# Appendix 1

Appendix 1 Literature review flowchart

Appendix 2 Summary of literature reviews identified from 2004 onward

Appendix 3 Papers included in the review reporting empirical research on patient/ carer experiences of disclosure of a diagnosis of dementia

Appendix 4 Data abstraction form for literature review

Appendix 5 Risk assessment protocol

Appendix 6 Consent protocol

Appendix 7 Recruitment Standard Operating Procedure: Manchester & Newcastle

Appendix 8 Recruitment Standard Operating Procedure: London

Appendix 9 Topic guide for patients: Before – After interviews

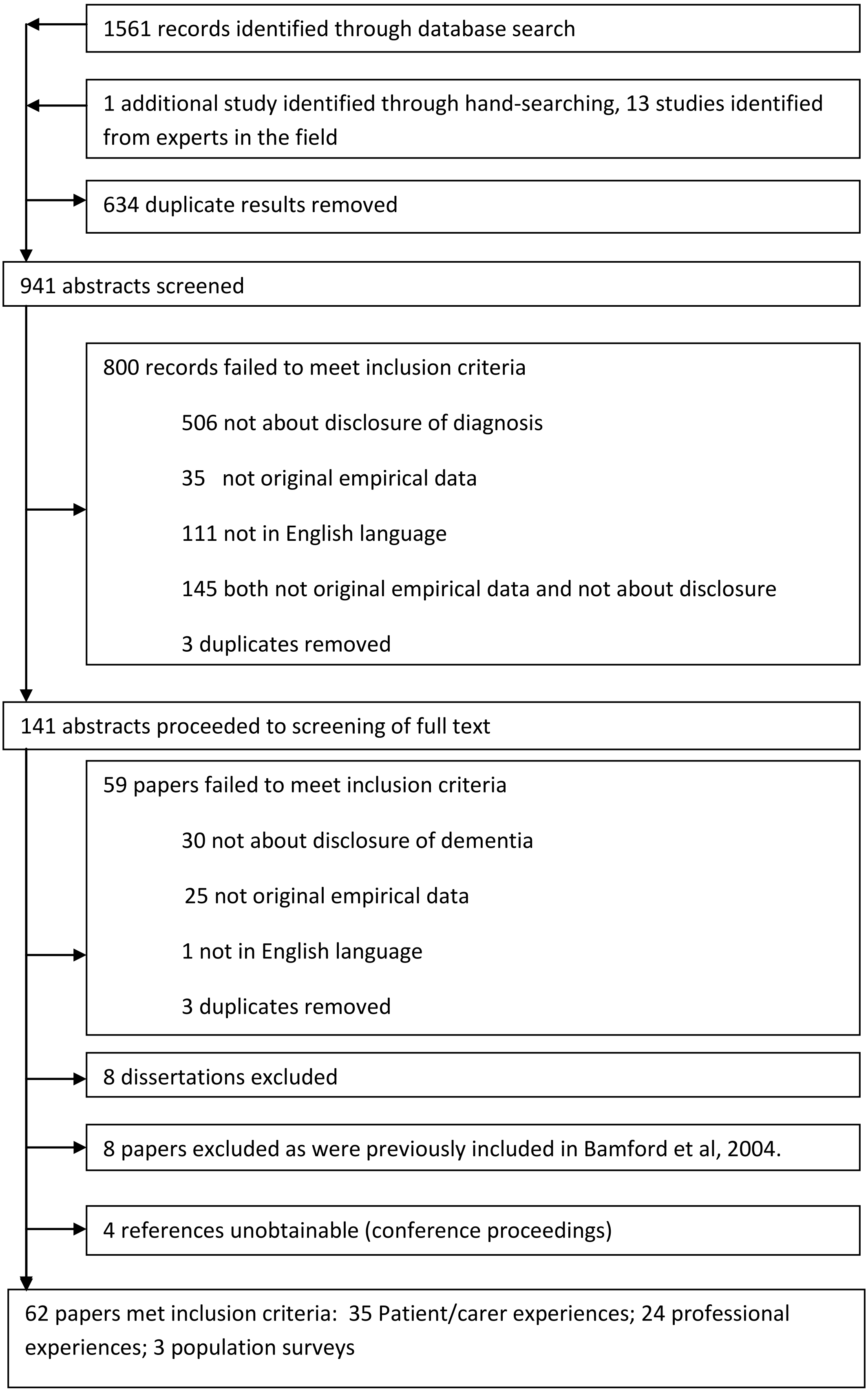
Appendix 10 Topic guide for patients: Retrospective interviews

Appendix 11 Topic guide for carers/ supporters: Before – After interviews

Appendix 12 Topic guide for carers/ supporters: Retrospective interviews

Appendix 13 Thematic table v.5

## Appendix 1: LITERATURE REVIEW FLOWCHART



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## Appendix 2: SUMMARY OF LITERATURE REVIEWS IDENTIFIED FROM 2004 ONWARD

| Reference | Focus of review | Databases searched | Time period searched | Inclusion criteria | Search terms | Papers included | Summary of findings / issues addressed |
|---|---|---|---|---|---|---|---|
| Carpenter & Dave, 2004 | To "document previous opinion and practice in diagnostic disclosure" in dementia | Medline<br>PsycINFO<br>Hand searching of reference lists, websites of "relevant professional organisations" | 1972 to 2002 | None given | "key words such as 'dementia,' 'diagnosis,' 'disclosure,' 'truth,' 'preferences,' and 'patient education.'" | Not explicitly stated<br>62 references listed | Discusses ethical issues and identifies "a broad list of arguments both for and against diagnostic disclosure". Describes reported practice as regards diagnostic disclosure: "Practice guidelines and professional opinion regarding disclosure appear to depart from the actual experience reported by clinicians, patients, and family members". "Process issues in disclosure, such as who is told, how and what they are told, and the impact of disclosure, are poorly understood" |
| Cornett & Hall, 2008 | Narrative review, to "discuss a number of issues that may affect the neuropsychologist's decision to | No detail given | No detail given | None given | No detail given | Not explicitly stated<br>38 references listed | "The impact of the patient's mental capacity and awareness of cognitive deficits on the decision process; respect for the autonomy of the patient; the ethical responsibility to 'do no harm'; the sometimes-competing wishes of the patient and their caregivers and the impact of |

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|  | disclose a dementia diagnosis” |  |  |  |  |  | not telling the truth” |
| De Boer, 2007 | “To gain a better understanding of how people with dementia experience and value their situation” | PubMED<br>PsycINFO<br>plus hand searching | No time limit (search date 14/09/2006) | “Publications describing aspects of dementia from the patient’s perspective in the form of quotations” | 1) “terms that capture all forms of dementia”<br>2) “all terms related to aspects of “suffering” and “personal experiences” of dementia”<br>3) “a third category was added to include different types of research”. | 50 | Emphasises the wide variability in reported experience of disclosure of a diagnosis of dementia. “People with dementia express both positive and negative experiences with care and assessment”. “Some feel that little information is communicated to them … while many people with dementia believe that full disclosure of the diagnosis is ‘the right thing’” “The way the diagnosis is communicated can be a devastating experience”. |
| Fisk et al, 2006 | Review to inform guidelines produced by the Canadian Consensus Conference on | PubMED<br>EMBASE | 1996 - 2006 | None given | Dementia OR Alzheimer’s disease AND ethics AND diagnosis. | Not explicitly stated<br>39 references listed | Discussion of ethical issues around disclosure of diagnosis, supported by evidence from the literature.<br>Suggest that “diagnostic disclosure for persons with dementia must be considered a process”, involving |

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|  | Dementia (CCCD), relating to ethical issues surrounding disclosure of a diagnosis of dementia |  |  |  |  |  | “not only the affected individual but also their family and/or other current or potential future care providers”<br>Gives explicit recommendations regarding disclosure approved at the Third CCCDTD Conference. |
| Illiffe et at, 2009 | Narrative review of the “roles of primary care practitioners in caring for people with dementia in the community” and. included diagnosis, and,disclosure. | Not stated explicitly: update of NICE/SCIE guidelines and Cochrane reviews. | January 2006 - | None given | No detail given | Not explicitly stated<br>66 references listed | Suggests that majority of PWD & carers wish to know the diagnosis, outlines benefits of disclosure, that disclosure “can be badly handled” but that non-disclosure can also have negative effects such as confusion. People with more severe dementia are less likely to be told diagnosis, and decision should be individualised. |
| Monaghan & Begley, 2004 | “To highlight the need for interprofessional collaboration when faced with ethical dilemmas such as diagnosis | No detail given | No detail given | None given | No detail given | Not explicitly stated<br>49 references listed | Identifies that the literature primarily focuses on views of physicians and carers. Describes reported practice. Uses dialogue / discussion of hypothetical case and identifies relevant ethical arguments with reference to published sources. “Ethical theories are of benefit in |

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| | disclosure in the care of adults with dementia” | | | | | | assisting the members of the multidisciplinary<br>team to reach a morally defensible decision “. |

## Appendix 3: PAPERS INCLUDED IN THE REVIEW REPORTING EMPIRICAL RESEARCH ON PATIENT/ CARER EXPERIENCES OF DISCLOSURE OF A DIAGNOSIS OF DEMENTIA

| Reference | Country | Methodology | Participants | Summary of key findings |
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| Adams, 2006 | United States | Qualitative interviews, grounded theory analysis | 20 carers of relatives with mild dementia / Mild Cognitive Impairment (MCI). | Experiences of partners of people with MCI did not differ markedly from those with mild dementia. Many reported taking over practical caring tasks, and difficulty in deciding "how much to do" was described. Many participants reported that the loving nature of the relationship with the people with dementia (PWD) had not changed; Some reported feelings of increased protectiveness and concern. Loss of the confiding relationship was frequently mentioned. Support from others was acknowledged but fear of burdening others and barriers to reliance were described. |
| Aminzadeh et al, 2007 | Canada | Audio tape of disclosure meeting, individual interview with patients and carers, focus groups | 30 patient / carer dyads (newly diagnosed dementia) in individual interviews, 12 carers in focus groups | Acceptance of diagnosis is a staged process - identified denial / grief / positive and coping themes. Disclosure of AD is associated with greater emotional response than disclosure of vascular dementia. Disclosure as an ongoing process, emphasises importance of instilling hope. |
| Barrett et al, 2006 | United States | Individual interviews with patients & carers | 52 patients<br>62 carers | Anosognosia is a common barrier to acceptance of diagnosis at time of disclosure. Many patients (59.6%) were unable to correctly report their diagnosis within |

