

## Research Article

# Mild Cognitive Impairment: A Qualitative Exploration of Older Adult's Understanding, Concerns and Expectations

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**Keywords**

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**Abstract**

**Background:** With an increasing drive to diagnose dementia, more people with mild cognitive impairment (MCI) will be identified. It is not known how best to manage those with MCI.

**Aims:** To examine older people's understanding of MCI, explore attitudes towards disclosure of a hypothetical diagnosis of MCI and the experience of receiving a diagnosis of MCI.

**Methods:** Qualitative study using thematic analysis of in depth, semi-structured interviews in cognitively intact older people (n7) and those following a diagnosis of MCI (n6).

**Results:** In a hypothetical scenario older people expressed a wish for the honest disclosure of a diagnosis of MCI. Although participants thought that memory loss in old age is expected and may be preventable, they described associated stigma. Patients with MCI who prompted their own referral for memory assessment acknowledged and better understood the condition. Those who acknowledged MCI displayed both practical and emotional coping strategies.

**Conclusions:** Clinical pathways for MCI should be patient centered and reflect the views and experience of older service users.

**ABBREVIATIONS**

MCI: Mild Cognitive Impairment; AD: Alzheimer's Disease

**INTRODUCTION**

Mild cognitive impairment (MCI) has been defined as "cognitive decline greater than that expected for an individual's age and education level but which does not interfere notably with activities of daily life" [1]. Debate exists regarding the exact definition and classification of MCI [1-3]. This lack of consensus results in difficulty estimating prevalence and uncertainty regarding 'disease' trajectory [1,4-6]. The clinical course of MCI is uncertain. Population-based studies report that 3-19% of 65 year olds may have MCI [1] with annual 'conversion' rates from 'amnestic' MCI to Alzheimer's disease (AD) ranging widely from 10-47%. [1,2] Conversely, other literature suggests that as many as 44% of those diagnosed with MCI may return to a state of normal cognition at one year [3]. This raises questions

about the clinical significance of MCI, whether MCI should be diagnosed at all, and if diagnosed, how such a diagnosis should be communicated to patients [2,7-9].

Regardless of this controversy, it is likely that increasing numbers of people with MCI will be identified worldwide as ageing populations carry with it the increased prevalence of cognitive decline. In the UK as an example, there are various reasons for expecting an increase identification of MCI due to a number of national policies and drivers. These include the National Dementia Strategy, [10] which emphasizes the importance of early diagnosis of dementia, [11] and the NICE delirium guidelines that promote assessment for dementia in those with persistent symptoms of delirium [12]. Furthermore the Commissioning for Quality and Innovation (CQUIN) targets attach a financial motivation for hospital trusts to screen for cognitive impairment [13] and financial incentives are being offered to general practitioners for every dementia diagnosis

made [14] Such pro-active case finding for dementia means it is likely that an increasing number of people with MCI will be identified. Despite this projected increase in the identification of people with MCI, there is no clear guidance regarding the necessity for follow up or repeat cognitive assessment. As the potential psychological and economic burden related to a diagnosis of MCI remains unclear, health care professionals continue to debate the appropriateness of this political drive to screen for 'pre' and early dementia [15,16]

A better understanding of whether patients want to know about MCI would inform the discussion about whether diagnoses should be actively sought, how information should be communicated and what the pathway of care following a diagnosis of MCI should look like. Overall, qualitative studies from various countries suggest that the outcome of disclosure of MCI is negative, with participants reporting confusion about the diagnosis, and burden associated with the label of MCI [17-22] It is potentially possible that studies conducted in different countries may yield different results that are contributable to different social 'norms'. The extent to which these findings can be translated from one country to another is uncertain. In contrast to the qualitative studies mentioned, one questionnaire based study reported that 98% of cognitively intact participants would want to know if they had MCI, [23] however; the conclusions from this are limited due to the study's methodology. Given the move towards active engagement and involvement of patients in their healthcare [24,25] and the increasing frequency with which health care professionals encounter those with MCI, this qualitative exploration of the views of older people was undertaken to address the following objectives;

1. To examine the understanding of MCI in older people
2. To explore attitudes towards disclosure of a hypothetical diagnosis of MCI in older people
3. To explore the experience receiving a diagnosis of MCI in older people
4. To examine coping strategies and concerns following diagnosis of MCI in older people

## MATERIALS AND METHODS

A qualitative study using semi-structured individual interviews and thematic analysis was undertaken. The study was approved by the NRES committee (Bromley) London (12/LO/0962).

