

Recommendations for involving people with dementia or mild cognitive impairment and their informal caregivers and relatives in the Assisted Living Project

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Foreword

This document has been produced as part of the Assisted Living Project: Responsible innovations for dignified lives at home for persons with mild cognitive impairment or dementia, a four year project led by the Oslo and Akershus University of Applied Sciences (HiOA) in partnership with Sensio and the Norwegian Board of Technology, and in collaboration with the University of Exeter, University of Bristol and the Karlsruhe Institute of Technology. The project is sponsored by the Norwegian Research Council and coordinated and led by Dr Ellen-Marie Forsberg.

The main goals of the Assisted Living Project are to:

“a) to map how stakeholders and experts perceive the state-of-the-art of responsible welfare technologies, focusing on ALT [Assisted Living Technology], in Norway and internationally;

b) develop ALT solutions for users with MCI/D, through an RRI approach;

c) judge by an integrated Health Technology Assessment approach whether technologies introduced through an RRI process score better than currently implemented welfare technologies;

d) create a wider dialogue on responsible welfare technologies for the future.”

(HiOA Research Group on Responsible Innovation)

This document has been developed to support the researchers, designers and engineers working on the Assisted Living Project in the aspects of the research which involve communication with people with dementia and mild cognitive impairment, and their caregivers and relatives. Recommendations for doing research with these participants are presented, which have been developed from evidence gathered from a literature review of both academic literature and information devised by dementia charities and groups led by people affected by dementia. The academic literature for this review was found utilising the following databases: PubMed, ProQuest, Scopus, Jstor, Web of Science and Google Scholar. Searches were limited from present to 1997 and, articles in English language. Other articles were also found via citations and Google search engine queries.

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Recommendations for the Assisted Living Project

Introduction

The “Assisted Living Project: Responsible innovations for dignified lives at home for persons with mild cognitive impairment or dementia”, is a four year project being led by the Oslo and Akershus University of Applied Sciences (HiOA) in partnership with Sensio and the Norwegian Board of Technology, and in collaboration with the University of Exeter, University of Bristol and the Karlsruhe Institute of Technology. The aims of the project are to:

“a) to map how stakeholders and experts perceive the state-of-the-art of responsible welfare technologies, focusing on ALT [Assisted Living Technology], in Norway and internationally; b) develop ALT solutions for users with MCI/D, through an RRI approach; c) judge by an integrated Health Technology Assessment approach whether technologies introduced through an RRI process score better than currently implemented welfare technologies; and d) create a wider dialogue on responsible welfare technologies for the future.”

(HiOA Research Group on Responsible Innovation)

There are a limited but growing number of projects developing assisted living technologies that actively involve People with Dementia (PWD) or Mild Cognitive Impairment (MCI), and their caregivers or relatives in the research and design process. Involving these stakeholders provides considerable benefits but also raises a number of ethical and methodological challenges which are considered in the accompanying literature review.

These recommendations have been created to assist researchers and designers involved in the Assisted Living Project to plan and conduct research and participatory design sessions with PwD/MCI and, their caregivers or relatives. The emphasis is to provide both practical and ethical advice in developing contact and dialogues with these stakeholders derived from the evidence gathered from reviewing literature from both academic and other relevant sources such as dementia charities, and advice developed by people with dementia. These recommendations discuss different stages of the project, from start to finish.

1. Set-up

1.1 Training

- The Assisted Living Project should consider providing some introductory training about MCI/D and the ways that individuals and their families may be affected, so that researchers and designers involved in the project have at least some basic knowledge about the potential needs and concerns of participants. Furthermore, it is important that the research team have sufficient understanding about MCI/D so as not to stereotype or stigmatise PwD/MCI.
- Ideally researchers involved in interviewing or facilitating the dialogue conferences should have some experience with working with PwD/MCI and receive training in interviewing and/or focus group skills and techniques.
 - It may be fruitful for members of the team to visit the day centre and spend some time interacting with PwD/MCI before commencing the research to gain lived experience, rather than just relying on indirect knowledge of the ways that MCI/D can affect people.
 - Visits to the recruiting day centre by the research team may also benefit potential participants because team members and the research can be introduced to people and may be more familiar to them if they later decide to participate in the research.
- Dementia experts should be available for the research team to consult if they have concerns or need advice during the course of the project.

1.2 Materials

- The Assisted Living project should strive to create 'dementia-friendly' documentation for participants with MCI/D.
 - Content and formatting of documents need to be carefully constructed¹.

¹ Please see methodological literature review for specific guidance.

- It may be helpful for the research team to develop materials in consultation with dementia experts or PwD/MCI themselves to ensure that materials are as widely accessible as possible.
- Researchers need to be prepared to verbally explain written documentation to individual participants in a manner that is accessible to them to facilitate their understanding.

2. Ethical considerations

- A person centred approach to research should be adopted by the Assisted Living Project.
 - Mahoney et al (2007) advise that an ethical framework where humanist concerns are central is vital to guide the research and development of ALTs for PwD/MCI.
- The autonomy of PwD/MCI needs to be respected but also, autonomy should be understood as relational (Nuffield Council on Bioethics, 2009).
 - The participants involved in the research: PwD/MCI and their families, formal and informal caregivers may all be affected by participation and the intervention of developed ALTs.

2.1 Informed consent

- PwD/MCI will be vary in terms of their cognitive impairment, and their capacity to give informed consent. Consequently, it is wise that the Assisted Living Project plans to recruit individuals who have been referred to them by care professionals who will have good background knowledge of individuals' circumstances and abilities. Indeed, this approach has been adopted by other ALT studies. However, it must be recognised that individuals' capacity may vary from day-to-day, or may deteriorate over the duration of the project. Therefore, an approach to informed consent must reflect this.

- It is recommended that the project adopts process consent methods (Dewing, 2002; 2007; 2008). Consent should be assessed moment-by-moment and researchers should provide on-going verbal reiteration about the project to participants as required, in addition to written information detailing the study.
- Researchers should:
 - Act with understanding and flexibility to make informed consent accessible to different individuals.
 - Be aware that capacity may vary and may also deteriorate over the duration of the project.
- Non-verbal and behavioural cues need to be monitored and considered as part of informed consent.
 - PwD/MCI may not be able to verbalise distress or desires regarding participation. It may be down the researchers to recognise these signs and stop participation either temporarily or permanently.
- The Assisted Living Project should develop protocols for dealing with on-going consent, participation breaks and withdrawal.
- Information provided to participants should be made accessible to them.
 - It should explain the purpose of the Assisted Living Project, expected roles of participants, research team members, any perceived harms and benefits, rights to confidentiality and to withdraw and, potential commercialisation of the developed ALT.

2.2 Burdens

- Careful and on-going consideration needs to be given to the potential implications that implementation of developed ALTs may have on both PwD/MCI and their relatives. In the observational stages of the research, where new technologies are being tested, this issue will be very important.
 - Participants will need to know where they can receive support from the research and design team and be clear that they can withdraw.
 - The research team also has a duty to monitor signs of distress, since PwD/MCI may have trouble verbally communicating stress or concerns.
- There is potential for researchers and designers to find the project emotionally burdensome, due to the sensitive issues that may be encountered by working with PwD/MCI and their relatives.
 - It is recommended that the Assisted Living Project develops a protocol to deal with researcher burdens.
 - Reflexive practice and supervision are advised.

2.3 Benefits

- The Assisted Living Project needs to decide from the outset whether participants involved in the testing and observation stages will get to keep the in-home ALT interventions if they wish at the end of the project.
 - Consideration needs to be given to the on-going maintenance and support of this technology if this is the case.

- Making the research and design process pleasant for participants and demonstrating that they are valued can make their involvement enjoyable and empowering.

3. Participants & Recruitment

- The study plans to recruit participants from the day centre and municipality. To identify potential participants for the project, the study will rely on recommendations from formal carers of people with early stage dementia and MCI on the basis of their perceived capacity to give informed consent.
 - The Assisted Living Project needs to be clear from the outset the role that stakeholders (PwD/MCI and their relatives/informal caregivers) will play in the design process. I.e. will they be informants or co-developers.
 - These roles need to be made clear to participants from the start.
 - The study needs to remain aware of the different perspectives and needs that different stakeholders may have and, be mindful of whose are prioritised in the development of the ALT, including the implications of these decisions.
 - The study also needs to be explicit about these decisions with participants involved in the development process.
- It is advised that to avoid confusion, the study contacts recommended participants individually, in-person, to provide information rather than relying on intermediaries to recruit participants to the research.
 - Since PwD/MCI deemed to have capacity will be selected, informed consent should be obtained directly from these individuals, not proxy consents.

- Participants should be provided with written information as well as verbal explanation in advance of any participation and given time to absorb information and discuss it further with relatives/caregivers and members of the study team.
- Information about the project and consent should be revisited regularly for participants who are involved in on-going interaction with the project.
- Members of the Assisted Living Project who are responsible for data collection should conduct informal pre-research meetings with participants who have MCI/D to determine their capabilities.
 - This will facilitate the process of informed consent and, enable the project to select data collection tools which are appropriate to individual abilities of participants.

4. Data collection & research strategies

- The study aims to utilise a variety of methods to collect data from both PwD/MCI and their relatives/caregivers. This mixed methods approach has been found to be beneficial in other projects that have taken an inclusive approach to developing ALTs for people with dementia/MCI (Meiland et al, 2012).
- The Assisted Living Project will need to take a flexible approach to data collection and be prepared for this.
 - It is recommended that the research team have a range of research strategies to elicit data that can be flexibly drawn upon depending on the requirements of individual research situations, including the particular abilities of individual participants.

4.1 Quantitative Surveys

- The Assisted Living Project proposes that the research will include surveys, where the following recommendations can be made:
 - It may be best to present survey questions as a questionnaire so that the information is written, placing less pressure on PwD who may struggle to remember questions and answer choices.
 - Surveys for participants with MCI/D need to be appropriately designed so that content, formatting and presentation are accessible².
 - PwD/MCI may need to complete surveys with assistance from caregivers or researchers.
 - Assistance poses a risk that responses will be influenced by others and not necessarily authentic to the intended participant.

4.2 Interviewing

- The Assisted Living Project intends to conduct in-depth qualitative interviews with approximately 25 PwD/MCI and 25 formal/informal caregivers. The perspectives of these different stakeholders will provide valuable information about the experiences and needs of PwD/MCI and their caregivers.
 - The Assisted Living Project will need to be aware that interviews may potentially identify competing interests of different stakeholders and be clear about which interests are prioritised as the development progresses.
 - It is recommended that in-depth interviews are conducted in the homes of participants with MCI/D and informal caregivers for a number of reasons:

² Please see guidance for 'dementia-friendly' writing in the methodological literature review.