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| | | immediately following diagnostic disclosure | | minutes of being told it, this was more likely with lower MMSE scores. 12.5% - 33% of carers were unable to correctly report diagnosis. Most carers (32/34) reported being given "just the right amount" of information. |
| Beard, 2004 | United States | Qualitative interviews – individual and focus groups. Grounded theory analysis | 10 "early stage" Alzheimer's Disease (AD) patients (focus group); 3 "early stage" AD patients (individual interviews) | People with dementia (PWD) identify disclosure of diagnosis as a "defining moment", with both positive and negative effects. This can lead to a dilemma regarding whether to inform others, PWD can use positive strategies to maintain identity. |
| Beard, 2008 | United States | Focus groups and individual interviews. Grounded theory analysys | 86 people with "early stage" AD or MCI | Receiving a diagnosis affects identity and can lead to feelings of exclusion, but can reinforce a shared identity with others. Respondents wished to proactively determine their reaction to being diagnosed and were able to make positive adjustments to their lives in order to achieve this. |
| Beattie et al, 2004 | United Kingdom | Semi-structured individual interviews | 14 younger people (<65y) with dementia | The manner in which disclosure takes place is seen as important by younger PWD, experiences are variable. Process of obtaining a diagnosis can be confusing, traumatic and lengthy. Age specific services are desired. |
| Benbow et al, 2009 | United Kingdom | Qualitative thematic analysis of a written narrative | 8 carers of people with dementia | Difficulty in obtaining a diagnosis was identified as a common theme. Diagnosis was commonly obtained from specialist services, whilst primary care was often seen as unreceptive to initial complaints of memory difficulty. |

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| Bouckaert & Van den Bosch, 2005 | Belgium | Self completion questionnaire | 100 family members of AD patients | 43% of relatives believed that PWD should be told the diagnosis. 90% would want to be told the diagnosis if they developed dementia themselves, and 75% would make use of a predictive diagnostic test. |
| Byszewski et al, 2007 | Canada | Interviews/focus groups | 30 people with dementia<br>30 Carers | Majority prefer full disclosure. People with dementia satisfied with disclosure meeting, physician's performance and having carer present but wanted more information: carers emphasised need to stress hope and positive aspects and to ensure disclosure is a process and need emotional support. |
| Campbell et al, 2008 | United States | Individual interviews | 149 people with dementia | A majority (64%) of PWD were aware that they had memory problems. 26% could recall being informed of a diagnosis, proxies reported that 69% of PWD had been informed. Disclosure was more likely in younger patients and those with milder disease. PWD who recalled a diagnosis were more likely to report poorer health status (OR 2.5, 95% CI 1.1-.5) |
| Carpenter et al, 2008 | United States | Self completion questionnaire, pre / post diagnosis<br>Included Geriatric Depression Scale and State / Trait Anxiety Inventory. | 90 patient / carer dyads | 28% of patients recalled previously being informed of a diagnosis of dementia, whilst 48% of carers reported that PWD had been informed. Patients with low GDS at baseline had significantly higher GDS score at follow up (P<0.001), whilst those with high GDS scores at baseline had significantly lower scores at follow up (P<0.001) though effect sizes were small. Patients (carers) with low STAI scores at baseline had no significant change at follow up, P=.19 (P=.30), whereas patients (carers) with |

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| | | | | high STAI scores at baseline had significantly lower score at follow-up P<0.001 (P<0.001) |
| Cloutterbuck & Mahonie, 2003 | United States | Focus group interviews | 7 family carers of people with dementia | Barriers to seeking and obtaining a diagnosis included the family dynamic of maintaining respect for the PWD's independence and wishes and the theme of perceived disrespect from healthcare providers. Facilitators to obtaining a diagnosis included informal networking, unambiguous communication from providers, self education and support groups. |
| Connell et al, 2004 | United States | Focus group interviews | 52 carers and 39 physicians | Carers reported resistance from physicians when trying to obtain initial assessment. Advantages of being told diagnosis included; being able to be more patient with PWD, less likely to blame person, increased incentive to take responsibility and to make decisions. Carers felt inadequately prepared to hear the word dementia / Alzheimers. Initial reactions included shock, anger, embarrassment and devastation but also relief & validation. Carers felt they did not receive adequate information about treatment or follow-up. Physicians reported pressure to give a diagnosis, and that time was limited to do this. |
| Derksen et al, 2006 | Netherlands | Semi structured interviews | 18 patient / carer dyads | Disclosure was not associated with harm and has benefits. Many patients and carers are expecting the diagnosis, but a minority who are not may exhibit a negative emotional response. Disclosure was seen as an important step even if the diagnosis was expected, marking the beginning of a partnership between patient |

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| | | | | and carer, and of the process of adapting to a caring role. Disclosure also fostered the process of planning for the future. |
| Derksen et al, 2005 | Netherlands | In depth individual interview, grounded theory analysis | 1 patient / carer dyad | 3 domains identified: increased awareness of dementia, impact on interpersonal relationships, and effects on social relationships. Receiving the diagnosis confirmed suspicions but led to patient confusion.. The carer became more aware of the consequences for her personal life. Diagnosis led the carer tried to change her responses to the patient's behaviour and to show an appreciation of his capacities. Disclosure enabled support from the couple's children and their church. Future care planning became an issue to address. |
| Elson, 2006 | United Kingdom | Individual interviews | 36 patients referred for investigation of memory complaints | Patients attributed memory problems to a variety of causes including physical and mental ill health and environmental factors. The most common attribution was "don't know" (13 definite, 11 tentative) and only 1 patient reported suspecting dementia. 86% definitely wanted to know the cause of their memory problems, 6% did not and 8% unsure. After being given basic information about Alzheimers disease, 69% wanted to know if this was diagnosis, 17% did not and 11% uncertain. Reasons for wanting to know included advance planning, wish to be well informed, to access treatment and to begin psychological adjustment. Reasons for not wanting to know included anxiety / distress, lack of effective treatment, fear of being a burden. |

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| Frank et al, 2006 | USA / UK | Structured focus group interviews | 20 AD patients and 16 informants, 20 MCI patients and 11 informants | Key themes included uncertainty of diagnosis, skill loss, social/family roles, embarrassment/shame, emotionality, insight and burden. Most MCI patients were not given a specific name for their disorder and several expressed concern about developing AD. Most AD patients had forgotten the diagnosis and tests they undertook. MCI patients reported more embarrassment about symptoms than AD patients, and described more effort in hiding symptoms from others. Differences in insight emerged between groups, AD patients were generally poorer reporters of deficits than MCI patients. |
| Georges et al, 2008 | France, Germany, Poland, Spain, UK | Postal questionnaire | 1181 carers of people with dementia who were in contact with an Alzheimer's Disease organisation. | Diagnostic setting was most often in primary care practice (31%) or hospital (31%). Most patients diagnosed by a neurologist (43%) though in Scotland most were diagnosed by a psychiatrist (34% v 17% internationally). The proportion of patients informed of their diagnosis ranged from 80% in Scotland to 24% in Spain. |
| Gaugler et al, 2003 | United States | Postal questionnaire | 1055 carers of people with dementia | Four distinct sequences of entry into the caregiving role were identified. There was an association between non diagnosis dependent groups and living in the community, and these groups were more likely to report a gradual onset of caregiving. |
| Harman and Clare, | United Kingdom | Semi structured interviews | 9 people with mild dementia | Two main themes emerged; "it will get worse", encompassing an understanding of the progressive nature of the problems along with uncertainty about what the |

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| 2006 |  |  |  | future holds, and “I want to be me”, describing a desire to maintain identity. People described a variety of attributions of their difficulties and compared their situation with that of others. Some felt socially stigmatised or excluded as a consequence of being given the diagnosis. |
| Hinton et al, 2003 | United States | Interviews | 39 ethically diverse family carers of people with dementia | Help –seeking behaviour initiated by 74% of families. Majority of families received final diagnosis (but minority of Chinese Americans do not). Four pathways to diagnosis: 1) shock, 2) fragmented, 3) crisis event, 4) dead end. Adverse experiences reported by carer. |
| Keady et al, 2005 | United Kingdom | Series of qualitative interviews using life story approach & grounded theory | 5 patient / carer dyads, 1 person with dementia living alone | Suggested that the usual and accepted (staff) practice of sharing a diagnosis of dementia was not seen in the same positive light by those on its receiving end. PWD placed a greater emphasis on the positive relationship they had with the person sharing the news, rather than the fact that it had to be a medical practitioner. Positive, reliable, close and trusting relationships were the embodiment of the transition to/during/from the point of diagnosis. |
| Laakkonen et al, 2008 | Finland | Postal questionnaire | 1214 carers of people with dementia | Almost all carers reported diagnosis had been openly disclosed (93%) and that this was was appropriate (97%). 71% were content with the information they received, only 49% felt follow-up care had been well arranged. Almost all discussed the diagnosis with family (97%) and friends (84%). 55% felt the PWD had |

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| | | | | developed depressive symptoms following disclosure, whilst 68% felt that awareness had caused symptoms of depression in themselves. Anxiety, grief, sadness and disappointment were reported. |
| Laakkonen et al, 2008a<br>(letter) | Finland | Postal questionnaire | 1214 carers of people with dementia | After the disclosure of a diagnosis, a large proportion of carers felt a need for discussion about advance care planning with their physician. 59% expressed that they would like to discuss ACP with their spouse's physician, although only 6% had conducted such discussions. Fewer than one-third of carers reported that they had discussed their spouse's medical care preferences with each other, and only 4% of the spouses with dementia had a written living will. |
| Langdon et al, 2007 | United Kingdom | Semi-structured individual interviews | 12 people with dementia | The words "Dementia" and "Alzheimer's" evoked visceral emotional responses, were seen as being technical and unhelpful terms.. Participants were very sensitive of how others responded to their diagnosis and there were mixed views about whether they should be treated differently as a result. Most participants felt able to share their diagnosis with their inner social circle but there was reluctance to share the diagnosis outside this with concerns about being treated differently or stereotyped. |
| Lin et al, 2005 | Taiwan | Self completion questionnaire | 150 relatives of people referred to memory clinic | 76% would want diagnosis of dementia disclosed to their relative, whilst 93% would want disclosure to themselves and family if they were to develop dementia. Reasons for favouring disclosure included 'right to know', helpful for coping, accessing treatment and support, planning for |