### Participants

Purposive sampling [26] was used to recruit two groups of participants. Participants recruited into group 1 were interviewed to examine their understanding of MCI, explore their attitudes towards disclosure of a hypothetical diagnosis of MCI and how they would wish for this to be communicated. Those recruited into group 2 were interviewed to explore their experience of receiving the diagnosis of MCI, their coping strategies and their ongoing concerns.

Inclusion criteria for group 1:

Aged over 65 years

Assessed to be cognitively intact by a geriatrician

Inclusion criteria for group 2:

Aged over 65 years

Attendance at hospital memory clinic within six months

Diagnosis of MCI

Exclusion criteria:

No capacity to consent

Language or other communication barrier precluding

Participation in interview

Diagnosis of dementia

### Setting

Participants were recruited from two clinics at an inner London teaching hospital. Group 1 participants were recruited from a consultant geriatrician delivered comprehensive geriatric assessment clinic. Group 2 were recruited from a consultant geriatrician delivered memory clinic where routine practice involves:

- The diagnosis of MCI was made in a clinic setting taking into account the history, blood work, brain scans results and validated scoring systems (including Addenbrooke's cognitive scoring, Bristol Activity Score to assess instrumental activities of daily living, Neuropsychiatric Inventory Score and Geriatric Depression Score)
- Communication of the diagnosis of MCI
- An explanation of projected disease trajectory (between 1 in 5 to 1 in 8 people with MCI go on to develop dementia)
- Discharge back to primary care with advice to request further memory clinic assessment as required
- A copy of the clinic letter addressed to the GP and the patient

### Recruitment and consent

Participants were identified by clinicians in both clinics and referred to the researcher. Capacity to consent was assessed by a clinical researcher and all participants provided written consent. Refreshments and travel costs were covered but participants did not receive remuneration.

### Demographic data collection

The researcher recorded age, ethnicity, previous occupation and living situation from the participant.

### Interviews

Individual semi-structured interviews were conducted with all participants. Different interview schedules were used in the two groups.

For Group 1, the interview schedule (Appendix 1) explored beliefs about memory loss in ageing followed by vignettes describing the disclosure of MCI in hypothetical clinical scenarios. Where the definitions of MCI were explained and discussed,

the interviewer assessed understanding before the vignettes were discussed further. During the interview, all participants were told that MCI could potentially develop into dementia or that conversely, it could improve over time. The uncertainty regarding prediction of the trajectory of MCI for an individual was explained. For Group 2 the interview schedule (Appendix 2) examined how their cognitive impairment was discovered, the participant's experience of memory clinic, what they understood of MCI, how it impacted on family or friends and the coping strategies they had employed since diagnosis.

The researcher was a general physician trained in geriatric medicine with no clinical responsibilities for participant patients.

## Data Analysis

Interviews were recorded using digital Dictaphone and transcribed verbatim. Thematic analysis aided by NVivo 10 software was undertaken [27]. The primary researcher read the transcripts repeatedly in order to familiarize herself with the data. She then began to separate the data into meaningful segments and codes were then applied. A hierarchy of codes was then created and overarching themes identified. The analysis process continued after the coding process and the practice of constant comparison was used as a way of ensuring validation of the results [28].

## RESULTS AND DISCUSSION

Group 1 consisted of seven participants and Group 2 of six participants.

Demographic data from each group is shown in Table 1.