- The practical requirements of participants can be more easily met by researchers.
 - The familiarity of the setting can help put participants at ease which may help the development of rapport.
 - The home environment may help participants remember aspects of their home routines and general day-to-day living needs that will be of interest to researchers.
- Whilst, some participants with MCI/D may benefit from the support of caregivers during interviews, it may be preferable, if possible, for interviews to be conducted individually for more useful research data:
 - The presence of caregivers may mean that PwD/MCI feel unable to talk freely and censor their responses and vice-versa.
 - Caregivers may dominate interviews and lead the talk of PwD/MCI.
- For PwD/MCI it may be best to conduct multiple interviews:
 - Abilities of PwD/MCI may vary from day-to-day.
 - PwD/MCI may have difficulty concentrating for long periods or dealing with lots of questions at once.
- Researchers should prepare a range of tools to facilitate interviewing as required:
 - Examples include: interview topic guides, visual and verbal prompts and scenarios or case studies.

4.3 Dialogue conferences

- The Assisted Living Project plans to conduct four dialogue conferences involving PwD/MCI and other stakeholders: two at the start of the process to **a.** assess needs and, **b.** to discuss initial ideas for solutions and explore potential ethical implications; one during technology development; and finally one at the end of the development. There are a number of practical and methodological recommendations that can be made regarding the successful planning and development and execution of these events:
 - The Assisted Living Project should provide participants with good notice and regular reminders about the dialogue conference events to facilitate their attendance.
 - It is important to provide information that clearly details the location of the event, transport options and an agenda.
- It is recommended that the Assisted Living Project carefully consider the planning of these events to ensure that they are held in accessible, 'dementia-friendly' locations.
 - Chose a centrally located, accessible building with good transport links or somewhere that is already familiar to participants such as the day centre:
 - Ensure staff are friendly and helpful.
 - Use clear signs to direct participants.
 - Consider room layouts.
- It is recommended that the Assisted Living Project make the events enjoyable for participants:
 - Begin events informally.
 - Allow plenty of time for breaks and space for people to get away from the main event if they need to.
 - Provide refreshments.
 - End the conferences on a positive note.

- To be inclusive of PwD/MCI and their relatives/caregivers in dialogue conferences researchers should:
 - Establish 'ground rules' at the start of each dialogue conference.
 - Take a creative and flexible approach to stimulate discussion.
 - Have a methodological 'tool kit'.³

- To ensure that discussions are accessible to all the stakeholders:
 - Avoid use of technical jargon, and find a 'common frame of reference' based on the talk of PwD/MCI and their relatives or caregivers.
 - Be aware that PwD/MCI may find mixed group discussions challenging to follow or contribute to which risks dominance from caregivers, researchers and designers.
 - Consider holding homogenous, small group discussions for PwD/MCI and caregivers separately so they have more privacy to talk freely.
 - Separate group discussions for PwD/MCI can be tailored to specifically facilitate their involvement (e.g. choice of methods used, time and pace).

- Researchers and designers need to be mindful of interpreting information provided by PwD/MCI and their caregivers:
 - It is important not to make assumptions or over-extrapolate the suggestions of PwD/MCI.
 - Be aware that information provided by both PwD/MCI and relatives or caregivers may be contradictory or inconsistent.

³ Please see methodological review for examples.

4.4 Observations in participants' homes/prototype testing

- The Assisted Living Project plans to install and test developed technologies in the homes of approximately ten PwD/MCI. In relation to this part of the project, the following recommendations are made:
 - Participants should meet members of the team (researchers and technicians) who will interact with participants and install the technology in their homes in advance.
 - It may be useful to provide documentation to participants explaining the research and with pictures of the team so that they have a point of reference and can be reminded about what they are doing and who they will meet.
 - Intrusion by the research intervention needs to be minimised.
- Researchers need to be aware of behavioural responses to technology that they have installed.
 - Behaviour of participants needs to be monitored as part of the process of on-going consent, since individuals may not be able to verbalise concerns or unwillingness to be involved and their desire to withdraw from the project.
 - Technology may provide a false sense of security that can alter caregiver behaviour causing safety concerns.
- The Assisted Living Project will need to consider other residents of the home:
 - The project may require their consent as well as the PwD/MCI.
 - Be aware that there may be competing interests of residents with regards to the installation and use of the ALT.
 - The project should devise a protocol for dealing with potential conflicts of interest.

- It is recommended that technology installed into homes should be stable and late-stage prototypes to minimise potential for distress of participants due to technology failure.
 - Technology installed into homes needs to be well supported:
 - Create a carefully written manual that is as accessible as possible for PwD/MCI and their relatives and caregivers.
 - Have an on-call technical support team who have received training in understanding the needs of PwD/MCI and effective communication with this demographic.

5. Concluding individual research sessions & the Assisted Living Project overall

- The project overall and each individual research session should be ended with thanks provided to all participants.
- Particular attention needs to be paid to reassure PwD/MCI so that they are left feeling positive about their involvement.
 - Research into ALT necessarily highlights cognitive impairment and may raise particularly difficult or sensitive issues.
 - PwD/MCI are vulnerable to low self-esteem and feelings of anxiety and depression if they struggle to meet research demands, such as being able to answer questions.
- The Assisted Living Project should collect ongoing feedback from participants during the research.

- Participants may require information or advice beyond the remit of the Assisted Living Project, therefore prior collection of relevant, local support organisations or leaflets is advisable so that individuals can be signposted where necessary.

- The Assisted Living Project needs to decide whether participants will have the potential to benefit from on-going use of technology and support at the end of the project.
 - This decision needs to be clearly communicated to individuals at the outset.

- Feedback should be provided to participants regarding the outcomes of the research and any ongoing commercial development project.
 - It may also be helpful to provide regular feedback at each stage of development to keep participants interested and involved, and demonstrate how their input is utilised by the design team.

Methodological literature review: practical and ethical aspects of conducting research involving people with dementia or mild cognitive impairment

1. Introduction

This literature review explores ethical and practical methodological considerations when involving People with Dementia (PwD) and Mild Cognitive Impairment (MCI) in research. To meet these aims, academic literature, as well as advice and information devised by dementia charities and groups led by people affected by dementia, will be drawn upon. Since this methods review is to inform the Assisted Living (AL) Project in research methods to involve PwD/MCI and their caregivers in the development of Assisted Living Technology (ALT), this review will purposefully draw upon pertinent information from this specific field of research as well as inclusion of PwD/MCI more generally. It must be recognised that this literature review is not a systematic review and so does not claim to draw from all possible evidence sources⁴.

Furthermore, the varied and complex nature of Mild Cognitive Impairment and Dementia (MCI/D), combined with the often small sample sizes involved in studies drawn upon in this literature review; means that this is not an exhaustive list of the ethical or methodological challenges that may be encountered, nor a definitive basis for developing best practices for involving PwD in research. The review does however, provide an invaluable evidence base of the experiences and advice of researchers and, people with expert knowledge or lived experience of dementia. The recommendations for the Assisted Living Project have been informed by these findings. Therefore, it is advised that these documents are considered together, along with other relevant guidelines, when planning this research.

To explore the potential methodological and ethical challenges of involving PwD/MCI and their caregivers and relatives in research and development of ALT, this review will first,

⁴ The academic literature for this review was found utilising the following databases: PubMed, ProQuest, Scopus, Jstor, Web of Science and Google Scholar. Searches were limited from present to 1997 and, articles in English language. Other articles were found via citations and Google search engine queries.

briefly outline what Mild Cognitive Impairment and Dementia are. Second, the challenges of involving these participants in participatory design work will be explored, with reference to specific aspects of MCI/D can pose difficulties for conducting research. And third, explore practical methodological and ethical considerations and advice extracted from reviewing the relevant literature. These will be presented according to the different stages of research, from set-up through to concluding the research.

1.1 Mild cognitive impairment and dementia

Mild cognitive impairment and dementia are conditions that affect individuals' in a multitude of complex and unique ways, depending upon the cause, the areas of an individual's brain that are affected, as well as being influenced by the surrounding environment, which may enable or disable a person (Alzheimer's Society, 2013; 2015). Both conditions reduce an individual's cognitive functioning, affecting one's memory, ability to think and problem solve and, causing difficulties with language, perception and emotions (Alzheimer's Society, 2013; 2015). Furthermore, later stages of dementia individuals may develop challenging or unusual behaviours and physical symptoms such as loss of appetite and muscle weakness (Alzheimer's Society, 2013). Dementia is an umbrella term referring to symptoms of brain damage with different aetiology; of which Alzheimer's disease is the most common (ibid). Dementia is progressive so that, although initial symptoms may be mild, the disease develops to severely affect an individual in their everyday life (ibid). MCI differs from dementia in that individuals are not affected severely enough to significantly affect their everyday functioning (Alzheimer's Society, 2015). People diagnosed with MCI are at a greater risk of going on to develop dementia and, depending on the cause of their MCI may be in a 'pre-dementia' state (ibid). However, MCI does not necessarily lead to the development of dementia (ibid). Indeed, some individuals diagnosed with MCI may have symptoms that remain constant or improve (ibid).

1.2 Challenges of involving PwD/MCI & caregivers/relatives in participatory design of ALT

It is arguably beneficial to include PwD/MCI and other stakeholders such as caregivers in the research and development of ALT. However, traditional participatory approaches to this endeavour cannot simply be transferred over for use in the dementia context (Lindsey et al,

2012; Hendriks et al, 2013; 2014). Certainly, Hendriks et al (2013; 2014) highlight a number of factors that have been identified in the literature as problematic in adopting a participatory approach to ALT design which is inclusive of PwD/MCI. It is argued that participatory design methods tend to be reliant on participants being able to describe or visualise abstracted concepts regarding technology, and past or future scenarios, all of which can be challenging to PwD/MCI (Hendriks et al, 2013). Thus, it is argued that these methods assume that all participants will be cognitively able (Lindsey et al, 2012; Hendriks et al, 2013), therefore, in order to make these processes accessible to PwD/MCI and facilitate the inclusion of these participant groups in research, methods need to be developed and adapted (Hendriks et al, 2013).

Research needs to be clear about the types of involvement they are striving for (Steen, 2008 in Span et al, 2013). Where the inclusion of PwD/MCI and their caregivers is being sought, it is argued that researchers should involve individuals 'upstream' in the process, as early as possible, to ensure that involvement is meaningful rather than tokenistic (Alzheimer's Disease International (ADI), [no date]). Furthermore, PwD and their caregivers are not homogenous groups, individuals will have different backgrounds and experiences, so recruitment needs to consider best means to encompass a diverse range of people.

Two central concerns regarding the participation of PwD in research are: first, individuals' levels of cognitive impairment, which can make research challenging (Wilkinson, 2002). And second, since PwD are a marginalised and vulnerable participant group, the inherent power imbalance in the researcher-participant relationships needs to be recognised and accounted for (Wilkinson, 2002). Thus, to meaningfully involve PwD/MCI in research, researchers need to adopt methods that facilitates choice regarding participation or not and, if individuals do participate, they need to be enabled to participate fully (Wilkinson, 2002).

Key points:

- Traditional approaches to participatory design need to be adapted for work involving PwD/MCI.
- The inclusion of PwD/MCI and caregivers in research should ideally be 'up-stream' in the process.
- Researchers need to be aware of inherent power imbalances and make the research accessible to PwD/MCI to enable their meaningful involvement.