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| | | | | future. Reasons for objecting to disclosure included causing emotional distress, rejection by family / friends, worsening disease, embarrassment and lack of effective treatment. A variety of preferred terms were identified including “memory loss” (26%) and the Chinese term “Sue-Zi” (21%). |
| Lingler et al, 2006 | United States | Semi structured interviews, grounded theory analysis | 12 people with mild cognitive impairment | The term MCI was only used by 1 participant. Positive (5) neutral (4) and negative (2) phrasing was employed to depict emotional reaction to receiving the diagnosis. Relief that a diagnosis of Alzheimers had not been given was encountered, but some participants feared progression to dementia in the future. Some were satisfied with professional validation of their symptoms. Participants framed constructions of the meaning of their diagnosis in terms of “face-value” (ie descriptive) and “prognosis-focused” appraisals. Meaning constructs were influenced by expectations of normal aging, personal experience of individuals with dementia, and concurrent health problems. |
| Moniz-Cook et al, 2006 | United Kingdom | Semi structured interviews<br>following referral but prior to assessment and diagnosis. | 48 patient / relative dyads, | Patients and relatives associated dementia with “loss of the self”. Desire to be informed of diagnosis was associated with perceptions of the consequences of dementia or previous family experiences. Fears of loss of control (particularly continence) and loss of well-being were expressed, along with family upset and the prospect of moving to a care home. Participants did not have specific expectations of support services, but expressed a |

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| | | | | desire for advice. |
| Pinner & Bouman, 2003 | United Kingdom | Semi structured interviews prior to diagnostic disclosure, followed by case note review after 1 year. Compared attitudes toward disclosure of diagnoses of dementia and cancer. | 50 patient / carer dyads | 92% of PWD wanted to be told of their diagnosis, 98% would want to be told of a hypothetical diagnosis of cancer. Reasons for disclosure included right to know, future planning and treatment, reasons for not wanting disclosure included emotional upset. All PWD would want access to treatment. 88% would make use of a predictive test. 28% of patients had insight that they currently had dementia. 98% of carers wished to know if they developed dementia or cancer;86% would use of a predictive test. 82% thought their relative had dementia; 26% did not want the diagnosis disclosed to the patient. At 1 year follow up 6% of patients had been treated for depression, with no suicides. |
| Rimmer et al., 2005 | France, Germany, Italy, Poland, Spain, UK | Telephone interviews and qualitative interviews | 1200 general public, 600 carers for people with AD, 96 people with AD. | 59% of carers were satisfied with the time it took to get a diagnosis of AD. Diagnoses were disclosed by specialists the majority of the time (73%), though most presentations were to primary care practitioners. Most reported receiving information about possible treatments at the time of disclosure. |
| Robinson et al, 2005 | United Kingdom | Semi structured interviews | 9 patient / carer dyads | Two ‘higher order’ themes were identified; “not quite the same person, tell me what actually is wrong”, incorporating issues of gradually noticing changes, concluding that something was wrong, seeking help / diagnosis and initial experiences of services, and “everything’s changed, we have to go from there”, incorporating issues of accepting and adjusting to the |

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| | | | | diagnosis, role changes from partner to carer and positive coping. The overarching theme of making sense and adjusting to loss was described as an ongoing process. |
| Shimizu et al, 2008 | Brazil | Semi structured interviews | 50 carers of people with AD plus 50 non-carer controls | Overall, 73% of participants favoured disclosure to an AD patient. Higher schooling was associated with a stronger wish of not revealing the diagnosis (P=0.028) 58% of carers favoured disclosure of diagnosis compared with 88% of controls (P=0.0007). 90% of carers and 98% of controls would wish disclosure if they developed dementia. AD was considered a reversible disease by 18% of carers and 52% of controls (P=0.00003). Main justifications for withholding the diagnosis were fears of provoking depression and a belief that the patient would not be able to understand the diagnosis. |
| Vernooij-Dassen et al,2006 | Netherlands | Semi structured interviews, 2 weeks and 12 weeks following diagnostic disclosure | 18 patient – carer dyads | 3 main themes identified at 2 weeks (awareness of dementia, partnerships and social relationships) were continued at 12 weeks. Some had ongoing problems accepting the diagnosis; others had developed ways of coping and changes in perception of problems and emotions. Both positive and negative changes in relationships were reported. Some dyads had made significant decisions about the future or practical changes. Telling friends and family often brought positive responses and surprises about what others already knew. |

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| Wain et al, 2009 | United States | Self report questionnaires and semi structured interviews | 24 siblings of patients with early onset AD | 46% were informed of their sibling's diagnosis the same day as their sibling. 28% noted difficulty in obtaining an exact diagnosis, 16% wished they had been given more information. 62.5% reported no change in how close they felt to their sibling following diagnosis, 20.8% felt less close and 16.7% felt closer. Women were more likely to be providing care, including meals (P=0.02) and "other" care (P=0.01). 92% were providing emotional support. 36% reported difficulty talking about AD within the family. Some participants had made a living will (45.8%) or advance directive (37.5%). |
| Wald et al, 2003 | United Kingdom | Semi structured interviews.. | 100 carers of people with dementia, recruited from memory clinics and community mental health teams. | Carers wanted to be given as much information as possible. When asked to prioritise the most important 3 things to be told, they chose "What is dementia" (60%), available treatments (60%), BPSD (46%), available services (44%), course of the illness (36%), what to do in a crisis (17%), support groups (17%), benefits (7%), financial & legal issues (5%), talking therapies (5%), effects on carers (2%), and complementary therapies (1%). 75-91% wanted information be given at the time of diagnosis rather than as the need arises. Most carers wanted several sources of information including from health professionals and written education from independent organisations. |

## Appendix 4: DATA ABSTRACTION FORM FOR LITERATURE REVIEW

| **Heading** | | **For completion by reviewer(s)** |
|---|---|---|
| Bibliographic Details | | Journal Article Report Website Book Chapter |
| Reviewer | *Circle* | Alan G Louise R Clare A |
| Eligible? | *Empirical data, in English, about disclosure?* | Yes No Unclear |
| Methodology | *Any concerns re methodological quality / appropriateness?* | |
| Typology | *Type of study?* | Systematic review Narrative review<br>Primary Research<br>Case studies Descriptive account |
| Participants | *Evidence from service users, carers, practitioners?* | …People with dementia<br>…Carers<br>…PWD & Carers<br>…Professionals<br>…Professionals & PWD<br>…Professionals & Carers<br>…Professionals, PWD and Carers |
| Study aims | *What were the study's aims and purpose?* | |

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| Key findings<br>Implications for policy/practice<br>Future research | *What are the key study findings?*<br>*What are its implications for policy, practice and theory?*<br>*? further research needed* | |
| Evaluative summary | *Brief comments on the study as a whole - strengths and weakness.* | |
| Stakeholder involvement | *Which groups involved?*<br>*What was their role in study?* | Users Carers Professionals<br>Advisors Design Participants Dissemination |
| Ethics | *Was ethical committee approval obtained?*<br>*Informed consent obtained?*<br>*Does the study address ethical issues adequately?* | Ethical approval Yes No Unclear<br>Informed Consent Yes No Unclear<br>Ethical issues addressed Yes No Unclear |

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| | *Has confidentiality been maintained?* | Confidentiality maintained Yes No Unclear |
| Aims | *Are the aims of the study clearly stated?* | Yes No Unclear |
| Setting | *What is the geographical and care setting for the study?* | Urban Rural Unclear<br>Semi-urban Semi-rural Mixed |
| Rationale | *What is the rationale and appropriateness for this choice?* | |
| Detail | *Is there sufficient detail about the setting?* | |
| Timing | *Period of data collection* | |
| Inclusion Criteria | *Who was included in the study?* | |
| Exclusion Criteria | *Who was excluded from the study?* | |
| Sample Selection | *How sample selected?*<br>*What factors influenced selection (eg timescale)* | |
| Sample size | *What is the size and characteristics of the sample (groups) in the study?*<br>*If people with dementia included, was the severity of their illness assessed* | Size<br>Age<br>Sex ratio<br>Ethnicity<br>Dementia severity<br>Other |
| Appropriateness | *Is the sample appropriate to meet the* | Yes No Unclear |

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| | *study aims?* | |
| Methods | *What data collection methods were used?*<br>*Was the data collection adequately described and rigorously conducted?* | Interview Focus Group Survey<br>Observation Mixed Methods<br>Yes No Unclear |
| Is Interview schedule /survey adequately outlined? | | Yes No Unclear |
| Is the development work for the above adequately described? | | Yes No Unclear |
| Role of researcher | *What is the role of the researcher within the setting?*<br>*Are the researches' own position, assumptions and possible biases outlined?* | |
| Data analysis | *How are the data analyzed?*<br>*How adequate is the description of the data analysis?*<br>*Is adequate evidence provided to support the analysis (eg use of original data, iterative analysis, efforts to establish validity and reliability)?*<br>*Is the study set in context in terms of findings and relevant theory?* | |

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| Reflexivity<br>Study limitations | *Are the findings substantiated by the data?*<br>*Has consideration been given to any limitations of the methods or data that may affect results?*<br>*Describe key limitations* | Yes No Unclear<br>Yes No Unclear |
| Outcomes | *What outcome measures were adopted (if any).*<br>*Are they validated measures?* | Yes No Unclear |
| Key results or<br>Themes identified | | |
| Main conclusions | *Summarise key points*<br>*Are the conclusions justified?* | |
| Generalisability | *To what extent are the study findings generalisable* | |
| Relevance to UK | *? What is the country of study?*<br>*How applicable to the study findings to the system in the UK?* | |
| Format | *Comment on study format (book, abstract etc) and how this may have implications for style and presentation of the text* | |
| Links to other references to be | *List any links to other references that should* | |

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| followed up | *be followed up* | |
| Second reviewer | *Add name* | |
| Agreement with first Reviewer | | |
| Inclusion | *Should study be included in final review?* | Yes No Unclear |
| Date | | |

## Appendix 5: RISK ASSESSMENT PROTOCOL

**Potential Risks:** Suicidal ideation, severe self neglect, driving, safety in the home, aggression toward other, sexually inappropriate behaviour, vulnerability to exploitation, abuse.