Eleven potential participants approached by the researcher declined to participate in the stud. (Non-MCI n=3, MCI n=8,). Medical illness was the only reason for not participating in the non-

MCI patients. Of those with MCI who declined study participation; two cited their memory problem was not severe enough, in one the patient's wife acted as a gatekeeper on the phone and stated her husband's memory problem was not bad enough to participate, one gave no reason, two potential participants were too unwell, one was unable to hear the researcher on the phone, and another was low in mood reportedly for other reasons.

Table 2 summarizes the themes identified.

### Group 1 (Cognitively intact)

None of the participants in Group 1 had heard of MCI prior to the study.

### Expectations of memory loss with ageing

All but one of the participants in Group 1 thought that cognitive decline was part of the ageing process.

'I think you tend to forget little things rather than, you know, you go upstairs for something and say what have I come up here for? I call it senior moments.' (Mary, 77, lives with husband).

Despite thinking it was part of ageing, all but one participant felt that memory loss was preventable.

'...If they don't keep their mind occupied. If you just sit there, just sit there watching the box and all that all the time. I should think if they are doing things, like I do, a bit of knitting or crocheting or something like that and I play on the DS and go on the computer.' (Jennifer, 81, lives alone).

The one participant who felt that memory loss was not preventable, justified this by naming medical conditions, such as stroke, that can affect memory. Most participants had a 'use it or lose it' philosophy, the belief that maintaining mental activity would preserve memory. Memory loss of any kind was thought

**Table 1:** Study participants' demographic data.

Pseudonym and gender	Group	Age	Ethnicity	Previous occupation	Living arrangements	Age at leaving full time education
Sally - Female	1	84	White British	Worked at Polytechnic	Lives with husband	18
Alfred - Male	1	89	White British	Plumber	Lives alone	14
Mary - Female	1	77	White British	Nursery assistant, lab technician	Lives with husband (Participant, Peter)	16
Peter - Male	1	77	White British	Ex Army, van driver	Lives with wife (Participant Mary)	15
Anne - Female	1	85	White British	Bank worker	Lives alone	14
Margaret - Female	1	84	White British	Telephone operator	Lives alone	14
Jennifer - Female	1	81	White British	Cook and cleaner	Lives alone	14
Charles - Male	2	78	Afro-Caribbean British	Soldier, newsagent	Lives alone	16
Lidia - Female	2	85	Afro-Caribbean British	House wife	Lives alone	15
Paul - Male	2	77	White British	Photographer	Lives alone	16
Jim - Male	2	67	White British	Engineer	Lives alone	15
Max - Male	2	82	White British	Diplomat	Lives with lodgers	18
Simon - Male	2	86	White British	Ex marine, worked with church	Lives alone	18

**Table 2:** Summary of themes identified.

Context	Themes identified
<b>GROUP 1</b>	
Expectations of memory loss in ageing	Part of ageing
	Inevitability versus preventability
	Memory loss as a negative event
Terminology	Simple language to explain MCI
Disclosure about MCI from health professionals	Unconditional honesty
	Conditional honesty
	Concealment
<b>GROUP 2</b>	
Understanding of MCI	Good understanding
	Poor understanding
	Poor recall
	Denial/lack of insight
Concerns regarding memory loss	Vulnerability
	Fear of progression
	Frustration
Consequences of having memory investigated	Positive outcome
	Neutral outcome
	Negative outcome

of as a negative event, surrounded by stigma, and described as undesirable and avoidable. Participants often associated MCI with dementia, despite the interviewer explaining that these were separate entities and the participants seemingly understanding the distinction. Dementia carried a greater sense of negativity than the memory loss 'expected' with ageing. This appeared to be the distinction between 'normal' and more serious memory loss.

'Well, I had a brother-in-law who went down with what's the name, with dementia you know, a little bit. I've always been, I'll rather always, said to myself I would rather have cancer than have that. That's my opinion.' (Mary, 77, lives with husband).

### Terminology

When considering the clinical vignettes all participants in group 1 felt that simple language should be used in the explanation of MCI to the hypothetical patients in order to aid understanding.