1.3 Specific aspects of MCI/D that are challenging for research

Methodological and ethical challenges are certainly not exclusive to doing research with PwD/MCI; but there are a number of characteristics of MCI/D that make certain issues (such as effective communication and informed consent) particularly pertinent for doing research with this group (Pratt, 2002). Mild cognitive impairment and dementia affect individuals in diverse ways (Nuffield Council on Bioethics, 2009; Hendriks et al, 2013), although typically, individuals affected by MCI/D have problems centred on language and communication and, cognitive difficulties affecting memory, understanding and decision making (Murphy et al, 2005). Furthermore, it is important to be aware that people may also have emotional difficulties and may demonstrate challenging behaviour (Nuffield Council on Bioethics, 2009). Although these features of MCI/D make research more challenging, it is argued that these issues should not be a reason to exclude these populations from research (Dewing, 2002; 2007; 2008; Hellstrom et al, 2007). Certainly, PwD/MCI are valuable participants in research pertaining to them since they are experts in their own lives (Clarke & Keady, 2002).

Research involving PwD/MCI as '*participants*' or '*informants*' rather than '*subjects*' or '*objects of study*', have tended to include individuals with MCI and early stage dementia because their levels of impairment are easier for research to accommodate (Hubbard et al, 2003), however, it is arguably possible to involve individuals who are in later stages of dementia too (Hubbard et al, 2007; Murphy et al, 2005). Combined with the accounts of other key stakeholders such as family members and informal caregivers of PwD/MCI, researchers and designers can gain a more holistic understanding of ALT requirements (Meiland et al 2012).

Nonetheless, the cognitive impairments of people with dementia or MCI means that they are arguably a more difficult population to include in research (Sävenstedt & Karlsson, 2010). MCI/D can make it more difficult for affected participants to understand research materials, information and questions (Hendriks et al, 2013), but also they may struggle to verbally communicate (Hubbard et al, 2003; Murphy et al, 2005). This means that observing non-verbal communication can be particularly valuable in research with PwD/MCI as data, but also as feedback regarding consent and individuals' willingness to participate (Clarke & Keady, 2002; Dewing, 2002; 2007; 2008; Nygard, 2006; Murphy et al, 2015).

In terms of the design and development of technology, PwD/MCI may have difficulties conceptualising future ideas or objects and articulating their thoughts about these things (Hendriks et al, 2013; Mayer & Zach, 2013), as well as adjusting to new technologies developed in the testing stages (Mayer & Zach, 2013). However, the abilities of PwD/MCI may fluctuate throughout the course of a day, from day-to-day, or week-to-week (Hubbard et al, 2003). The literature demonstrates that researchers can adapt their methods to make it accessible to PwD/MCI. Thus, adopting a creative and flexible approach to research with PwD/MCI means that it is quite feasible to enable their meaningful involvement in research.

Some attempts have been made to devise guidelines for involving people who have dementia in research. These include guidelines devised by PwD involved in the Scottish Dementia Working Group (SDWG) Research Sub-group, supported by the University of Edinburgh (SDWG Research Sub-group, 2013). Moreover, Murphy et al (2014) reviewed the main approaches that can be adopted to conduct inclusive qualitative research with PwD, and concluded that key areas for researchers are: "gaining COnsent, maximising Responses, Telling the story and Ending on a high (CORTE) (Murphy et al, 2014 pg. 800). Furthermore, guidelines have been developed specifically for ALT development research (Hendriks et al 2013; Mayer & Zach, 2013), including ethical guidelines for research and development of in-home monitoring technology (Mahoney et al, 2007). Nevertheless, in a later article reporting conclusions from a workshop with researchers in the field of participatory research, Hendriks et al (2015) argue that set universal guidelines for involving participants who have cognitive impairments such as MCI/D are not viable. Instead, they argue that researchers need to adopt an individualised approach, flexibly drawing upon a wide

methodological tool kit learnt through shared experiences of researchers and designers⁵. Certainly, a key message in this review is that a 'one-size-fits-all' approach to involving PwD/MCI in research and development projects cannot be taken. Instead, the experiences and advice of researchers and PwD are described, to provide the reader with an awareness and understanding of the various methods that can be utilised to make the research and design process more inclusive of PwD/MCI.

Key points:

- PwD/MCI are experts in their own lives.
- PwD/MCI may have difficulties with communication, cognition, emotions and behaviour which can be challenging for researchers and designers.
- Despite the challenges it is possible to include PwD/MCI as informants or participants in research, but researchers need to attend to individual differences of participants.
- Attempts have been made to devise guidelines for doing research with PwD/MCI.

2. Setting up the research:

From the outset, the AL project needs to be clear what role stakeholders will play in the research i.e. whether they will act as informants, co-designers or partners (Steen, 2008 in Span et al, 2013). The role of participants will influence the extent of their involvement in the project and, the methods that are adopted in the research, which need to be clearly communicated to them. An important consideration is how impairments are conceptualised in the research which can influence the focus on individuals' abilities or disabilities by the research team (Hendriks et al, 2015). Indeed, central to the success of the project will be having an awareness of the situational factors which can act to disable participants (Wilkinson, 2002; Hendriks et al, 2015). Hendriks et al (2015 pg. 75) emphasise the importance of 'equivalence' amongst all participants in a co-design process. Therefore in the AL Project, it may be beneficial to collaborate with PwD/MCI in the planning and preparation stages as well as in the design process (Hendriks et al, 2015). Nevertheless,

⁵ Hendriks et al, 2015 promote 'method stories' as a useful way in that participatory design researchers can share their experiences and learn from one another.

power imbalances in research could remain unavoidable and, it is important the researchers and developers remain aware of this (Wilkinson, 2002; Hendriks et al, 2015).

Key points:

- Researchers need to be clear about the role of stakeholders in the research.
- It is important to be aware of how PwD/MCI may be 'enabled' or 'disabled' in research.
- Involving PwD/MCI in the planning of research can help to mitigate inevitable power imbalances.

2.1 Researcher experience & training:

It is arguably important and valuable to include PwD/MCI in research, but Wilkinson (2002) advises that researchers need be prepared before undertaking research with PwD due to potential sensitivities and ethical problems. Several publications have specifically commented upon these issues, where having appropriate research skills, experience of working with PwD/MCI, the involvement of supportive others and training, are all proposed as beneficial to conducting research that meaningfully involves PwD/MCI. These will be briefly discussed below:

2.1.1 Skills

It is advised that researchers involved in collecting data and analysis should have an appropriate skills set to be able to effectively involve PwD/MCI in the research (Murphy et al, 2015). Thus, researchers will need skills that are relevant to the research, such as qualitative interviewing (Sixsmith et al, 2006). As well as a broad collection of strategies to be able to adapt to individual participants' abilities (Murphy et al, 2015). Furthermore, in research involving PwD, skills in recognising non-verbal communication are particularly important because participants are likely to have limited verbal communication abilities (Hendriks et al, 2015). Thus, being able to interpret and analyse non-verbal behaviour is an important expertise for researchers to develop (Hendriks et al, 2015).

2.1.2 Experience of working with PwD/MCI

Several studies working with participants who have MCI/D report employing researchers who have experience of working with this demographic for data collection (Sixsmith et al,

2006; Hanson et al, 2007; Hellstrom et al, 2007). For example research nurses who have worked in the field of dementia (Hanson et al, 2007; Hellstrom et al, 2007) or co-researchers who are PwD conducting research with other PwD (McKillop & Wilkinson, 2004; Tanner, 2012). Implicit in this decision is that people with experience of working with PwD/MCI will have an understanding of how individuals may be affected by MCI/D and be better able to communicate or empathise with participants (McKillop & Wilkinson, 2004). Indeed, Hellstrom et al (2007) suggest that prior experience of working with people with dementia is beneficial to developing rapport with participants and pleasant research encounters. Another significant reason for researchers to be experienced with dealing with PwD/MCI is that the complex process of informed consent requires that researchers have the expertise to communicate effectively with these participants and their families (McKeown et al, 2010).

2.1.3 Supportive others

The helpful role of supportive others (individuals who help facilitate the research but who are not part of the research team) has been highlighted in several studies. Here support may come from gatekeepers such as formal caregivers who provide access to individuals for recruitment (Pratt, 2002) and, valuable background information about PwD/MCI (Bamford & Bruce, 2002). Furthermore, specially trained dementia staff have been utilised to assist workshops in a project developing ALT (Robinson et al, 2009). However, it is the presence of informal caregivers or relatives of PwD/MCI participating in the research (who may also be participants themselves), who can play a vital supportive role in many ways. For example: encouraging ongoing participation (Hellstrom et al, 2007), facilitating interviews or group sessions (Nygard, 2006; Sixsmith et al, 2006; Lindsay et al, 2012; Hendriks et al, 2013; 2014) and, including during testing and evaluation stages of the research (Mayer & Zach, 2013)⁶. However, the impact of caregiver involvement and support in the research process needs to be carefully attended to by researchers (Pratt, 2002; Lindsay et al, 2013; Hendriks et al, 2013).

2.1.4 Training

It is reported that designers working with older people feel unprepared due to their lack of skills and experience of working with these individuals (Hendriks et al, 2013). This issue may

⁶ See below for more information regarding the ways that caregivers can help researchers.

be exacerbated by individuals having diagnoses of dementia or MCI (ibid). Therefore, becoming familiar with and developing understanding of MCI/D is advocated as a useful practice for researchers; since the cognitive and physical impairments experienced by these participants may be quite different to the experiences of the research and design team (Hendriks et al, 2013; 2015). Indeed, it is recommended that members of the research team, both those collecting data and individuals who are designing, installing or supporting the implementation of technology, should have training in how to interact with PwD/MCI, including strategies to not upset or distress them (Mahoney et al, 2007). Training has also been reported to ensure that researchers are adopting a similar approach, Sixsmith et al (2006) reported that they provided “project-specific training” (pg. 6). However, what this entailed was not described.

Ultimately, the AL Project will benefit if the staff involved are skilled communicators as well as being knowledgeable and aware about MCI/D and how individuals and families may be affected (McKeown et al, 2010). Therefore, the AL Project may want to consider that part of staff training involves spending some time in a dementia setting such as a care home or day centre. Being involved in tasks with PwD/MCI is a means by which researchers and designers can gain experience and, more nuanced understandings of how different PwD/MCI may be affected by any cognitive or physical impairments (Branco et al, (2015). Arguably, more can be gained from direct experience than from reading about dementia and MCI and the way it affects individuals (ibid).

Key points:

- It is beneficial for researchers to have previous experience of dealing with PwD/MCI and possess relevant skills to effectively work with these participants.
- Formal and informal caregivers can provide invaluable support of the research process and help facilitate participation of PwD/MCI.
- Previous participatory research has found that designers and technical support workers have felt unprepared and inexperienced in dealing with PwD/MCI.
- Projects should provide training to individuals who may interact with PwD/MCI and their caregivers so they feel more prepared and able to deal with them.