Notify interviewee of limits of confidentiality – obligation to disclose significant risks to self or others.

If risk mentioned, assess severity, discuss strategies available to interviewee, where possible access PI for urgent supervision, (especially if interviewee is not happy about disclosure plan/willing to approach team themselves) and if necessary notify plan to disclose to relevant memory service team.

Assess the risk:

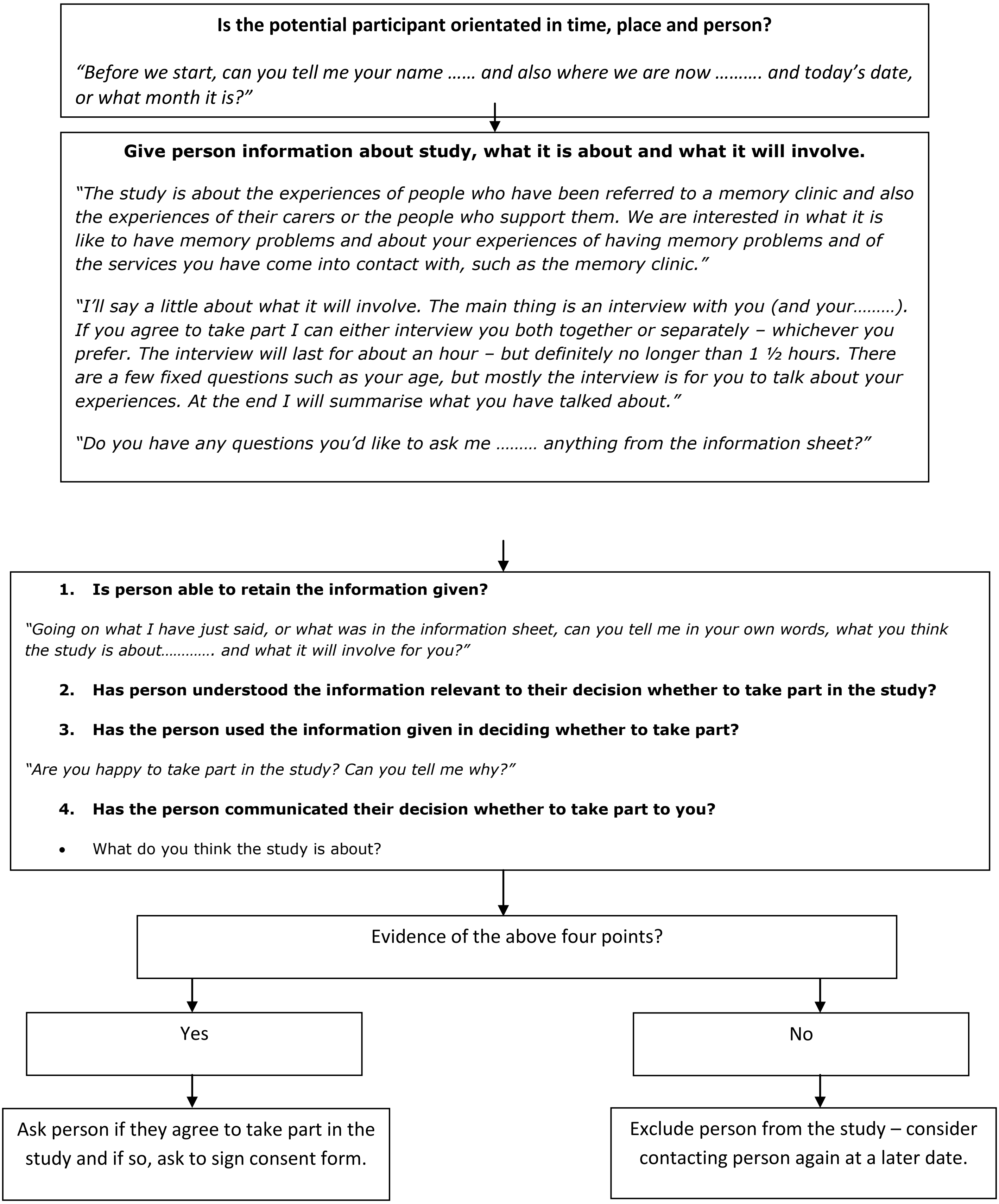
1. **Severity:** how likely, how extreme, examples (need enough information that you could dramatise information)
2. **Opportunity:** means, plans developed as to how would self harm etc, likelihood of opportunity in immediate future.
3. **Vulnerability:** Lives alone/alone at present, alcohol consumption, drugs (street and prescription), impulsivity, male.
4. **Protective factors:** supportive carer/others, beliefs, high levels of monitoring.
5. **Plans to manage distress:** actions taken by client, whether risk disclosed to others, response to advice, actions client could take (information about available services can be supplied).

**ACTIONS:**

1. **If no imminent risk, take to supervision/contact supervisor for discussion**
2. **If imminent risk, check that patient or carer contacts service, or contact service for them**
3. **Provide clear account of information gained, including behavioural details, and any contact information supplied.**

1. Other Report - Secondhand account – need all the information as above, plus assessment of whether issues are based on **recent** actual events and concerns. Explain limits to confidentiality and negotiate strategies to address.
2. Self Report – Re-assure of non-disclosure to other than team members (i.e. not to family).

## Appendix 6: CONSENT PROTOCOL



**Is the potential participant orientated in time, place and person?**

*"Before we start, can you tell me your name …… and also where we are now ………. and today's date, or what month it is?"*

**Give person information about study, what it is about and what it will involve.**

*"The study is about the experiences of people who have been referred to a memory clinic and also the experiences of their carers or the people who support them. We are interested in what it is like to have memory problems and about your experiences of having memory problems and of the services you have come into contact with, such as the memory clinic."*

*"I'll say a little about what it will involve. The main thing is an interview with you (and your………). If you agree to take part I can either interview you both together or separately – whichever you prefer. The interview will last for about an hour – but definitely no longer than 1 ½ hours. There are a few fixed questions such as your age, but mostly the interview is for you to talk about your experiences. At the end I will summarise what you have talked about."*

*"Do you have any questions you'd like to ask me ……… anything from the information sheet?"*

1. **Is person able to retain the information given?**

*"Going on what I have just said, or what was in the information sheet, can you tell me in your own words, what you think the study is about………… and what it will involve for you?"*

2. **Has person understood the information relevant to their decision whether to take part in the study?**
3. **Has the person used the information given in deciding whether to take part?**

*"Are you happy to take part in the study? Can you tell me why?"*

4. **Has the person communicated their decision whether to take part to you?**

- What do you think the study is about?

Evidence of the above four points?

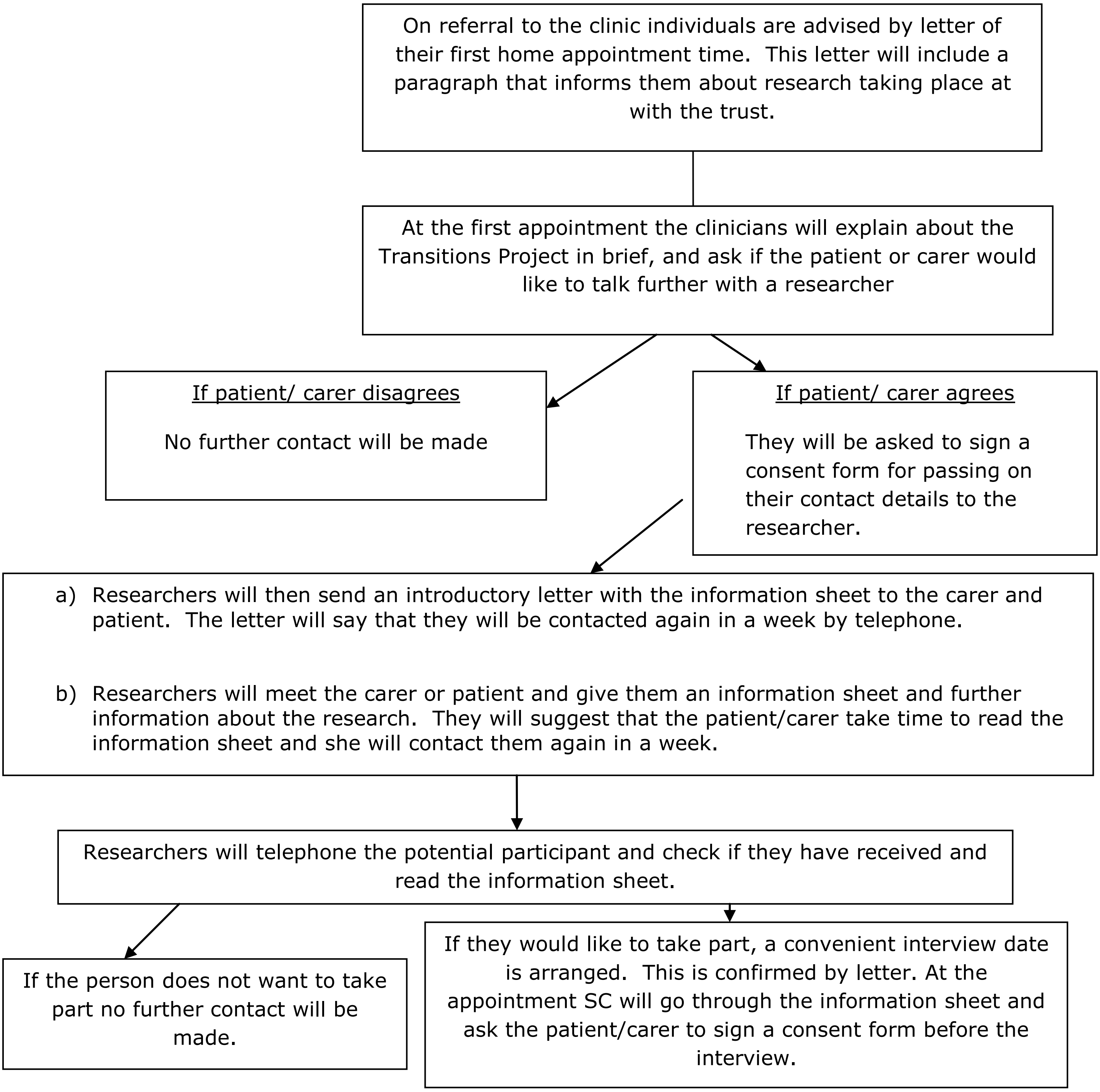
Yes

Ask person if they agree to take part in the study and if so, ask to sign consent form.