'...spread it out a bit [referring to the use of mild memory problems in preference to MCI] because even at my age I do not understand what it meant and being as old as you are you are, a little bit deficient up here or so, I think it wants explaining more to understand it.' (Alfred, 89, lives alone).

One participant felt that the use of the medical term may add to the potential stigma of having MCI, however, other participants felt the medical term was useful in order to educate patients.

### Disclosure

All but one participant felt that patients should be told about the diagnosis of MCI. However, honesty could be divided into unconditional and conditional. Participants reporting what they would wish for themselves described a desire for unconditional

honesty, despite the uncertain clinical course of MCI for an individual.

In other words but I would like it explained to me. Speaking personally.' (Alfred, 89, lives alone).

Conditions were applied to honesty. For example two female participants thought that MCI should be explained to women but not men whilst others stated that the diagnosis of MCI should be disclosed only if treatment was available. Some participants discussed the need for sensitive approach to the disclosure of a MCI diagnosis especially if it was unexpected.

'I would say yes, tell a woman but not necessarily a man, because from my experience with men, although I have only had one husband! I don't think men take kindly to being told that they have got something being wrong with them because a lot of men think they know all the answers don't they. (Laughs).' (Margaret, 84, lives alone).

One participant advocated complete concealment of MCI, however, her responses generally displayed a strong stigma surrounding memory loss.

Yeah, you should say "as you get older your memory goes a bit and everyone is the same, not only you". (Anne, 85, lives alone).

### Group 2 (MCI)

Four participants in Group 2 had prompted referral for memory assessment, themselves, having noticed a decline in cognition. Two participants did not acknowledge any memory problems and their referral to memory clinic had been prompted by family members. No one used the term MCI during the interviews and several participants brought their clinic letters with them to the interviews to aid their memory.

### Understanding of MCI

Those that had self-referred for memory assessment had a good understanding of MCI. Two participants discussed the potential progression to dementia.

'They cannot say whether I will have it [dementia] 2-3 years from now. I understand that perhaps in the future it will develop.' (Charles, 78, lives alone).

In those who lacked an apparent understanding of MCI, this could be consequent to forgetting what was said in clinic and denial or lack of insight.

Well I don't think I have any [memory] problems. I can't remember what was said! (laughs)' (Jim, 67, lives alone).

The two participants whose relatives had instigated memory assessment did not identify with having memory problems at all and displayed what appeared to be denial or possibly lack of insight.

'I have a strong memory. This answers to my memory pattern, it's intact, it's agile, it's versatile.' (Paul, 77, Lives alone).

### Concerns regarding memory loss

Participants who recognised their memory problems expressed concerns regarding Fear of progression, frustration,



and vulnerability. Vulnerability appeared to be compounded by social isolation.

'I get frequent telephone calls asking me about, wanting me to agree to various changes, like my subscriptions to things.....I avoid making commitments over the phone.' (Max, 87, lives alone).

### Consequences of having memory investigated

No participants expressed regret at having undergone memory assessment. Positive outcomes included receiving an explanation for the symptoms they had been experiencing and relief at not having dementia.

'Well, it does help me to understand but it doesn't solve the problem. There are a lot of people a lot worse than I am.' (Jim, 67, lives alone).

Neutral reactions included acceptance of the problem. It is possible those experiencing denial had negative reactions to the news or purely had lack of insight, however, they portrayed neutrality.

'It was fine, it was fine, it was ok [Referring to his memory]. I think there was a report here to say it was 19 out of 26, attention and memory and then attention and orientation 18 out of 18 and then fluency was 10 out of 14, and visual and spatial was 16 out of 16 [Reads from his clinic letter]. So essentially it's a combination of all my senses that are fairly combined...'. (Paul, 77, lives alone).

Negative outcomes included family members treating the individual with MCI differently and the concern that no routine follow-up was offered to monitor for potential progression.

'I'm sorry I told them [his daughters] now! (Laughs). Even when I have told them now they are all over me saying do not do this, do not do that. I said, 'I am not [an] invalid''. (Charles, 78, lives alone)

'I'm still worried that they [the clinic] don't, for example, want to see me once a year, they haven't even asked me to come back in a year's time.' (Max, 87, lives alone).