2.2 Materials

The Dementia Empowerment and Engagement Project (DEEP) have published some invaluable recommendations about involving PwD. They advise that any written communication to PwD/MCI and their caregivers, such as information sheets about the research, should be 'dementia friendly' (DEEP, 2013a). Written information about the research can be extremely useful for PwD/MCI and their relatives because it is something that is concrete detailing the research that they are involved in and, because it can be kept and re-read as required (DEEP, 2013a). As with verbal communication, written documents need to portray information clearly and simply to maximise its accessibility to a wide range of PwD/MCI, whose abilities cannot be assumed (DEEP, 2013b). Indeed, researchers may want to consult with PwD/MCI when devising documents to best ensure their suitability (DEEP, 2013b). Researchers need to be careful to strike a balance between providing enough information to meet ethical requirements of informed consent or fulfil the needs of a research task on the one hand (Dewing, 2002). And, not overwhelming individuals with paperwork which may be daunting and off-putting to PwD/MCI (DEEP, 2013b) on the other; which could also have both practical and ethical ramifications for the research.

Both the way that documents are written and the way they are presented are important to consider when developing written materials for PwD/MCI (DEEP, 2013a). PwD/MCI can experience difficulties with documents that are too long, written using complicated language or technical jargon (*ibid*). But also they may struggle if presentation is cluttered or the font style is complicated or too small (*ibid*). Some suggestions regarding written documentation taken from advice that has been devised by PwD as part of the activities of the DEEP (*ibid*) include:

- Present information in a clear and logical manner
- Use simple but not patronising language
- Be concise, present one subject per sentence
- Paragraphs should make sense on their own
- Use of relevant examples or quotations can aid understanding
- Use of images can be beneficial as long as they are relevant to what is trying to be conveyed and not childish or patronising or something that could be easily misunderstood

- Text should not be written over photographs/pictures

DEEP also advise that formatting and layout can help readers with dementia or MCI follow and make sense of written documentation (DEEP, 2013a). Here they highlight that colour and text boxes can be used to distinguish or highlight important information (ibid).

Furthermore use of white space, bullet points, bold text and headings can help to chunk information and make it appear less daunting to PwD/MCI (ibid). Finally, it is recommended that a large font size (14pt) and clear font (such as Arial) are used and that information is presented in a booklet rather than as loose sheets of paper (ibid).

Key points:

- Care needs to be taken to develop 'dementia-friendly' research materials.
- Information should be clear, concise, jargon free and well designed.
- A balance needs to be struck between ethical requirements of provision of sufficient information to participants and, not overwhelming participants.

3. Ethical issues:

Whilst there is good reason to include PwD/MCI in the development of ALTs, there are a number of ethical issues that require special consideration which have been highlighted in the literature. PwD/MCI are considered a vulnerable population because of their impaired cognition that may affect their ability to understand the research process and their role in participation (Mahoney et al, 2007). This means that individuals may have limited capacity to provide informed consent (Mahoney et al, 2007). Certainly, a great deal of discussion in the literature centres on the process of informed consent with PwD/MCI. However, the ethical principles of beneficence and non-maleficence also require careful consideration when conducting research involving PwD/MCI (Berghmans & ter Meulen, 1995). Therefore, it is also important to consider the potential benefits and burdens of doing such research.

The ethical aspects of a project are important for researchers to address at the start of the research through initial ethical review of a project, but they also require on-going consideration by researchers (Hellstrom et al, 2007). Nevertheless, initial ethical review is key stage in the research process that requires significant attention and can be challenging

(Martin et al, 2013). One such challenge is that dementia can affect individuals unpredictably (Hubbard et al, 2003). Thus, conducting qualitative research involving PwD/MCI requires a particularly flexible approach to ensure that it is accessible and inclusive to participants, making it difficult for researchers to fully anticipate methods and account for all the potential ethical issues that may occur (Hellstrom et al, 2007). Indeed, it is impossible that researchers can anticipate every ethical challenge that may be faced in the research (Pratt, 2002; Hubbard et al, 2003; Pesonen et al, 2011). Furthermore, since PwD/MCI may be deemed a vulnerable population, with diminished autonomy, reviewers may adopt a particularly protective stance towards them as research participants (Mahoney et al, 2007). Indeed, there exists much concern about obtaining informed consent from PwD (Dewing, 2007). Importantly, Mahoney et al (2007), highlight that ethical overview of research and development of technology involving PwD is far from conclusive and, there remain inconsistencies between reviewers regarding their assessment of risk, as well as some bias against technology. Hence, these issues can make the ethical review of AL projects involving PwD/MCI a complicated and time consuming process (Martin et al, 2013). Certainly, it is posited that the ethical review process can be inhibitive of ALT research and development for PwD/MCI (Mahoney et al, 2007) and, can unnecessarily act to exclude PwD/MCI from being involved in research (Dewing, 2007). One way to mitigate these problems is for researchers to actively develop good communication and relationships with research ethics reviewers, so that problems can be quickly addressed (Mahoney et al, 2007). Despite the ethical challenges of involving PwD/MCI in research, there is a strong argument for the inclusion of individuals from these populations in research pertaining to them (Wilkinson, 2002; Hellstrom et al, 2007; Dewing, 2007; 2008). Particularly in the area of research and design of AL technologies (Topo, 2009; Span et al, 2013).

Key points:

- PwD/MCI are a vulnerable research population because they may have impaired and varying levels of capacity.
- It is difficult to anticipate all the potential ethical problems that may be encountered in research.
- The ethical review process may be complex and time consuming.
- Good relationships and effective communication with research ethics reviewers throughout research projects can help overcome problems efficiently.

3.1 Person centred approach

Mahoney et al (2007 pg. 219) argue that “humanistic concerns” should be at the centre of research and development of technology that involves monitoring PwD in their homes. Certainly, the meaningful inclusion of PwD in research and development of technologies is important in respecting their ‘personhood’ (Dewing, 2002; Lindsay et al, 2012). PwD/MCI are valuable participants in this process because of their unique experiences as individuals affected by dementia (Dewing, 2002; Lindsay et al, 2012). Importantly, there is a need to recognise that the ways that designers perceive and experience the world may be vastly different to those of PwD/MCI, creating a further argument for involving PwD/MCI in research and development of technology that will impact the lives of them and their caregivers (Lindsay et al, 2012). Thus, it is important to consider the needs of participants and plan research accordingly.

McCormack, argues that for research to be person centred it needs to meet conditions of: “informed flexibility; sympathetic presence, negotiation, mutuality and transparency” (McCormack, 2003 in Dewing, 2007 pg. 13). Indeed, what is evident in the literature is that due to the complex and varying ways that individuals can be affected by dementia, adopting a ‘one-size-fits-all’ approach to research with this population is not appropriate for research adopting an inclusive approach (Hubbard et al, 2003; Hendriks et al, 2015). It is essential that researchers reflect on the individual abilities of participants and be flexible, drawing upon multiple tools to enable individuals to participate (ibid). The various methodological tactics that a researcher can employ will be discussed in the data collection section below.

Another aspect of respecting individuals' personhood in the research process is the adoption of a caring approach towards participants, which puts their well-being first (Hanson et al, 2007; Robinson et al, 2009). Central to this are researchers' attitudes and actions towards participants. Researchers need to treat PwD/MCI positively, and not approach dementia or cognitive or physical impairments in negative or stigmatising ways (Mahoney et al, 2007; DEEP, 2013c; Aveyard et al, 2015). Also, researchers need to value PwD/MCI and be demonstrable of this to participants (Clarke & Keady, 2002). For example developing empathy with individuals (Clarke & Keady, 2002; Lindsay et al, 2012) and, regularly communicating with participants throughout the design process to keep them informed and involved (Orpwood et al, 2005). It is also important to remain mindful of potential burdens of participation that may be experienced by individuals during the research process (Pratt, 2002; McKillop & Wilkinson, 2004; Hellstrom et al, 2007).

To support the welfare of PwD whilst they are involved in research, it may be useful to liaise with formal and informal caregivers (Pratt, 2002); or involve individuals who have professional experience of dementia in the planning and conduct of the research (Hanson et al, 2007; Robinson et al, 2009). However, the involvement of PwD in research planning is also advocated (McKillop & Wilkinson, 2004; Tanner, 2012). Finally, researchers should ensure that the process of research and design is enjoyable for PwD/MCI (McKillop & Wilkinson, 2004; Hellstrom et al, 2007). Indeed, PwD/MCI may personally value their opportunity to be involved in research and, research sessions might also be an important opportunity for them to connect with other people living with dementia or MCI (McKillop & Wilkinson 2004; Aveyard et al, 2015).

Key points:

- Participatory approaches to research aim to respect personhood of PwD/MCI.
- Adopting a caring approach with consideration of the needs and abilities of individual participants is essential.
- PwD/MCI need to feel valued and positive about their involvement in research.

3.2 Informed consent

Capacity is a central consideration when doing research with PwD/MCI since traditional models of informed consent rely on individuals' being cognitively able (McKeown et al, 2010). For PwD/MCI, the necessary cognitive abilities to give informed consent are affected, for example: being able to retain and understand information and, make a judgement about whether or not to participate in research (Downs, 1997). Nevertheless, just because an individual is diagnosed with dementia or MCI, this does not automatically mean that they do not have the capacity to make informed decisions about participating in research (Downs 1997; McKeown et al, 2010; Dewing, 2002; 2007; 2008). Nor should they be excluded from research because of the challenges associated with obtaining informed consent (Lloyd et al, 2006; Hellstrom et al, 2007; Dewing, 2002; 2007; 2008). Individuals' capacity may fluctuate or vary depending on the type or complexity of decision they are being asked to make (McKeown et al, 2010). This places an emphasis on researchers presenting and communicating information in a manner that is accessible to PwD/MCI, enabling them to make decisions about research participations and provide informed consent (Mahoney et al, 2007, McKeown et al, 2010). However, flexibility required to achieve this may be contrary to the demands of formal informed consent processes necessitated by research ethics committees (McKeown et al, 2010).

One method of obtaining informed consent from PwD who are deemed legally incompetent is the use of proxies (people who can provide consent on behalf of cognitively impaired individuals), however, this approach to consent is arguably problematic (Dewing, 2002; 2007; 2008). First, this approach disempowers the individual with dementia and is therefore incongruent to a person-centred approach to research (Dewing, 2002) and, the inclusive goals of participatory design involving PwD/MCI. Second, there is evidence suggesting that there can be disagreement between proxies and PwD regarding consent and, that PwD can be unhappy with the proxy consent approach (Dewing, 2002). Dewing (2002, pg. 159) argues that traditional cognitively biased consent practices "amount to exclusionary ethics" because they focus on the responsibilities and actions of proxies and researchers.

Advance directives made by PwD whilst they still have sufficient capacity have been suggested by some as a means of dealing with consent when people become incompetent

(Bartlett & Martin, 2002). However, the practicalities of this are questioned (ibid). Indeed, advance directives highlight a problem in dementia where people with dementia are viewed from the perspective of who they used to be, ignoring the “here and now voice” of PwD, effectively rendering them invisible (Dewing, 2002, pg. 159). Furthermore, in making advance directives people may not have sufficient insight to their future circumstances (Dewing, 2002).