No

Exclude person from the study – consider contacting person again at a later date.

## Appendix 7: Recruitment Standard Operating Procedure: Manchester & Newcastle



On referral to the clinic individuals are advised by letter of their first home appointment time. This letter will include a paragraph that informs them about research taking place at with the trust.

At the first appointment the clinicians will explain about the Transitions Project in brief, and ask if the patient or carer would like to talk further with a researcher

<u>If patient/ carer disagrees</u>

No further contact will be made

<u>If patient/ carer agrees</u>

They will be asked to sign a consent form for passing on their contact details to the researcher.

a) Researchers will then send an introductory letter with the information sheet to the carer and patient. The letter will say that they will be contacted again in a week by telephone.

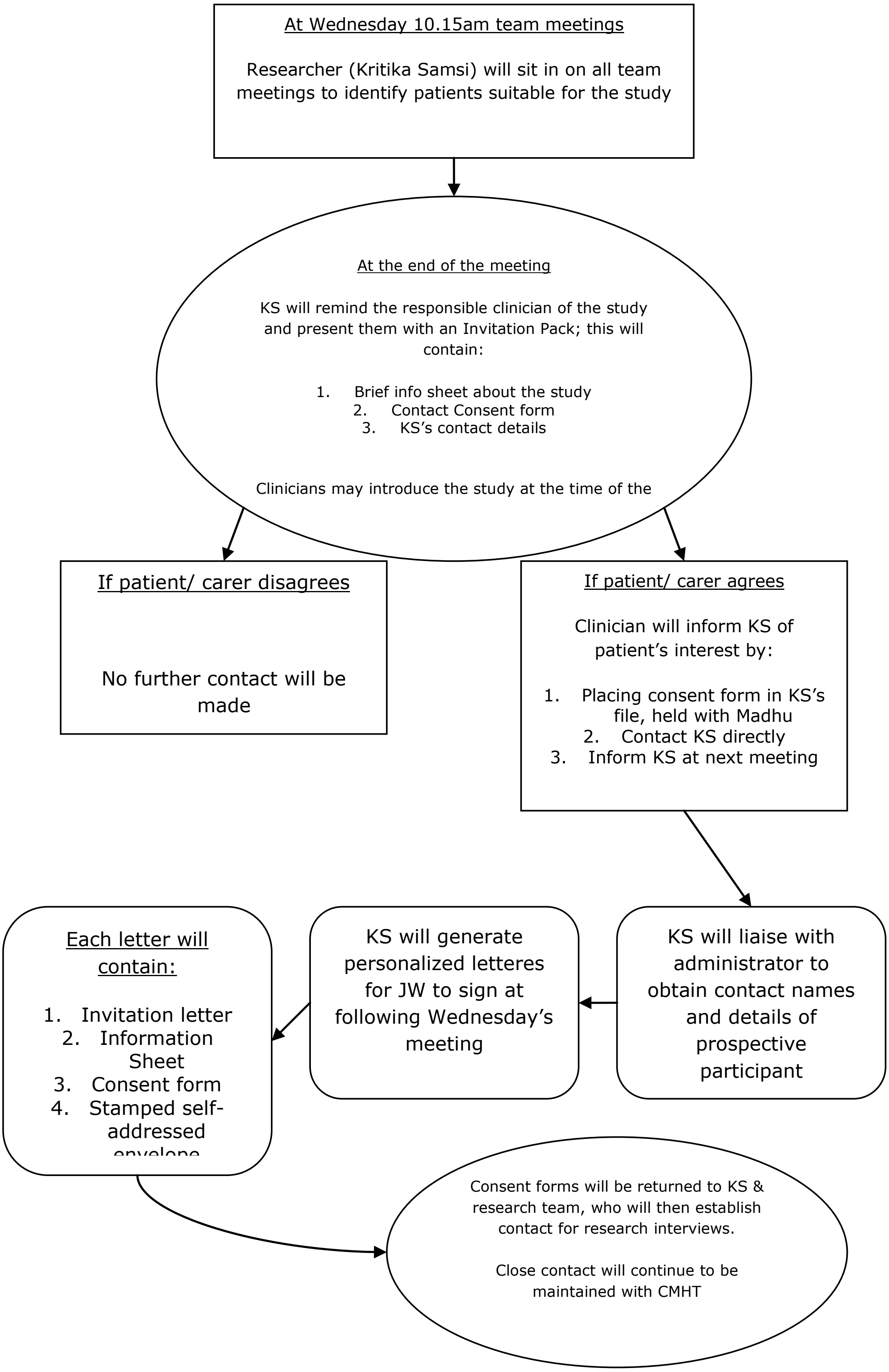
b) Researchers will meet the carer or patient and give them an information sheet and further information about the research. They will suggest that the patient/carer take time to read the information sheet and she will contact them again in a week.

Researchers will telephone the potential participant and check if they have received and read the information sheet.

If the person does not want to take part no further contact will be made.

If they would like to take part, a convenient interview date is arranged. This is confirmed by letter. At the appointment SC will go through the information sheet and ask the patient/carer to sign a consent form before the interview.

# Appendix 8: Recruitment Standard Operating Procedure: LONDON



At Wednesday 10.15am team meetings

Researcher (Kritika Samsi) will sit in on all team meetings to identify patients suitable for the study

At the end of the meeting

KS will remind the responsible clinician of the study and present them with an Invitation Pack; this will contain:

1. Brief info sheet about the study
2. Contact Consent form
3. KS's contact details

Clinicians may introduce the study at the time of the

If patient/ carer disagrees

No further contact will be made

If patient/ carer agrees

Clinician will inform KS of patient's interest by:

1. Placing consent form in KS's file, held with Madhu
2. Contact KS directly
3. Inform KS at next meeting

KS will liaise with administrator to obtain contact names and details of prospective participant

KS will generate personalized letteres for JW to sign at following Wednesday's meeting

Each letter will contain:

1. Invitation letter
2. Information Sheet
3. Consent form
4. Stamped self-addressed envelope

Consent forms will be returned to KS & research team, who will then establish contact for research interviews.

Close contact will continue to be maintained with CMHT

## Appendix 9: INTERVIEW TOPIC GUIDE FOR PATIENTS – BEFORE – AFTER INTERVIEWS

**Prompts to researcher:**

1. Ask permission to record the discussion and explain that data will be transcribed anonymously, kept confidential to the study research team and stored securely.

2. Check that they have had time to read the Participant Information Sheet and ask whether they have any questions.

3. Check Consent Form has been completed fully.

4. Allow time for questions.

**Date of interview: (DD/MM/YYYY) : _______________**

**Researcher initials: _________**

## Interview with patients - early assessment:

### Introduction:

*Thank you for making time to talk to me today and agreeing to take part in this study. We are talking to a number of people at this clinic about their experiences of being assessed for their memory problems.*

*This interview will last about [1-2 hours tbc post piloting].*

### Topics and questions:

1. Can you tell me a bit about yourself?
   Prompt: Establish whether they live alone, network of professional and social support and nature of the carer relationship.

   And as much of the biographical data required as possible, such as background and history.

2. We're talking to people who are being seen by professionals at [name of recruiting clinic]. We are interested in what led up to you going to [name of clinic]. Can you tell me what it's been like in your own words, starting with what led up to you going to the clinic?
   Prompts: How long did you have to wait for your appointment? Did you have any thoughts about what might be going on with your health?

3. What has it been like going to appointments at [name of recruiting clinic] (or having appointments at home from staff at [name at recruiting clinic]) and talking to professionals about your memory difficulties?
   Prompt: What was it like talking to your GP?

   Prompts for both parts: Were you alone? Was that your choice (either to go alone or be accompanied)?

4. What have you been told about your problems?
   Prompt: Who was it that told you that?

   What did your GP or nurse tell you about your problems?

   What did you think about the way in which you received this info?

5. Is there anything else you want to know or wished you had discussed with the professionals?
   Did you feel you had enough time to discuss things with professionals?

6. Did you receive any written information from your doctor? from the clinic ?
   If yes, what did you think about it? How could it be improved?

   If no, would you have liked to have received some information? If yes what would have been helpful?

   Is there anything else you think would have been helpful at this stage?

7. We would like to come back and talk to you again in XX weeks. Can I check that you're happy for us to contact you again then?
   (NB check that this tallies with consent form)

**Summarise main points. Explain that you will be sending the person a summary of the main points for them to check.**

**Closure prompts to researcher:**

Thanks for taking part. Travel expenses (if appropriate).

**DEMOGRAPHIC INFORMATION**

I think we have covered most of these questions; there are just a few demographic details that I would like to check I have got correct.

Age:

| | |
|---|---|
| Gender: | Male |
| | Female |
| Living arrangements: | Co-resident carer (either own home/home of PWD) |
| | Not co-resident carer (own home) |
| Relationship to person you care for: | Spouse |
| | Child |
| | Other family member (define): |
| | Friend |
| | Neighbour |
| | Other (define): |

May I ask what age you were when you left school ?  What about after that?