### Coping strategies

Participants employed both practical and emotional strategies, namely: maintaining mental activity, creating lists, denial, normalization and acceptance of memory loss as well as anxiety.

'Well, if I am making a telephone call I write down the essential words, erm. It's awkward you see, if people call me, erm, I can get confused but if I initiate the phone call, before I initiate the phone call I write down the essential words that I want to talk about or particular matters I want talk about, a little memo. I tend to write down a memo before I make an important telephone call. Oh and when try to stay awake then I take a little notebook with a pencil and I try to make notes when the person is speaking. Yes, that helps. Those are the main things I can think of there.' (Max, 87, lives alone).

## DISCUSSION

This is the first qualitative study to examine the extent to

which cognitively intact older people would want to know if they had a hypothetical 'diagnosis' of MCI and of what influences these opinions. The 'use it or lose it' belief in terms of memory seen in this study has been found elsewhere [29] and this belief may add to the potential stigma around memory loss as, if memory becomes impaired it implies that blame needs to be given to that individual. Another interesting point is that the cognitively intact participants often spoke about MCI and dementia interchangeably although the difference was clearly explained; this may be the way in which the participants made the distinction in their minds between memory loss that is expected with age and more serious entities. The study suggests that older patients would wish to know if they had a diagnosis of MCI, despite the uncertainty of the disease trajectory and limited treatment options. This desire for honesty exists despite the perception of memory loss as a negative event with associated stigma. Interestingly this is in keeping with the literature examining older people's views on disclosure of a diagnosis of dementia [23].

In contrast to other qualitative studies, participants with MCI in our study viewed the diagnosis of MCI more positively [17-22]. Notably no participants expressed any regret about receiving the diagnosis of MCI, although those that acknowledged memory loss were concerned about their memory deteriorating further. The concern regarding deterioration of memory in those with MCI has also been echoed in a recent qualitative study that followed up people with stable MCI over seven years [30].

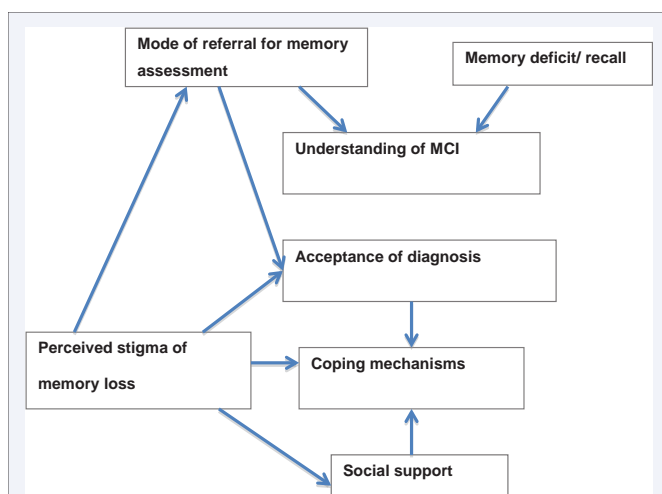
This is the first study to suggest that the referral pathway into memory clinic (self-referral versus others suggesting referral) may affect the understanding and acceptance of the diagnosis of MCI. Those who did not acknowledge a decline in their memory may be more likely to reject the diagnosis of cognitive impairment. This could be secondary to denial or purely a lack of insight. The recollection of memory clinic experience may impact on the understanding of MCI as suggested in previous qualitative work [31]. Furthermore, our study suggests that acknowledgement of MCI potentially improves coping strategies. The coping strategies identified in this study, namely; maintaining mental activity, creating lists, denial, normalization, acceptance of memory loss and anxiety, have previously been described [17-22]. The impact of suggesting practical coping strategies for example maintaining mental activity, would need to be assessed but could potentially be helpful for both cognitively intact as well as those with MCI. Participants who recognized their cognitive decline also expressed a wish to be monitored. A Swedish study following individuals with stable MCI over seven years demonstrated that follow up appointments went some way to alleviating the distress caused by the possibility of developing dementia [30]. It is important to consider the impact of the diagnosis of MCI on individuals and consider the psychological impact of this and how best to manage it [15,16].