Research and development of ALTs involving multiple stakeholders will necessarily require multiple consents from all the different individuals involved. These may include formal and informal caregivers, family members who may also be end users or share the home of the PwD/MCI where technology is installed (Mahoney et al, 2007). In addition, it is advisable that researchers are considerate of cultural differences and the implications that these may have for the consent process (Mahoney et al, 2007). Furthermore, as dementia is progressive, researchers need to be aware that willingness to participate and capacity of individuals may alter over time, so that the consent process may need to be adapted, potentially requiring the involvement of significant others (Hubbard et al, 2003; Pesonen et al, 2011). Researchers may want to consider whether in these circumstances the use of designated proxies or advance directives is acceptable (Hubbard et al, 2003).

Dewing (2007; 2008) argues that capacity is situational and as such, can exist even when PwD are deemed legally incompetent. Therefore, she proposes “process consent” that is grounded in an ethic of care (Dewing, 2007; 2008). This approach recognises peoples’ ‘interconnectedness’ and ‘interdependence’ and, takes a person-centred approach, making the person with dementia central to the consent process (ibid). Dewing argues that consent with PwD should be ‘particularistic’ and ‘inclusionary’ and therefore, viewed as a process rather than a one off event (Dewing, 2002; 2007; 2008). Indeed many researchers interested in actively involving PwD as participants rather than subjects in their work report adopting this sort of approach (Hubbard et al, 2003; Nygard, 2006; Hellstrom et al, 2007; Murphy et al, 2015).

Dewing (2007; 2008) outlines a 5 part method of process consent that has been developed over many years working with PwD (see below). Although this 5 part process consent provides guidance to researchers, Dewing (2007; 2008) specifies that the process relies upon researcher expertise in being able to effectively communicate and interact with PwD;

indeed, it is imperative that researchers' evaluations of consent are nuanced and contextualised.

Dewing's 5 part process consent (Dewing, 2007; 2008)

1. Background and preparation

This element of process consent is where researchers clarify permissions to access PwD, possibly through liaising with 'gatekeepers' such as formal caregivers or relatives, but certainly involving the PwD themselves. These permissions must be distinguished from obtaining proxy consents. Furthermore, it is important to check the individual abilities of PwD as well as establish some biographical information about them to help the researcher evaluate a baseline of their general wellbeing.

2. Establishing a basis for capacity and other abilities

In this part of the process, researchers need to establish if legal capacity exists and consider existing information about an individuals' capacity, such as assessments or the views of individuals who know the person with dementia. Here it is important to recognise poor scores in assessments, indicating significant cognitive impairment should not be grounds to exclude individuals from participating in the research. The aim is for researchers to establish the best ways to inform and communicate with PwD according to their individual abilities.

3. Initial consent

At this point researchers provide information to individuals in a manner that corresponds with their individual abilities to obtain their consent. Researchers need to be flexible and creative in presenting information to PwD, to enable their understanding. For example, some individuals may be able to understand information presented in the form of slightly adapted information sheets and consent forms, whereas others may require information to be presented in the form of pictorial information or props.

4. On-going consent monitoring

Consents of PwD are an on-going process and therefore need to be reviewed and re-established on each occasion and potentially within the course of a research session. This monitoring and re-establishment of consent needs to be transparent process and can include validation by a person known to the person with dementia. It is important to ensure that the wellbeing of the PwD is maintained.

5. Feedback and support

Researchers may sometimes feel it necessary to provide feedback to significant others such as formal or informal caregivers, or members of the research team, regarding issues of concern. The emphasis here is on the wellbeing of participants. In providing feedback, researchers need to be particularly careful regarding confidentiality and should involve the person with dementia in this process if possible. Researchers also need to be aware that PwD may require some support in transitioning between the research context and their daily life.

It is also useful to reflect on some of the reports of researchers who have adopted a process consent strategy in their work with PwD. As we will describe in the discussion of recruitment below; some studies have recruited individuals with the assistance of formal caregivers who have prior knowledge and experience about people and, can advise researchers regarding individuals' abilities to participate (Hellstrom et al, 2007; Hendriks et al, 2013). Murphy et al (2015) reports that in their study, research assistants underwent training in consent procedures in an attempt to safeguard that consents given would be voluntary. Taking time to interact with individual participants and carefully communicate information to them in a way that they can understand is something that is deemed very important (ibid). Certainly, 'pre-meetings' with PwD are advocated as a good practice that enables researchers to access the abilities of participants and how they may deal with consent as well as different data collection methods (Hubbard et al, 2003; Hendriks et al, 2013). They are beneficial for participants who are able to meet members of the research team, discuss aspects of the research and negotiate their involvement (ibid). In the case of group work, researchers should talk to and invite individuals to participate in advance of the session and collect consent individually (Bamford & Bruce, 2002). Furthermore, timing is a key consideration, so that researchers interact with PwD/MCI on a 'good day' when their capacity and ability to communicate are at their best (McKeown et al, 2010). Interestingly, one study reported that written consent was not sought because it was feared that individuals may potentially become worried or distressed about recalling signing an official looking document, but may not remember what it is for, therefore verbal and behavioural cues were utilised to signal consent (Bamford & Bruce, 2002).

In terms provision of information, studies describe communication with participants utilising both verbal and written explanations about the nature of the research in advance of beginning data collection (Hendriks et al, 2013). PwD/MCI may have difficulties communicating which can reduce their capacity to consent, therefore both verbal and non-verbal cues need to be considered in researchers' continuous assessment of whether individuals want to remain involved in the research (Hubbard et al, 2003; Hellstrom et al, 2007; McKeown et al, 2010). Moreover, in qualitative research, PwD/MCI may raise unexpected sensitive issues. Researchers report that in these moments, people may not

wish audio recording to remain on, or may wish that certain aspects of the data are not included in the study (Clarke & Keady 2002).

Another consideration researchers should be mindful of is that participants may conceal their desire to not take part from them (McKeown et al, 2010). To deal with this, one study enlisted the help of caregivers to monitor verbal and non-verbal behaviours using a standardised form after each research encounter as part of the consent process (ibid). However, other research has found that participants with dementia are very able to withdraw their participation through a number of means, including flat refusals to participate, to leaving group sessions before they had formally come to an end, or remaining present but withdrawing from discussions or falling asleep (Bamford & Bruce, 2002). These examples demonstrate the fluid nature of participation and consent, whereby PwD/MCI may opt-in and out of research on different occasions or even within one session (McKeown et al, 2010).

A limitation of process consent is the reliance on researchers' having sufficient communication skills and understanding of the experiences of PwD/MCI to be able to effectively inform and ethically involve these participants in research (McKeown et al, 2010). Furthermore, it is important to recognise that in following Dewing's proposals for process consent, whilst a researcher may be obtaining consent from individuals with dementia or MCI, these consents are not necessarily 'informed consent' (Dewing, 2008). Finally, whilst process consent differs from traditional, formalised informed consent procedures, this does not mean that these consents should not be auditable (Dewing, 2008). It is essential to gather evidence detailing on-going consent, so that researchers can justify their decisions and actions regarding this process (Dewing, 2008; McKeown et al, 2010). Here meetings, field notes and caregiver assessments of individuals post-research encounter can be utilised (McKeown et al, 2010).

Key points:

- Traditional models of informed consent are unsuitable for conducting research involving PwD/MCI.
- Researchers should adopt a process consent approach to enable PwD/MCI to define their own participation in research.
- Researchers will have to take a flexible approach to communicate necessary information about the research.
- Both verbal and non-verbal communication of PwD/MCI are vital considerations in the consent process.

3.3 Confidentiality

Confidentiality is an important consideration if researchers feel it necessary to provide feedback about a participant to someone else, such as a formal or informal caregiver or relative (Dewing, 2007; 2008). In addition, in research involving group sessions, confidentiality is an important consideration since sensitive information may arise but researchers cannot control how group participants deal with the information disclosed by others (Bamford & Bruce, 2002). This issue may be compounded when groups include PwD/MCI because they may not fully recall where the information has come from or group boundaries of confidentiality that apply to the information (Bamford & Bruce, 2002).

Key points:

- Researchers need to consider confidentiality if feedback about PwD/MCI to others is required.
- Researchers cannot control the use of disclosed information by participants involved in group sessions.

3.4 Burdens

There are a number of burdens discussed in the literature regarding the involvement of PwD/MCI in research, including participatory design for the development of ALT. Burdens will be described in terms of those potentially faced by participants and those faced by researchers and designers involved in projects.

3.4.1 Burdens for participants

Several potential burdens facing participants in research are reported in the literature. First it has been highlighted that participation in research can be challenging for both PwD and caregivers because individuals may have to confront sensitive and personal issues about diagnoses of dementia or MCI and, the limitations or difficulties faced because of cognitive and/or physical impairments or their support needs (Pratt, 2002; Hendriks et al, 2015). Indeed, some individuals may not have accepted their diagnosis, or may not have even been told (Reid et al, 2001; Hellstrom et al, 2007). Furthermore, in group sessions individuals could encounter others who are more severely affected by dementia or MCI, which may be emotionally challenging, especially when faced with a progressive form of dementia (Hendriks et al, 2015). In addition, participants may just become agitated or anxious by the prospect of research visits because they may forget or be confused about their purpose (Hellstrom et al, 2007). These instances require researchers to act with sensitivity and awareness of their potential to cause distress. Prior consideration of these potential issues and the ways that researchers may deal with distressed participants, such as developing protocols, can be helpful for researchers (Pratt, 2002; Hellstrom et al, 2007).

In the design process, distress of participants has been reported during early prototype testing, where PwD have become anxious and agitated by poorly functioning prototypes, which can reduce their confidence (Orpwood et al, 2005). However, also in observational stages, where ALT systems have been installed in people's homes, multiple stakeholders have, for different reasons, found testing newly developed technology burdensome and in some instances upsetting (Topo, 1997). Thus, researchers need to carefully consider the potential for causing distress to all stakeholders in the process of research, particularly amongst PwD/MCI who may be more vulnerable to confusion and anxiety.

Certainly, there are a number of concerns regarding the potential burdens of home-based ALT that may be developed and tested in a project (Mahoney et al, 2007). It is argued that research should be aware about the potential for technology to infringe the privacy of participants, including individuals who may live with or visit participants, and consequently may also be affected by the implementation of these technologies (ibid). Furthermore, researchers need to be aware that at-home testing of ALT prototypes can be harmful because it may alter the normal patterns of behaviours of users (both PwD/MCI and their

caregivers) (ibid). Here, installing technology may provide a sense of security, or individuals may feel assured that the technology is working efficiently and, as a consequence, adapt their normal routine (Mahoney et al, 2007). With technology that is still under development there may be faults, making these assumptions unreliable, which may result in things being unchecked or not done, potentially placing a PwD/MCI in danger (ibid). Thus, safety issues are an important consideration in planning and conduct of ALT research and development (ibid). Furthermore, testing stages of technology, could identify cases of neglect or abuse; so that studies need to have a plan for dealing with these circumstances that meet legal and ethical requirements which must also be communicated to participants as part of the consent process (Mahoney et al, 2007).