Previous Occupation:

**Ethnic Group**. *Chose ONE from A to E, then indicate cultural background.*

A **White**. options of: **British**; **Irish** or **Any other White background** (*please describe*).

B **Mixed**. options of: **White and Black Caribbean**; **White and Black African**; **White and Asian** or **any other Mixed background** (*please describe*).

C **Asian or Asian British**. options of: **Indian**; **Pakistani**; **Bangladeshi**; **Any other Asian background** (*please describe*).

D **Black or Black British**. options of: **Caribbean**; **African**; **Any other Black background** (*please describe*).

E **Chinese or other ethnic group**. options of: **Chinese**; **Any other** (*please describe*).

## Interview with patients post-assessment:

## Introduction

*Thank you for making time to talk to me again today and agreeing to take part in this study. We are talking to a number of people at this memory service about their experiences of memory problems and finding a diagnosis of their cause. This interview will last about [1-2 hours tbc post piloting].*

## Topics and questions:

1. I just wondered if anything has changed for you in your personal circumstances, since the first time I saw you? (living arrangements)
   Can you tell me what's happened since I last saw you? How have things been in your own words? Has anything changed? If yes, what has changed?

2. Can you tell me about any visits to the (name of clinic)? What have you been told about your memory difficulties by the staff there?

3. What happened when you were told [about the cause of your memory problems / that you have a diagnosis of dementia / MCI / or as appropriate]?
   Prompts: who was there, what did they say, what did you say, what did you think? Did you feel you had enough time to discuss concerns that you had? Could anything have been done better? What, if anything, went well?

4. Has being told [about the cause of your memory problems / you have dementia / MCI / or as appropriate] changed the way you feel? Has it changed anything else? If so, what has it changed and in what way?

5. Did you look up any information yourself, eg, from the library, on the internet, ask anyone for information/advice, and so on?

6. Have you made any specific decisions or any plans since being told …………?

7. Have you spoken to anyone, such as friends or family members about your diagnosis? What reaction did they have?

8. Or someone else perhaps like your GP, solicitor, bank manager or religious figure? If so, what reaction did they have? Who was most helpful? And why?

9. Is there anyone who you specifically avoided speaking to? If so who? Why?

10. What help did you get during the time leading up to the [diagnosis / or as appropriate], :
    a. Any information about what was available and services perhaps? (including medication),
    b. Any counselling or emotional support?
    c. Any practical help or suggestions?

11. Has any follow-up been suggested?
    Prompts: What? By whom? What do you think about that?

12. Has taking any tablets/ pills/ medicines for your problems been discussed with you?
    **If yes:** Can you tell me about those discussions?

    Prompts: Who by? Where? What did you think about the advice? Why was that? What did you think about medication, then and now? At the time did you know anything about tablets that can be taken to help memory problems / dementia? Had you heard any press coverage about the subject? Were you given any written information?

***If offered medication:*** What did you expect from medicines/ tablets/ pills, if anything?

Prompts: Were you told about what to look out for or expect? What were you told about it being reviewed, if anything?

13. What were your experiences with the medicines/ tablets/ pills?
    Prompts: What has happened to you as a result? How do you feel about the ways you were told about it? Could anything have been done better?

14. Some people these days are trying out and using other forms of medicines or alternative therapies, such as yoga, meditation, aromatherapy; what do you think about all of that?

15. Did you have the opportunity to ask questions, if yes what?
    Prompts: About side effects perhaps?

13. Is there anything else that you would like to tell me?

---

14. May I finally ask what prompted you to take part in this study?

**Summarise main points. Explain that you will be sending them a summary of the main points for them to check.**

## MEDICATION

Finally, would it be possible for me to take down a list of all the **medication** that you are currently taking?

1. ____________________________________________________________

2. ____________________________________________________________

3. ____________________________________________________________

4. ____________________________________________________________

5. ____________________________________________________________

6. ____________________________________________________________

7. ____________________________________________________________

8. ____________________________________________________________

9. ____________________________________________________________

10. ___________________________________________________________

11. ___________________________________________________________

12.____________________________________________________________

13.____________________________________________________________

14.____________________________________________________________

15.____________________________________________________________

**CLOSURE PROMPTS TO RESEARCHER:**

Thanks for taking part. Inform participants of what will happen to the findings of the project. Travel expenses (if appropriate).

## Appendix 10: INTERVIEW TOPIC GUIDES FOR PATIENTS – RETROSPECTIVE INTERVIEWS

**Prompts to researcher:**

5. Ask permission to record the discussion and explain that data will be transcribed anonymously, kept confidential to the study research team and stored securely.

6. Check that they have had time to read the Participant Information Sheet and ask whether they have any questions.

7. Check Consent Form has been completed fully.

8. Allow time for questions.

**Date of interview: (DD/MM/YYYY) : ________________**

**Researcher initials: __________**

**Interview with patients post-assessment:**

**Introduction:**

*Thank you for making time to talk to me today and agreeing to take part in this study. We are talking to a number of people at this clinic about their experiences of being assessed for their memory problems.*

*This interview will last about [1-2 hours tbc post piloting].*

**Topics and questions:**

8. We're talking to people who have been seen by staff at [name of recruiting clinic]. Firstly can I ask you to tell me a bit about yourself (collecting as much of the biographical info as possible).

9. Can I take you back a bit and ask you what led up to you coming to see the staff here / at the clinic?
   Prompts: please tell us what led up to this, in your own words, what was the story? How long did you have to wait for your appointment? Did you have any thoughts about what might be going on with your health?

10. What [has it been / was it] like going to appointments at [name of recruiting clinic] (or having appointments at home from staff at [name of recruiting clinic]) and talking to professionals about your problems?
    What was it like talking to your local GP or nurse?

    Prompts for both parts: Were you alone? Was that your choice (either to go alone or be accompanied)?

11. What have you been told about your problems?
    Prompt: Who was it that told you that?

    What did your GP or nurse tell you about your problems?

    What did you think about the way in which you received this info?

12. Is there anything else you wished you had discussed with the doctors earlier? Why didn't you at the time? Did you feel you had enough time to discuss things with professionals?

13. Did you receive any written information from your doctor or nurse?; from the [name of recruiting clinic]?

    If yes, what did you think about it ? How could it be improved?

    If no, would you have liked to have received some information?

    If yes what would have been helpful?

14. What happened when you were told [about the cause of your memory problems / that you have a diagnosis of dementia / MCI / *or as appropriate*]?
    Prompts: who was there, what did they say, what did you say, what did you think? Did you feel you had enough time to discuss all the issues you were concerned about? Could anything have been done better? What, if anything, went well?

    a. What help did you get during the time leading up to the assessment / diagnosis, Any information about what was available and services perhaps (including medication)?,
    b. Any counselling or other emotional support?
    c. Any practical help or suggestions?

15. What happened when you were told [about the cause of your memory problems/ that you have a diagnosis of dementia/ MCI/ as appropriate]?

    Prompts: Who was there? What did they say? What did you say? What did you think? Did you feel you had enough time to discuss concerns that you had? Could anything have been done better? What if anything went well?

16. Has being told [about the cause of your memory problems / you have dementia / MCI / or as appropriate] changed the way you feel? Has it changed anything else? If so, what has it changed and in what way?

17. Did you look up any information yourself, eg, from the library, on the internet, ask anyone for information/advice, and so on?

18. Have you made any specific decisions or plans, since being told…………?

19. Have you spoken to anyone, such as friends or family members about your diagnosis? What reaction did they have?

20. Or someone else perhaps like your GP, solicitor, bank manager or religious figure? If so what reaction did they have? Who was the most helpful and why?

21. Is there anyone who you specifically avoided speaking to? If so, who? Why?

22. Has any follow up been suggested?
    Prompts: What? By whom? What do you think about that?

23. Has taking any tablets/pills/medicines for your memory problems been discussed with you? If yes, can you tell me about those discussions?

> Prompts: Who by? Where? What did you think about the advice? Why was that? What did you think about medication then and now? At the time did you know anything about tablets that can be taken to help memory problems / dementia? Had you heard any press coverage about the subject? Were you given any written information?

***If offered medication: (if not already covered)***

24. What did you expect from medicines/tablets/pills, anything?

> Prompts: Were you told about what to look out for or expect? What were you told about it being reviewed, if anything?

25. What were your experiences with the tablets/ medicines/ pills?

> Prompts: what has happened to you as a result; how do you feel about the ways you were told about it? Could anything have been done better?

26. Did you have the opportunity to ask questions, if yes what?

> Prompts: About side effects perhaps?

27. Some people these days are trying out and using other forms of medicines or alternative therapies, such as yoga, meditation, armomatherpay; what do you think about all of that?

28. Is there anything else that you would like to tell me?

29. May I finally ask what made you agree to take part in this study?

Summarise main points. Explain that you will be sending the person a summary of the main points for them to check.

## DEMOGRAPHIC INFORMATION

I think we have covered most of these questions; there are just a few demographic details that I would like to check I have got correct.

Age:

| | |
|---|---|
| Gender: | Male |
| | Female |
| Living arrangements: | Co-resident carer (either own home/home of PWD) |
| | Not co-resident carer (own home) |

| | |
|---|---|
| Relationship to person you care for: | Spouse |
| | Child |
| | Other family member (define): |
| | Friend |
| | Neighbour |
| | Other (define): |

May I ask what age you went to school till? What about anything after?

Previous Occupation:

---

**Ethnic Group**. *Chose ONE from A to E, then indicate cultural background.*

A **White**. options of: **British**; **Irish** or **Any other White background** (*please describe*).

B **Mixed**. options of: **White and Black Caribbean**; **White and Black African**; **White and Asian** or **any other Mixed background** (*please describe*).

C **Asian or Asian British**. options of: **Indian**; **Pakistani**; **Bangladeshi**; **Any other Asian background** (*please describe*).

D **Black or Black British**. options of: **Caribbean**; **African**; **Any other Black background** (*please describe*).

E **Chinese or other ethnic group**. options of: **Chinese**; **Any other** (*please describe*).

## MEDICATION

Finally, would it be possible for me to take down a list of all the **medication** that you are currently taking?