We need to consider the potential participants that were approached to participate in the study and then declined. Although no reason was asked for, the individuals often volunteered their rationale. Eight of the eleven who did not proceed with the study would have been in the MCI group and this number is greater than the six with MCI who did take part. Two expressed directly that they felt their memory was not bad enough to take part; for

one, the wife acted as a gatekeeper for one potential participant and again expressed that her husband's memory was not bad enough and a fourth potential participant felt they were too low in mood for other reasons. These replies may be an indication of the perceived stigma associated with memory loss, the issue of denial found in the MCI participants who did take part and potentially the neuropsychiatric issues that may accompany cognitive loss.

Figure 1 depicts the theoretical interplay of factors that may contribute to the practical and emotional outcomes of those with MCI, informed by the findings of this study. The mode of referral (self versus referred by others) may affect both understanding and acceptance of a diagnosis of MCI. Understanding of MCI can be affected by memory and cognitive capabilities and the perceived stigma of memory loss may affect how someone accepts the diagnosis. This acceptance can affect coping mechanisms, as may the perceived stigma attached to MCI and the availability of social support. Such factors can be complexly linked with the stigma of memory loss impacting on the social support received by those with MCI (particularly by family) and on whether, how and when people present for memory assessment in the first place.

These findings have implications for clinicians, policy makers and the research agenda. For clinicians it is important to understand that older people wish to have a diagnosis of MCI disclosed, even if no further information or treatment is available. An understanding of the referral pathway to memory clinic may help clinicians anticipate the patient reaction to the diagnosis of MCI. Sensitivity in communicating the diagnosis is important given the stigma associated with MCI. Those who have MCI desire clear and digestible, written and verbal information. The latter aforementioned suggestion is consistent with the results from a qualitative study examining the healthcare experience of MCI patients, [31] it concluded that impaired recall and limited insight were strong arguments to support the need for robust provision of information. Patients with MCI desire structured hospital follow-up. Theoretically such follow-up may enable the detection of neuropsychiatric symptoms, [32] the early detection of dementia and assess the need for ongoing support. Developing



**Figure 1** Factors affecting practical and emotional outcomes of those with MCI.

**Table 3:** Suggestions from the study and the current evidence base for memory services to consider.

Recommendation	Rationale
Those with MCI should be told about their condition using simple language. Those who are not expecting to receive the diagnosis of MCI may need a graduated and sensitive disclosure.	<ul style="list-style-type: none"> <li>To aid understanding simple language should be used. Honesty and explanation of the uncertainty of the condition should be promoted.</li> </ul>
With the diagnosis of MCI, an information sheet should be given to those with MCI indicating currently known information (both general and specific to the patient).	<ul style="list-style-type: none"> <li>Aids understanding and helps recollection of information.</li> </ul>
Patients with MCI should be offered planned follow-up.	<ul style="list-style-type: none"> <li>May aid early detection of dementia if there is progression.</li> <li>Offers opportunity to monitor for neuro-psychiatric symptoms, instrumental activities of daily living and social support.</li> </ul>
Explore the mode of referral when seeing patients with MCI in clinic.	<ul style="list-style-type: none"> <li>Those who have not identified any memory loss themselves may need extra support in understanding and accepting the condition, as well as both emotional and practical coping strategies.</li> </ul>

patient centered pathways of care, incorporating assessment, management and adequate follow up requires strengthening of the evidence base; longitudinal studies defining the trajectory of MCI, examination of patient views over time and assessment of the impact of formalized follow up (Table 3). In terms of the current understanding of MCI the argument would be that actively trying to seek out those specifically with MCI would be unethical. However, if we consider the appropriate drive to look for the more advanced condition of established dementia or to assess people cognitively in order to pre-empt their risk of for example, post operative complications and delirium [33]; for which there are current solid clinical arguments, we can envisage that we will continue to uncover more of those with MCI.