Researchers need to be aware of distress that may be caused to participants as a consequence of their expectations regarding their participation in a design process. For example, if stakeholders feel that the information they provide is not acted upon, this may annoy them or make them feel used or undervalued. This may be particularly damaging and disempowering to PwD/MCI (Aveyard et al, 2015). Consequently, it is important for researchers to provide feedback regarding what they have found and design decisions made (DEEPb). Finally, ending the research relationship with PwD/MCI can be difficult and upsetting, because researchers and participants will have developed trust and familiarity, particularly in longitudinal work (McKeown et al, 2010). Moreover, where participants have tested technology in their homes, this will probably require removal at the end of the project. This could be distressing if participants have found the ALTs useful or have come to rely on them (Mahoney et al, 2007). Being open and honest about these issues from the start and making sure that participants are aware that the researchers are grateful to their contributions are recommended as a means to ameliorating any distress caused (McKeown et al, 2010).

Key points:

- Research with PwD/MCI may be upsetting for both PwD/MCI and their caregivers or relatives.
- Developed technologies can be distressing or frustrating to PwD/MCI.
- Installation of in-home technology can infringe on privacy and potentially alter the behaviour of PwD and caregivers which is an important safety consideration.
- The removal of technology from people's homes at the end of the research could be distressing.

3.4.2 Burdens for researchers

As well as participants, potential research burdens and distress to researchers and designers also needs to be considered. It is reported that researchers and designers can find working with people with dementia emotionally challenging because they are confronted by the reality of the effects of dementia and, the difficulties experienced by PwD and their relatives (Clarke & Keady, 2002; Pratt, 2002; Pesonen et al, 2011; Hendriks et al, 2014; 2015).

Participants may disclose upsetting information (Pratt, 2002; Hendriks et al, 2014), ask the researcher difficult questions (Pratt, 2002), or could have challenging behaviour. Indeed, it is reported that researchers and designers can feel unprepared and unsure of how to deal with participants at the beginning of projects (Hendriks et al, 2015). Furthermore, technology support technicians may also experience similar difficulties during prototype testing in individuals' homes (Topo, 1997). Researchers may also forge close relationships with participants during the process of research which can accentuate feelings of concern and make ending research relationships upsetting (Pesonen et al, 2011). These issues indicate the importance of preparation and training for researchers and designers at the start of projects, especially if they have little experience of working with PwD/MCI (Pesonen et al, 2011; Hendriks et al, 2015). But also keeping a reflexive journal and regular supervision sessions are recommended as a means by which researchers can alleviate some of these burdens (Pratt, 2002; Pesonen et al, 2011). It is advised that these issues should be something to consider and plan ahead for (Clarke & Keady, 2002; Hendriks et al, 2015).

Key points:

- Researchers, designers and technicians can find working with PwD/MCI and their caregivers emotionally demanding.
- Researchers may face difficult questions from participants.
- Training, supervision and reflexive practice can help mitigate burdens on researchers, designers and support staff.

3.5 Benefits

Despite the potential for burdens, outlined above, there are strong arguments in support of involving PwD/MCI, their relatives and other stakeholders in the research, design and development of AL technologies that are purposely for them. Nevertheless, researchers and designers need to be aware about who stands to benefit from the technology that is being developed and, the potential implications that the technology will have on other stakeholders (Downs, 1997). For example, what is beneficial to carers, may be paternalistic and unwelcome to PwD/MCI (Downs, 1997). Therefore, competing interests need to be carefully balanced when developing and introducing new technology (Downs, 1997).

In terms of conducting the research, it has been observed that the process can provide benefits to PwD who participate, since individuals may enjoy participation and feel empowered through their involvement (McKillop & Wilkinson, 2004; Hanson et al, 2007; Robinson et al, 2009; Aveyard et al, 2015). Indeed, Dewing (2002, pg. 165) argues that “all person-centred research encounters are potentially therapeutic encounters for persons with dementia and must be considered from this position”. Certainly, Pratt (2002) observed that some of her participants found the research provided them with a safe space to discuss sensitive issues. Furthermore, if technology developed is tested by individuals and this is found to be beneficial to them, this can added benefit of participating, particularly if they are able to retain the technology at the end of the project.

Finally, some benefits of doing research and design projects involving PwD is that this work has potential to benefit society as a whole by improving ALT. Participatory projects adopt bottom-up, inclusive approaches which will arguably result in ALTs that better meet the needs of stakeholders (Topo, 2009; Span et al, 2013). Ultimately the research has the

potential to help improve the lives of future PwD/MCI, their caregivers and relatives. Indeed, these wider social aims may be a central motivator for participation in research amongst PwD/MCI (Robinson, 2002; McKillop, 2002; Aveyard et al, 2015).

Key points:

- PwD/MCI can find being involved in research empowering and enjoyable.
- Person-centred research encounters can be therapeutic.
- The development of ALTs have the potential to bring future societal benefits.

4. Recruitment:

There are a number of approaches that the AL Project can take to recruiting PwD/MCI and their informal caregivers or relatives to the research. Approaches and advice about recruiting these populations outlined in the literature, including reflections from other AL projects are detailed below.

4.1 Sampling

Researchers may choose to sample individuals according to a diagnosis of 'dementia' or 'MCI', however, people with dementia or MCI are not a homogenous participant group, there will exist variation between participants on many levels connected to their social situation, support and living environment and socio-cultural factors (Sixsmith et al, 2006). Also, the type of dementia or MCI that individuals have and, the multitude of ways that symptoms may manifest physically, psychologically or cognitively, make this participant population extremely diverse (Hendriks et al, 2013). Indeed, the variety of dementia needs poses a challenge to participatory design of ALT, since it is difficult to broaden out the applicability of findings from sessions involving relatively small numbers of individuals to a wider population of individuals (Hendriks et al, 2014).

With this in mind, AL projects have utilised a number of means to maximising variation in participants to gain a wider account of perspectives to draw upon in the design of ALT. For example, Sixsmith et al (2006) purposively sampled individuals with the aim of maximise variation between participants. Here, they focussed on involving people living in different

ways: independently at home, supported in the community, or living in residential homes, as a means for the research to explore different perspectives and experiences of PwD (Sixsmith et al, 2006). In another project that recruited PwD/MCI and their caregivers, new dyads (PwD and their caregiver) were recruited at each cycle of development and evaluation, with the aim of increasing participant numbers to widen the scope of perspectives and experiences of participants included in the research (Meiland et al, 2012). Furthermore, the COGKNOW and Rosetta projects both involved multiple locations within the EU in the research (Meiland et al, 2012; Meiland et al, 2014). It was hoped that this would contribute to a better representation of end-users in cross-cultural contexts and this would subsequently improve the functionality and acceptance of the ALT developed (ibid).

The inclusion of both formal and informal caregivers is also very beneficial to research and development of ALTs. In the case of informal carers, the use of care dyads (a person with MCI/D and their main informal caregiver) is a useful way that the research can obtain more detailed, elaborated information about individual cases of dementia because the dyad enables a view from two perspectives (Hellstrom et al, 2007; Sävenstedt & Karlsson, 2010; Meiland et al, 2014). Certainly, informal caregivers will necessarily have some involvement in the research. For example they may live with PwD/MCI and therefore will be affected by the introduction of prototypes in the home during the testing phases, but also their views are valuable to the research-design team in their own right, since they too are potential beneficiaries and users of the ALT developed (Orpwood et al, 2005 Meiland et al, 2014). Obviously it is important to recognise that dyads provide two distinct perspectives, however, accounts of caregivers may be used as a means to verify and clarify those of PwD (Orpwood et al, 2005). This approach is arguably problematic and potentially undermines a person centred approach to research with PwD (Nygard, 2006). But it is reported that individuals in these dyads often report more in common than they do differences (Sävenstedt & Karlsson, 2010).

Key points:

- The variation in individual differences between PwD/MCI means that maximum variation sampling strategies can be beneficial for research.
- Including formal and informal stakeholders as participants in ALT development research offers several benefits.

4.2 Eligibility to participate

In a review of qualitative studies involving PwD, Murphy et al (2015) found that some have utilised diagnostic scales as part of their eligibility criteria for individuals. Hanson et al, 2007 advise that individuals with early stage dementia should be recruited as early into their illness as possible and have a Mini Mental State Examination (MMSE) score of >25 to maximise their ability to be actively involved in the research. However, the Hanson et al study was a particularly long-term project, requiring the on-going participation of individuals. Certainly, the progression of some forms of dementia can be problematic for participatory design; for example, one AL project (developing the NOCTURNAL system) reported that attrition of individuals, due to deterioration in their condition was a significant issue affecting the project (Martin et al, 2013).

To the contrary, some argue that measures such as MMSE are not indicative of individuals' ability to participate (Pratt, 2002; Hellstrom et al, 2007) and certainly, individuals with mild to moderate dementia can be quite capable of engaging in research (Mozley, 1999 cited in DEEP, 2012; Hellstrom et al, 2007; Murphy et al 2015), including participatory design (Robinson et al, 2009). This highlights that in selecting the eligibility criteria of participants, research needs to be careful not to pose unnecessary barriers to participation (DEEP, 2012; Murphy et al, 2015). Indeed, due to the varied ways that individuals can be affected by their cognitive impairments, it is arguably best to assess individuals' ability to participate on an individual basis, where it is important that researchers have the understanding and flexibility to work with people's different abilities (Hellstrom et al, 2007; Murphy et al, 2015). For instance, to maximise inclusion, certain research tasks can be provided to those individuals who are best able to meet the specific demands of that stage in the design process. An example of this is where individuals who are better able to verbally

communicate are involved in sessions that are particularly demanding in this respect (Hubbard et al, 2003; Moffat et al, 2004, in Hendriks et al, 2013). Nevertheless, most research gathering the views of PwD tend to focus on recruiting people who are not severely impaired, who are in early to mid-stage dementia and presumably more able to understand the research and communicate (Span et al, 2013).

Key points:

- Use of dementia diagnostic scales as eligibility criteria can exclude participants who are capable of participating in research.
- Attrition can be a problem in longitudinal research involving PwD.
- Ability to participate should be assessed on an individual basis.