16.__________________________________________________________

17.__________________________________________________________

18.__________________________________________________________

19.__________________________________________________________

20.__________________________________________________________

21.__________________________________________________________

22.__________________________________________________________

23.__________________________________________________________

24.__________________________________________________________

25.____________________________________________________________

26.____________________________________________________________

27.____________________________________________________________

28.____________________________________________________________

29.____________________________________________________________

30.____________________________________________________________

**CLOSURE PROMPTS TO RESEARCHER:**

Thanks for taking part. Inform participants of what will happen to the findings of the project. Travel expenses (if appropriate).

## Appendix 11: INTERVIEW TOPIC GUIDE FOR CARERS/ SUPPORTERS – BEFORE – AFTER INTERVIEWS

**Prompts to researcher:**

1. Ask permission to record the discussion and explain that data will be transcribed anonymously, kept confidential to the study research team and stored securely.
2. Check that they have had time to read the Carer/Supporter Information Sheet and ask whether they have any questions.
3. Check Consent Form has been completed fully.
4. Allow time for questions.

**Date of interview: (DD/MM/YYYY) : ________________**

**Researcher initials: __________**

## Interview with carers/supporter early assessment:

### Introduction

*Thank you for making time to talk to me today and agreeing to take part in this study. We are talking to a number of carers / supporters about their experiences of supporting people who are being assessed for memory problems.*

*This interview will last about [1-2 hours tbc post piloting].*

### Topics and questions:

1. Ask the carer to tell you something about themselves, collecting biographical information and to establish the relationship of the carer / supporter with person with memory problems and how long they have known them.

2. We're talking to people who are being seen by staff at [name of recruiting clinic] and their carers / supporters. We are interested in what led up to [person being cared for] going to [name of recruiting clinic] and what's happened since; your experiences? Can you tell me what it's been like, in your own words, starting with what led up to [person being cared for] going to the [name of clinic]?

3. If not already covered: Did you go with [person being cared for] to any of the appointments?

If yes: What has it been like going to appointments and talking to professionals about [person being cared for]'s problems?

If no: Why was that?

Prompts: did the professionals ever talk to either of you alone? If yes, what was that about?

4. What have you been told about [person being cared for]'s problems?

5. Is there anything else you want to know or wished you had discussed with the staff?

Prompt: Did you feel you had enough time to discuss things with staff?

6. Did you receive any written information from your doctor?; from the clinic ?
If yes, what did you think about it? How could it be improved?

If no, would you have liked to have received some information? If yes what would have been helpful?

7. We would like to come back and talk to you again in XX weeks. Can I check that you're happy for us to contact you again then?
   (NB check that this tallies with consent form)

Summarise main points. Explain that you will be sending the person a summary of the main points for them to check.

**Closure prompts to researcher:**

Thank for taking part. Travel expenses (if appropriate).

## Interview with carers/supporters post-assessment:

### Introduction

*Thank you for making time to talk to me again today. We are talking to a number of carers / supporters about their experiences of supporting people who have memory problems and finding a diagnosis of their cause.*

*This interview will last about [1-2 hours tbc post piloting].*

### Topics and questions:

Establish the relationship of the carer / supporter with person with memory problems (again).

1. Can you tell me what's happened since I last saw you? How have things been, in your own words? Has anything changed?

2. Can you tell me about any visits to the [name of recruiting clinic]? What have you been told about [name]'s difficulties by the people at [name of recruiting clinic]?

3. If relevant: What happened when [name] was told [about the cause of their memory problems / that they have a diagnosis of dementia / MCI / or as appropriate]?

Prompts: who was there, what did they say, what did you say, what did you think? Did you feel you had enough time to discuss any issues you were concerned about? Could anything have been done better? What, if anything, went well?

4. How, if at all, has being told about [the cause of [name]'s memory problems / that [name] has dementia], changed the way you feel? Has it changed anything else? If so, what has it changed, and in what way?

Did you look up any information yourself, eg, from the library, on the internet, ask anyone for information/advice, and so on?

5. Have you made any specific decisions or any plans since being told ………..?

6. Have you spoken to anyone, such as family members or friends about [name]'s diagnosis?

Or someone else perhaps like your GP, solicitor, bank manager or religious figure? If so, who was most helpful? And why?

Is there someone who you specifically avoided speaking to? If so, why?

7. Thinking about it now, were you offered any help during the period leading up to the [diagnosis / or as appropriate]?

a. Any information about what was available and services perhaps? (including medication),
b. Any counselling or emotional support?
c. Any practical help or suggestions?

8. Has any follow-up been suggested?

Prompts: What? By whom? What do you think about that?

9. Has taking any medicines/ pills/ tablets been discussed with [name]?

If yes, can you tell me about those discussions?

Prompts if necessary: Who by? Where? What was said? What did [name] think about the advice? Why was that? What did [name] think about medication then and now? At the time did you know anything about tablets that can be taken to help memory problems/dementia? Had you heard any press coverage about the subject?

9a. ***If person with memory problems/dementia was offered medication:***

What did [the person you care for] expect from medicines/ pills/ tablets, if anything?

Prompts: were you told about what to look out for or expect? What were you told about it being reviewed, if anything?

10. What was [name]'s experiences with the medicines/ pills/ tablets?

Prompts: what has happened to them as a result; how do you feel about the ways you were told about it? Could anything have been done better?

11. Have you been involved in any discussion about medicines/ pills/ tablets for [memory problems/dementia]?

Prompts: by whom and where? What was said? Were you given any written information?

12. Did you have the opportunity to ask questions, if yes what?

Prompts: about side effects perhaps?

13. Some people use the term 'carer' to describe the role that you play in

supporting [person you care for]; how do you feel about that?

Prompts: Would you describe yourself as a carer? How do you feel about being asked to be a 'carer' for your relative?

## DEMOGRAPHIC INFORMATION

I think we have covered most of these questions; there are just a few demographic details that I would like to check I have got correct.

Age:

Gender: Male

Female

Living arrangements: Co-resident carer (either own home/home of PWD)

Not co-resident carer (own home)

Relationship to person you care for: Spouse

Child

Other family member (define):

Friend

Neighbour

Other (define):

May I ask what age you were when you left school?  What about after that?

Previous Occupation:

Ethnicity (census categories):

**Ethnic Group**. *Chose ONE from A to E, then indicate cultural background.*

A **White**. options of: **British**; **Irish** or **Any other White background** (*please describe*).

B **Mixed**. options of: **White and Black Caribbean**; **White and Black African**; **White and Asian** or **any other Mixed background** (*please describe*).

C **Asian or Asian British**. options of: **Indian**; **Pakistani**; **Bangladeshi**; **Any other Asian background** (*please describe*).

D **Black or Black British**. options of: **Caribbean**; **African**; **Any other Black background** (*please describe*).

E **Chinese or other ethnic group**. options of: **Chinese**; **Any other** (*please describe*).

Summarise main points. Explain that you will be sending the person a summary of the main points to check.

## CLOSURE PROMPTS TO RESEARCHER

Thank person for taking part. Inform participant(s) of what will happen to the findings of the project. Travel expenses (if appropriate).

## Appendix 12: INTERVIEW TOPIC GUIDE FOR CARERS/ SUPPORTERS – RETROSPECTIVE INTERVIEWS

**Prompts to researcher:**

1. Ask permission to tape record the discussion and explain that data will be transcribed anonymously, kept confidential to the study research team and stored securely.

2. Check that they have had time to read the Carer/Supporter Information Sheet and ask whether they have any questions.

3. Check Consent Form has been completed fully.

4. Allow time for questions.

**Date of interview: (DD/MM/YYYY) : ________________**

**Researcher initials: __________**

## Interview with participants post-diagnosis:

### Introduction

*Thank you for making time to talk to me today and agreeing to take part in this study. We are talking to a number of carers / supporters about their experiences of supporting people who are being assessed for memory problems.*

*This interview will last about [1-2 hours tbc post piloting].*

### Topics and questions:

1. Can you tell me a bit about yourself and your relative?

e.g. Establish the relationship of the carer / supporter with person with memory problems and its length and collect biographical information.

2. We're talking to people who are being seen by staff at [name of recruiting clinic]. We are interested in what led up to [name] going to the {name of clinic} and what's happened since; your experiences? Can you tell me what it's been like in your own words, starting with what led up to [name] going to the [name of clinic]?

3. If not already covered: Did you go with [name] to any of the appointments?

If yes: What has it been like going to appointments and talking to professionals about [name]'s problems?

If no: Why was that?

Prompts: did the professionals ever talk to either of you alone? If yes, what was that about?

4. What have you been told about [name]'s problems?

5. Is there anything else you want to know or wished you had discussed with staff?

Prompt: Did you feel you had enough time to discuss things with staff?

6. What happened when [name] was told [about the cause of their memory problems / that they have a diagnosis of dementia]?

Prompts: who was there, what did they say, what did you say, what did you think?, find out about their diagnosis

Did you feel you had enough time to discuss any issues that you were concerned about?

Could anything have been done better? What, if anything, went well?

a. How if at all, has being told about the cause of [name]'s memory problems / that [name] had dementia, changed the way you feel? Has it changed anything else? If so, what has it changed and in what way?

7. Did you look up any information yourself, eg, from the library, on the internet, ask anyone for information/advice, and so on?

8. Have you made any specific decisions or any plans since being told………?

9. Have you spoken to anyone such as family members of friends about name]'s diagnosis?

10. Or someone else perhaps like your GP, solicitor, bank manager or religious figure? If so, who was most helpful and why?

11. Is there someone who you specifically avoided speaking to? If so, why?

Thinking about it now, were you offered any help or support during the period leading up to the diagnosis?:

b. Any information about what was available and services perhaps? (including medication),
c. Any counselling or emotional support
d. Any practical help and suggestions?

Prompt: What help do you think might have been helpful to you or someone else in your situation during that time?

12. Has any follow-up been suggested?

Prompts: What? By whom? What do you think of that?

13. Has taking any medicines/pills/tablets been discussed with [name]? If so, can you tell me about those discussions?

Prompts if necessary: Who by? Where? What was said? What did [name] think about the advice? What was that? What did [name] think about medication then and now? At the time did you know anything about tablets that can be taken to help memory problems / dementia? Had you heard of press coverage about the subject?