**LIMITATIONS**

Limitations of this study include selection bias with patients with MCI declining participation. Reasons for non-participation may have included a lack of acknowledgement of cognitive decline or the burden of stigma; those that do not acknowledge cognitive decline may be the most vulnerable in terms of coping with memory deficits and may potentially need more support, adding weight to the case for offering follow up to those with a diagnosis of MCI.

Recruitment from a single centre may reflect practices unique to that institution introducing bias. However, the relative standardization of memory services should mitigate this. The method of sampling was purposive, which by its nature of predetermined criteria may allow for outlier opinions [26] however, by virtue of its encompassing nature may equally have added to our understanding.

## CONCLUSION

This study suggests that older people wish to know if they have a diagnosis of MCI. Those who acknowledge memory impairment are more likely to accept the diagnosis and develop coping strategies. Clinical pathways for MCI should be patient-centered reflecting the views and experience of older service users.

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## APPENDIX 1

### Indicative questions to ask Group 1 (at the beginning of the interview)

- a) What do you expect to happen with memory, as people grow older?
- b) What things do you think affect memory as people become older?
- c) What does the term 'mild cognitive impairment' mean to you?

The researcher can explain: 'This is the name doctors give to memory problems that are minor, and more serious than 'normal' ageing, but which are definitely not as serious as dementia or Alzheimer's disease.'

Explain at this point you will go through some hypothetical cases and ask questions around them. The vignettes will be the presented in the same manner for all participants.

### Vignettes

Scenario 1: An 80 year old person goes to their GP, as they have noticed problems with their memory and are concerned about it. Their GP refers them to hospital and after some questions and tests from the doctor, the doctor thinks that the patient may have mild cognitive impairment (Please note this is not dementia or Alzheimer's disease).

- 1) Assuming the doctor tells the patient their findings, do you think they should use the medical term 'mild cognitive impairment' or should they describe it as mild memory problems? Explain your reasons.

Scenario 2: A woman in her 70s notices that her husband is becoming forgetful and she is worried about him. Her husband, who is 80 years old, has not noticed any problems himself. She persuades him to go the GP who refers him to hospital. The doctor in hospital discovers during the consultation that he has mild cognitive impairment (Please note this is not dementia or Alzheimer's disease).

- 1) Do you think that the doctor should tell the man that he has memory problems? Why do you think so?
- 2) Assuming the doctor tells the patient their findings, do you think they should use the medical term 'mild cognitive impairment' or should they describe it as mild memory problems? Explain your reasons.

Scenario 3: An 80 year old person goes for a hospital appointment regarding shortness of breath and increasing difficulty in walking. During the consultation the doctor performs an initial exploration of the person's memory status and discovers that they have mild cognitive impairment (Please note this is not dementia or Alzheimer's disease).

- 1) Do you think that the doctor should tell the person that they have found evidence of memory problems? Why should they be told or not told?
- 2) Assuming the doctor tells the patient their findings, do you think they should use the medical term 'mild cognitive impairment' or should they describe it as mild memory problems? Explain your reasons.

If having mild cognitive impairment might lead to the development of dementia in the future, but it was not possible to be 100% sure that this would happen, would this change your answers? If so, how?

If there was also a possibility of the memory problem getting better after one year by itself but it was not possible to be 100% sure that this would happen, would this change your answers? If so, how?

## APPENDIX 2

### Indicative questions to ask Group 2

- a) How was your memory problem discovered?
- b) What was your experience of receiving the news about your memory problem?
- c) Do you think that anything should have been done differently in how you received the news?
- d) Can you explain to me what type of memory problems you have and what causes them?
- e) How have things been for you since you received the news about your memory problems?
- f) If you have any close friends or family, how do you think it has affected them to receive the news about your memory problems?
- g) How do you cope with your memory problems? For example, are there any tricks or strategies you use in order to try to compensate for such problems?
- h) Is there anything else you want to tell me about living with memory problems?