4.3 Accessing PwD/MCI

A beneficial means of recruiting PwD/MCI is through tapping into existing dementia support groups, centres or other organisations to make contact with individuals (Hendriks et al, 2013). It can be helpful to consult dementia experts in initial stages of research to help identify these recruitment possibilities (Lindsay et al, 2012). In approaching local dementia groups to recruit individuals, researchers enable individuals to self-select to participate (Inns et al, 2009). Another valuable source of potential participants are local service providers such as care homes or social services (Sixsmith et al, 2006). Here, intermediaries or ‘gatekeepers’ (e.g. formal caregivers) can be helpful to researchers in recruitment because they are able to identify individuals who they think will have sufficient capacity to consent as well as the ability to participate in the research (Hubbard et al, 2003; McKeown et al, 2010). Furthermore, initial contacts with potential participants can be made through individual who is well known and trusted by the person with dementia (Hendriks et al, 2013). These gatekeepers play a vital role in protecting the interests of PwD during research, (Pratt, 2002). However, gatekeepers are also a key challenge for researchers because of the central role that they play in the research access to participants (McKeown et al, 2010). Indeed, gatekeepers can be a barrier to research by being over-protective of potential participants (Sherratt, 2007). Subsequently, it is important for researchers to identify and develop relationships with gatekeepers, demonstrating their competencies as

professional researchers at the start of a project to overcome potential barriers (Pratt, 2002; Sherratt, 2007; McKeown et al, 2010).

Gatekeepers can be helpful collaborators in terms of developing research protocol or providing useful background information about potential participants (Pratt, 2002; McKeown et al, 2010). Furthermore, gatekeepers can provide invaluable information regarding the on-going health and well-being of participants over the course of the research (ibid). However in terms of recruitment, Hendriks et al (2013) have reported some difficulties when information about the research has been presented to participants by intermediaries. In these instances, family members and participants have been confused regarding the purposes and remit of the research (ibid). Therefore, it is advised that whilst it is beneficial to utilise organisations and liaise with gatekeepers when sampling participants, researchers should directly talk to potential participants so that the aims of the research are clearly outlined (Hendriks et al, 2013). Organising 'pre-meetings' with PwD to discuss participation are advocated as a good practice because participants are able to meet members of the research team, talk about the research and negotiate their involvement (Hubbard et al, 2003; Hendriks et al, 2013). This is an important part of recruitment and the informed consent process (Murphy et al, 2015), but it also has the benefit of enabling researchers to assess the abilities of participants and plan strategies for data collection.

Key points:

- Gatekeepers are play a vital role in access to participants and their ongoing participation.
- Researchers should develop good relationships and communication with gatekeepers.
- Relying on intermediaries to convey information about the research to PwD/MCI and their caregivers during recruitment, can be problematic.
- Having pre-meetings directly with potential participants is highly beneficial.

5. Data collection:

A variety of methods have been utilised by research and design teams developing AL technology involving PwD/MCI. These include the use of standardised measures, observation, one-to-one interviewing and group work sessions, which are discussed below. What appears to be important when thinking about data collection with PwD/MCI is that

methods may require adaptation to meet the specific abilities of participants, so that it is best to adopt a flexible approach to data collection to facilitate the inclusion of PwD/MCI (Hubbard et al, 2003; Hanson et al, 2007). Furthermore, using mixed methods approach to data collection is argued to be beneficial for gaining a more holistic understanding (Meiland et al, 2012).

5.1 Use of standardised measures/questionnaires/surveys

Standardised measures, questionnaires and surveys have been reported as useful tools in the development of ALTs for assessing things such as participant characteristics, quality of life, needs, level of cognitive impairment and experienced autonomy of PwD/MCI (Meiland et al 2010a; Meiland et al, 2012). These quantitative measures can be considered in conjunction with other data collected to assess the functional requirements of ALTs developed for PwD/MCI (Meiland et al, 2010a), as well as the impact of ALT on individuals' lives in later testing stages of final prototype iterations (Meiland et al, 2010b), and evaluation of ALTs developed (Sävenstedt et al, 2010; Craven et al, 2014). However, researchers should be aware that the application of measures such as the MMSE can have a negative effect on the participant-researcher relationship, due to the negative connotations participants may have with diagnostic measures (Hellstrom et al, 2007).

Surveys and quantitative measures can be useful objective tools to ensure that designers have a good objective understanding of the needs of PwD/MCI and their caregivers, enabling the identification of particular problem areas on a wider scale than qualitative investigations alone (Orpwood et al, 2005). It also allows researchers to quantify the importance of needs (ibid). Furthermore, structured and validated measures enable comparisons across research projects (Sävenstedt et al, 2010). However there are a number of issues to consider regarding the limitations when using standardised measures. A key consideration is whether measures are reliable and valid for use in the target population: namely PwD/MCI (Meiland et al, 2010b). Indeed, to assist researchers in appropriate selection of psychometric measures for PwD/MCI a list of best outcome measures has been drawn up by the European organisation on early detection and timely psychosocial INTERventions in DEMentia (INTERDEM) (Meiland et al, 2010b). Certainly, different measures for PwD/MCI to that of caregivers may be required (Meiland et al, 2010b). Moreover, measures that collect pertinent issues of interest to designers may not be

available or fully captured by pre-existing quantitative tools (Meiland et al, 2010b; Craven et al, 2014). However, Craven et al (2014) highlight that some scales exist which have been developed to specifically measure usability and user satisfaction after testing an AL prototype. These are: the Psychosocial Impact of Assistive Devices Scale (PIADS) (Jutai & Day, 2002 in Craven et al, 2014) and the Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) (Demers et al, 2002 in Craven et al, 2014). Where specific measures for AL projects exist, researchers can adapt old measures or develop new ones; or alternatively collect data by other means, such as semi-structured interviews (Meiland et al 2010b).

An important consideration is that the subjective nature of some of the measures, such as quality of life, means that it is preferable that PwD/MCI complete these themselves rather than using proxy measures, which are completed about PwD/MCI by others (Meiland et al, 2010b). However, Guendouzi & Pate (2014) suggest that standardised assessments can be difficult for PwD, because the requirement for specific answers imposes boundaries on the interaction and puts stress on an individuals' memory function, which may well be impaired. Thus, where standardised measures are used, researchers need to be aware of these issues. Consideration of the abilities of the participant are important, for example, questionnaires may function better than verbally communicated surveys for PwD/MCI because both the question and choice of answers do not need to be memorised since they are visually displayed (Powell, 2007). However, this may not be suitable for individuals with visual perception problems. Therefore, it may be best to present surveys to participants both verbally and visually to PwD/MCI (Sävenstedt et al, 2010).

PwD/MCI may need some assistance in completing questionnaires. Here, researchers rather than caregivers may be most suitable because they are trained and experienced in data collection, but also there may be more privacy, thus facilitating participants to respond open and honestly (Bamford & Bruce, 2002). Finally, consideration needs to be given to the time that participants spend completing these measures, as this process can be quite tiring and burdensome for both PwD/MCI and their caregivers (Meiland et al, 2010b).

Key points:

- Standardised measures can be a useful tool in ALT development projects.
- Ideally PwD/MCI should self-complete measures targeted for them.
- The pros and cons of using standardised measures for PwD/MCI need to be carefully considered by researchers.

5.2 Observational methods

Observational methods, both structured and unstructured have been developed and utilised by researchers to study the social worlds of PwD since methods relying on verbal communication with individuals alone (such as interviewing) can be challenging (Hubbard et al, 2003). PwD/MCI may struggle to articulate their thoughts, may not follow common structure of speech and, may also find it difficult to answer questions directly (Hubbard et al, 2003). Observation is good way of examining the present life of PwD, thus, it a useful method to gain understanding regarding individuals' needs (ibid). Furthermore, observational methods are a useful means by which to include individuals who would be unable to participate in individual or group interviews, as well as supplementing data collected through verbal communication (Hubbard et al, 2003, Nygard, 2006).

5.2.1 Structured observations

Dementia Care Mapping is a standardised, structured observation tool which has been developed from a person centred approach (Brooker, 2005). This tool can be used to observe individuals at all stages of dementia to measure aspects of wellbeing (Craven et al, 2014). Dementia Care Mapping has been utilised in research investigating the social worlds of PwD (Hubbard et al, 2003). However, the use of this particular tool is not reported in literature detailing the design and development of ALT involving PwD/MCI, although it has been listed as a potentially useful standardised measure for this purpose (Craven et al, 2014).

5.2.2 Unstructured and semi-structured observation

Ethnographic, unstructured observation is method that has been utilised to study the lives of PwD and, is particularly useful for investigating lived experiences of these individuals

(Hubbard et al, 2003). The strengths of adopting an unstructured approach is that questions can be posed during observations, which is a useful means of involving people who would struggle to communicate effectively with researchers in an interviewing situation (ibid). In unstructured observations, questions arise from the observational context rather than being pre-defined (ibid). In the development of the COGKNOW ICT, Sävenstedt et al (2010) reported utilising observations which had an open structure, but yet followed an observation scheme that co-ordinated research across three European test sites, enabling the project to compare users from these sites. The COGKNOW team found observing how PwD/MCI interacted with prototypes was an invaluable method for gaining data about the functionality and user-friendliness of the system (Sävenstedt et al, 2010). However, observational work could also be adopted in earlier stages of the design process, for example alongside interviewing to explore individual daily routines and ascertaining needs.

Key points:

- Structured and unstructured observational methods can be very useful in research involving PwD/MCI, due to difficulties with communication.
- Observational methods are useful for examining functionality and user-friendliness in ALT development.

5.3 Qualitative Interviewing

Unlike standardised quantitative interviews or questionnaires that utilise pre-constructed questions and answer ranges, the benefits of adopting a qualitative approach to interviewing is that it enables researchers to be more open to explore the experiences and views of PwD/MCI and their caregivers from their own perspectives (Inns et al, 2009). Adopting a broad and exploratory approach (such as qualitative research) is useful in the initial phases of participatory design with PwD/MCI because it provides the environment for developing understanding, a “common frame of reference” and, ideas from which designers can begin to develop designs (Lindsey et al, 2012⁷ pg. 523).

⁷ Although Lindsey et al (2012) conducted focus group sessions rather than individual interviews for this purpose.

Nevertheless, for research involving PwD/MCI, using qualitative interviews can be challenging because the methods rely on cognitive and verbal abilities that may be reduced in PwD/MCI (Nygard, 2006; Lloyd et al, 2006). Communication can be affected in a number of ways including: difficulties with discussing abstract issues, vague or incoherent speech and difficulties in structuring language (Murphy et al, 2005; Nygard, 2006). Furthermore, PwD seemingly have reduced vocabulary and can be forgetful of words and information, which can make conversation disjointed and repetitive (ibid). Lloyd et al (2006) conducted a review of qualitative projects involving participants who have problems with verbal communication, including PwD. A number of challenges in doing research with these participants were identified including: concerns about the richness of data collected due to disordered or empty speech, the credibility of participants' responses due to problems with dealing with abstract questions, remembering, and a tendency to agree with the researcher (Lloyd et al, 2006).

Meiland et al (2012) also report that PwD in their study tended to provide socially desirable answers; although they thought that provision of socially desirable answers is not necessarily a problem limited to participants who have dementia (Meiland et al, 2012). Furthermore, Lloyd et al (2006) highlighted issues regarding the researcher-participant relationship, in particular the power imbalance that can be instrumental in participant responses as well as researcher's influence, both in research encounters and in the interpretation of PwD's talk. These challenges mean that it may be advisable that researchers have experience of qualitative research with PwD (Sixsmith et al, 2006). Central to conducting qualitative interviews with PwD/MCI is developing good research relationships and effective communication, which are discussed below.