***If person with [memory problems/dementia] was offered medication:*** What did [name] expect from the tablets if anything?

Prompts: Were you told about what to look out for or expect? What were you told about it being reviewed, if anything?

14. If this hasn't already come out in the above – What was [name]'s experience with the tablets?

Prompts: What has happened to [name] as a result? How do you feel about the ways you were told about it? Could anything have been done better?

15. Have you been involved in any discussion about medication for [memory problems/dementia]?

Prompts: by whom and where? What was said? Were you given any written information?

16. Did you have the opportunity to ask questions, if yes what?

Prompts: about side effects perhaps?

17. May I ask how things have changed for you, if at all, since [name] received their diagnosis?

Prompt: What do you think about the diagnosis? How has it affected you? Has it had any impact on your caring role?

18. Is there anything else that you would like to tell me?

19. May I finally ask what prompted you to take part in this study?

I think we have covered most of these questions; there are just a few demographic details that I would like to check I have got correct.

**Demographic information:**

Age:

| | |
|---|---|
| Gender: | Male |
| | Female |
| Living arrangements: | Co-resident carer (either own home/home of PWD) |
| | Not co-resident carer (own home) |
| Relationship to person you care for: | Spouse |
| | Child |
| | Other family member (define): |
| | Friend |
| | Neighbour |
| | Other (define): |

May I ask what age you left school?  What did you do after?

Previous Occupation:

Ethnicity (census categories):

**Ethnic Group**. *Chose ONE from A to E, then indicate cultural background.*

A  **White**. options of: **British**; **Irish** or **Any other White background** (*please describe*).

B  **Mixed**. options of: **White and Black Caribbean**; **White and Black African**; **White and Asian** or **any other Mixed background** (*please describe*).

C **Asian or Asian British**. options of: **Indian**; **Pakistani**; **Bangladeshi**; **Any other Asian background** (*please describe*).

D **Black or Black British**. options of: **Caribbean**; **African**; **Any other Black background** (*please describe*).

E **Chinese or other ethnic group**. options of: **Chinese**; **Any other** (*please describe*).

Summarise main points. Explain that you will be sending the person a summary of the main points for them to check.

**Closure prompts to researcher:**

Thank person for taking part. Inform participants of what will happen to the findings of the project. Travel expenses (if appropriate).

## Appendix 13: THEMATIC TABLE v. 5

| **Theme:** | **Subcategories:** | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 1. Personal Background / Biography | 1. Significant personal memories | | | | | | | |
| | 2. Relationships | *a. Family* | *b. Other* | *c. Dynamics* | | | | |
| | 3. Living Arrangements | | | | | | | |
| | 4. Faith | | | | | | | |
| | 5. Occupational History | | | | | | | |
| | 6. Educational History | | | | | | | |
| | 7. Meanings of demographics: Age | | | | | | | |
| | 8. Meanings of demographics: Gender | | | | | | | |
| | 9. Meanings of demographics: Ethnicity | | | | | | | |
| | 10. Interests / hobbies | | | | | | | |
| | 11. Life Event | *a. Bereavement* | *b. Other loss* | *c. Accident* | *d. Other serious health problem* | *e. Retirement* | *f. Timeframe* | *g. Moving home* |

| **Theme:** | **Subcategories:** |
|---|---|

| | |
|---|---|
| 2. Health Issues | 1. Type of health issue |
| | 2. Relationship to memory problems / cognitive impairment |
| | 3. Interventions |
| | 4. Complimentary or alternative medicine |
| | 5. Impact of health issues |
| | 6. Medicines (other) |

| **Theme:** | **Subcategories:** | | | | |
|---|---|---|---|---|---|
| 3. Advice / Help prior to contacting services | 1. Seeking advice | *a. From whom?* | *b. Seeking help for self* | *c. Seek help under pressure* | *d. Carer seeks help first* |
| | 2. Receiving advice | | | | |
| | 3. Perceived triggers for seeking advice | | | | |
| | 4. Barriers to advice | | | | |

| **Theme:** | **Subcategories:** |
|---|---|
| 4. Awareness of cognitive | 1. Personality trait (self-perception) |

| | |
|---|---|
| condition | 2. Self monitoring (relating to person with dementia) |
| | 3. Change or transition (relating to person with dementia) |
| | 4. Diagnosis (relating to person with dementia) |
| | 5. Drift (awareness fluctuating) – person realising changes going on in self – not able to reflect – changing to this (relating to person with dementia) |
| | 6. Views of others – self monitoring (relating to carer’s view) |
| | 7. Views of others – change or transition (relating to carer’s view) |
| | 8. Views of others – diagnosis (relating to carer’s view) |

| **Theme:** | **Subcategories:** | |
|---|---|---|
| 5. Examples of memory problems / cognitive impairment | 1. Personal (relating to transcript of case):<br>*a. Positive* | *b. Negative* |
| | 2. Previous (relating to past experience with caregiving):<br>*a. Positive* | *b. Negative* |
| | 3. Others (relating to understanding/ media/ societal attitude):<br>*a. Positive* | *b. Negative* |

| **Theme:** | **Subcategories:** | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 6. Response to memory problems / cognitive impairment | 1. Normalising | *a. I’ve always been like this/ personality trait* | *b. It’s part ageing* | | | | | | | | |
| | 2. Self acceptance (positive) | a. Resignation / conflict avoidance (negative) | | | | | | | | | |
| | 3. Finding a life philosophy / coping style | *a. Take each day as it comes/ Getting on with it* | *b. Staying positive* | *c. Keeping it private* | *d. Maintaining personhood* | *e. Avoidance* | *f. Professional trust* | *g. Keeping it simple* | *h. Shared togetherness* | *i. humour* | *j. Desire to help others/ altruism* |
| | 4. Coping strategy | *a. Practical (e.g. finding out info, putting affairs in order / future planning* | *b. Interventions* | *c. Others* | | | | | | | |
| | 5. Withdrawal | | | | | | | | | | |
| | 6. Response to diagnosis (include worry) | | | | | | | | | | |
| | 7. Not coping | | | | | | | | | | |

| **Theme:** | **Subcategories:** | | |
|---|---|---|---|
| 7. Telling / sharing with / talking to others (or lack thereof):<br>Including who/ why/ perceived impact | 1. Who: *a. Family* | *b. Friends* | *c. Others* |
| | 2. Why: *a. Stigma* | *b. Right time and place* | |
| | 3. Perceived impact: *a. Leads to their disclosure* | *b. Changes their behaviour* | |

| | | |
|---|---|---|
| 7a. Telling others – who<br>7b. Telling others, or not telling others – Why<br>7c. Telling others – perceived impact | | |

| **Themes:** | **Subcategories** |
|---|---|
| 8. Emotional Responses to condition/ process/ diagnosis<br>a. subtle/b. evident | 1. Tired |
| | 2. Shock |
| | 3. Humour |
| | 4. Frustration / Aggravation |
| | 5. Denial |
| | 6. Worried/Concern |
| | 7. Anger |
| | 8. Fear |
| | 9. Relieved |
| | 10. Depressed |
| | 11. Upsetting |

| **Theme:** | **Subcategories:** |
|---|---|
| 9. Service pathway | 1. Waiting (subjective experience) |

|  |  |  |  |  |
|---|---|---|---|---|
| (including assessment, disclosure, treatment and follow up) | 2. Lack of clarity |  |  |  |
|  | 3. Timeframe (measurable) |  |  |  |
|  | 4. Testing or scoring |  |  |  |
|  | 5. Scans |  |  |  |
|  | 6. Medical Exam (including bloods) |  |  |  |
|  | 7. Referral by | *a. GP* | *b. Other* |  |
|  | 8. Questions asked | *a. Of person* | *b. By person* |  |
|  | 9. Information received | *a. Written* | *b. Verbal* | *c. Other* |
|  | 10. Experience of process (Include description of and experience of environment) |  |  |  |
|  | 11. Satisfaction with service |  |  |  |
|  | 12. Dissatisfaction with service |  |  |  |
|  | 13. Satisfaction with individuals |  |  |  |
|  | 14. Dissatisfaction with individuals |  |  |  |
|  | 15. Initial expectations |  |  |  |
|  | 16. What’s helped (specific examples) |  |  |  |
|  | 17. What hasn’t helped (specific examples) |  |  |  |
|  | 18. What could have helped (specific examples) |  |  |  |

|  |  |
|---|---|
| **Theme:** | **Subcategories:** |

| | |
|---|---|
| 10. Support (structural, practical, emotional, services) | 1. Extended family |
| | 2. Spouse |
| | 3. Friends |
| | 4. Church / religious institution |
| | 5. Day centre / club |
| | 6. Other support (service support) |
| | 7. Primary care giver |
| | 8. Secondary care giver |
| | 9. Absence of support and unmet needs |

| **Theme:** | **Subcategories:** |
|---|---|
| 11. Other Support (including practical, emotional and information) | 1. What's helped |
| | 2. What hasn't helped |
| | 3. Support received |
| | 4. Support given |
| | 5. Burden of care given |
| | 6. Ideas |
| | 7. Information needs and unmet needs |

| **Theme:** | **Subcategories:** | |
|---|---|---|
| 12. Future | 1. Expectations | |
| | 2. Hopes | |
| | 3. Plans | *a. Reasons* |
| | 4. Fears | |

| **Theme:** | **Subcategories:** |
|---|---|
| 13. Desire to help others | |

| **Theme:** | **Subcategories:** |
|---|---|
| 14. Contested territories | |

| **Theme:** | **Subcategories:** |
|---|---|
| 15. Maintenance of independence | |

| **Theme:** | **Subcategories:** |
|---|---|
| 16. Anti dementia drugs | 1. Effect (including side effects) (perceived) |
| | 2. Feelings |

| | |
|---|---|
| | 3. Expectations |
| | 4. Management |

| **Theme:** | **Subcategories:** |
|---|---|
| 17. Reason for taking part in study | |

## Disclaimer

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## Addendum

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Although NETSCC, SDO has managed the project and conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.