or in a home or whatever. [Yeah] I mean I don't want that to happen to me. If, will mine go (.) worse *or what*?	"different levels" – like a hierarchy of memory loss. "severe case" – not explicitly mentioned dementia – is this what he is referring to or not? "in a home" – dementia? Ageing? Putting interviewer in expert position.
William	… Cos I don't I don't want dementia (.) *you know, I'm still young*. (laughs) (.) No. We'll see how it goes anyway.	"I don't" – repetition, difficult to say. Quiet – emotive? Laughs – minimising, masking emotive aspect of what he previously said.
William	Well it's in the package they give me it's early onset, Alzheimer's and all this, and I thought well that's not going to happen to me. (.) So I'm not, **I'm not going to sit here** worrying about it, I know a lot of people would. [Yeah] Well let it get on with it, if it happens it happens. [Yeah] I won't know will I (laughs)!	"package" – lots of information? "and all this" – too much information? Repetition "I'm not" followed by louder speech – fighting against dementia discourse. Inevitable – means no need to worry. Laughs – masking, minimising.

Appendix 3.1: Word Count Statement

Thesis Abstract	297		
Total			297
Literature Review			
Abstract	258		
Main text	4518		
References		1320	
Figures/tables		1896	
Total			7992
Empirical Paper			
Abstract	143		
Main text	6288		
References		648	
Figures/tables		44	
Total			7123
Reflective Paper			
Main text	3433		
References		596	
Total			4029
Appendices			
Appendix 1.1		320	
Appendix 2.7		9134	
Appendix 2.8		3090	
Total			12544
Totals	**14937**	**17048**	**31985**