Key points:

- Qualitative interviews are a beneficial means of data collection with PwD/MCI, particularly in early stages of ALT development projects.
- Qualitative interviews with PwD/MCI can be problematic due to their reliance on verbal communication.
- It is advisable that researchers conducting qualitative interviews with PwD/MCI are skilled in this method and have experience of communicating with PwD/MCI.

5.3.1 Building and maintaining good research relationships

Building rapport and trusting research relationships with participants is particularly important in one-to-one qualitative interviewing because it creates an environment in which participants feel able to reveal and share their lived experiences with researchers (Nygard, 2006). Indeed, taking the time to build good research relationships helps to create a “safe context” for participants which is argued to be particularly important when working with vulnerable individuals such as people with MCI/D (Pratt, 2002 pg. 166; Hellstrom et al, 2007). Creating a safe research environment protects individuals involved and is argued to be significant in reducing power imbalances inherent in research with PwD/MCI (Pratt, 2002). Central to this are the role of gatekeepers and carers, who can advise both the researcher and participants about important issues, facilitating the research relationship (Pratt, 2002). This can be helpful for the on-going process of informed consent and maintaining research participation with individuals who may not remember researchers and previous research encounters (Nygard, 2006; Hellstrom et al, 2007). Furthermore, gatekeepers and caregivers can play an important role in monitoring the effects of the research upon participants (Pratt, 2002).

Pre-research meetings between researchers, PwD/MCI and their caregivers can be invaluable for researchers because they provide an opportunity to build rapport and understanding (Hubbard et al, 2003; Murphy et al, 2015). These meetings are a good way to develop research relationships, and develop effective communication and understanding with participants and caregivers (ibid). They also allow researchers’ opportunity to evaluate the abilities of participants and devise methods best suited to their individual requirements (ibid). It can be helpful for researchers to involve and consult with caregivers, even if they

are not participating themselves, because they can be a valuable support in explaining and facilitating participation (McKillop & Wilkinson, 2004). Caregivers can also provide useful background information about the particular needs of participants with MCI/D, including any sensitive issues that could cause distress (Hubbard et al, 2003; McKillop & Wilkinson, 2004). Importantly, researchers need to be considerate of the demands that research can place on carers as well as PwD/MCI (McKillop & Wilkinson, 2004; Hellstrom et al, 2007).

Nygard (2006) argues that different contexts can bring out different presentations of individuals in research interviews and, can also lead to PwD/MCI having different perceptions of researchers and their role within research encounters. Thus, contextual factors of the research environment require some consideration in terms of how this may affect research relationships and rapport. For example, conducting research interviews at home arguably helps to address the power imbalances of the research setting by placing interviewees at the advantage of being in their own environment (Clarke & Keady, 2002). Moreover, carers can also be a support and reassurance to PwD, who may request their presence (Pratt, 2002; Sixsmith et al, 2006; Martin, 2013). However, researchers need to ensure that the presence of caregivers does not detract attention from the PwD/MCI if they are the target interviewee (Pratt, 2002; McKillop & Wilkinson, 2004).

Another contextual factor that requires consideration is how PwD/MCI may perceive the researchers themselves (McKillop & Wilkinson, 2004; Nygard, 2006). Researchers need to realise that they can be misconstrued as being health or social care professionals to PwD/MCI due to participants' forgetting the purpose of their visit (Pratt, 2002). In these scenarios it is important that researchers reaffirm their role and the reason that they are there to participants (Pratt, 2002). In particular, participants can feel uncomfortable and under evaluation if researchers bring large quantities of documents or do lots of notetaking in interviews (McKillop & Wilkinson, 2004); or if diagnostic tests such as the MMSE are utilised (Hellstrom et al, 2007), which can damage rapport.

Another key factor in developing rapport and trust with gatekeepers, carers and participants is the demeanour of the interviewer. It is essential that researchers are friendly and approachable, showing genuine interest and warmth towards participants (McKillop & Wilkinson, 2004). Moreover, researchers need to have sensitivity and awareness of participants' feelings since interviews can highlight to participants the extent of cognitive

impairments which can be both distressing and embarrassing to participants and, may lead to them becoming agitated during interviews (Hubbard et al, 2003). Demonstrating understanding and empathy, such as sharing experiences of dementia (where possible) can be helpful, although showing pity is not (McKillop & Wilkinson, 2004).

The beginning and end of interviews are crucial moments in developing rapport and good relationships with participants (McKillop & Wilkinson, 2004; Hellstrom et al, 2007). It is advised that researchers take time at the start of interviews to include 'ice breakers' such as bringing a small gift like sweets or biscuits (McKillop & Wilkinson, 2004), or a flower (Hellstrom et al, 2007). In addition, it is important to take time to put participants at their ease (Nygard, 2006; Hellstrom et al, 2007), therefore, starting with informal talk (McKillop & Wilkinson, 2004; Murphy et al, 2015), things in the immediate environment like pets or photographs of family can be good topics if the interview is being conducted in a participant's home (McKillop & Wilkinson, 2004). The acceptance of tea/coffee before, during or after interviews, is seen as an important gesture of reciprocity, therefore it is advised that researchers should be polite in accepting these offers (McKillop & Wilkinson, 2004; Hellstrom et al, 2007). When ending interviews, it is important that interviews end positively and participants are left with feeling valued and having a sense of achievement (McKillop & Wilkinson, 2004). It is recommended that time is taken for informal talk (Hellstrom et al, 2007). Finally, it is good for researchers to remember participants after interviews by sending them a thank-you card or any promised information such as feedback about the research (McKillop & Wilkinson, 2004). Indeed, if multiple interviews are to be conducted, finishing on a positive and fostering remembrance and continued contact are expedient to developing and maintaining good relationships (McKillop & Wilkinson, 2004; Hellstrom et al, 2007).

Key points:

- Developing rapport, good research relationships and a trusting, safe environment are essential aspects of qualitative interviewing involving PwD/MCI.
- Pre-meetings are an extremely valuable way of developing rapport and assessing the abilities of participants who have MCI/D.
- Context and situational factors are important considerations when conducting interviews.
- Beginning and ending interviews positively is important.

5.3.2 Developing good communication

In addition to the challenges posed by cognitive impairment, co-morbidities such as deafness are common amongst older people with dementia/MCI, which also increase difficulties in verbal communication (Hubbard et al, 2003; Powell, 2007). Deafness is a challenge for conducting research with PwD/MCI (Hubbard et al, 2003). Unlike people without dementia, PwD/MCI may not realise or remember to inform researchers that they have not heard properly (Powell, 2007). This can be difficult for both researchers and participants because it can damage rapport where researchers may feel tired and frustrated from needing to use raised voices and greater repetition (Hubbard et al, 2003), and participants may feel confused and become increasingly distressed (Powell, 2007). Indeed, it is recommended that one should not shout to be heard by deaf individuals as this can distort words (Powell, 2007). It is prudent to ensure that participants are assisted to use any hearing aids appropriately and, researchers may find it useful to specifically acquire a ‘Converser’⁸ to help with one-to-one communication such as interviews (Powell, 2007). Researchers may find it helpful to make sure that they follow the guidelines detailed below to maximise effective communication with PwD/MCI. Of course it is important to remember that each individual will have different abilities, so that researchers will need to adapt their approach to communication accordingly.

⁸ A converser comprises of a small device into which head phones and microphone are plugged into (Powell, 2007). To purchase see: <http://www.sarabec.com/crescendo-50-headset-and-plug-in-mic/p685>.

Recommendations for verbal communication with PwD/MCI (Powell, 2007)

- Make sure that the environment is not too busy with background noises
- Face the person and wait until you have eye contact before starting to speak to them
 - using their name or touching them on the arm can be helpful in gently gaining their attention
- If you want to discuss something long or complicated, be clear and set the scene to help PwD/MCI get into the conversation
- Use short and simple sentences
 - Do not use too many words
 - Use concrete, literal words
- Emphasise important words
- Speak clearly
- Use pauses - Allow time for the person to understand each sentence
- Repeat or rephrase sentences if they have not been understood

5.3.3 Questioning

One of the benefits of qualitative interviewing is that it has some similarity to having an everyday conversation. The in-depth, open-ended approach of qualitative interviews has been reported as being a beneficial method because they allow researchers to explore and understand lives of people with dementia, without necessarily imposing specific areas for discussion or importance on things (Hubbard et al, 2003; Sixsmith et al, 2006). However, cognitive impairment can make it difficult for individuals to think things through, find words and talk fluidly, all of which are highlighted as a challenge for researchers when adopting this type of approach (Sixsmith et al, 2006; Nygard, 2006; Lloyd et al, 2006). Qualitative interviews do enable PwD/MCI greater freedom in their communication, not only enabling them to steer conversation (Hubbard et al, 2003; Sixsmith et al, 2006). But also, if a person with MCI/D is struggling to answer a question, they can draw on linguistic tools to keep the conversation flowing⁹ (Guendouzi & Pate, 2014). Thus, qualitative approaches can be less challenging to PwD/MCI than standardised methods that have set answers (Guendouzi & Pate, 2014); although some researchers have found standardised questions an extremely

⁹ Please see below.

useful tool for involving PwD/MCI in the development of ALTs (Sävenstedt & Karlsson, 2010).

A reported area of difficulty that requires consideration in interviewing is that PwD¹⁰ may find it quite difficult to answer direct questions about seemingly everyday things that may rely on short or long term memory (thus, both recent and older memories can be affected) (Hubbard et al, 2003; Guendouzi & Pate, 2014). This means that interviewing situations can be embarrassing or distressing for PwD as it highlights areas of cognitive deficiency (Hubbard et al, 2003; Guendouzi & Pate, 2014). Furthermore, semi-structured interviewing (frequently adopted in qualitative research) means that interviewers may quickly move from one topic to another, which can be challenging to PwD as they may struggle to keep up (Guendouzi & Pate, 2014). Compounding this, individuals may be reluctant to ask for clarification because it indicates their cognitive deficit, something that some PwD may be very aware of (Guendouzi & Pate, 2014). Researchers need to be cognisant of these challenges when planning and conducting interviews with PwD/MCI. It is also important to realise that rather than replying with requests for clarification or admitting that they cannot answer a question, PwD may utilise other linguistic skills to maintain communication, so as not to 'lose face' (Guendouzi & Pate, 2014).

Certainly, research investigating speech amongst PwD has concluded that individuals who have a desire to socially interact will adopt certain strategies to maintain conversation (Davis & Maclagan, 2014). Strategies adopted by PwD that have been identified include the use of repeated stories, which may be a means by which PwD can control conversation and prevent other speakers asking questions that they will struggle to answer (Davis & Maclagan, 2014). But repetition is also thought to be a mechanism used by PwD/MCI to move conversation on when a difficult question is encountered (Hubbard et al, 2003). Other conversational strategies used by PwD/MCI include using pauses and use of formulaic language such as chunked groups of words that are remembered as one whole, or the use of fixed expressions (Davis & Maclagan, 2014; Guendouzi & Pate, 2014). These tactics provide a means by which PwD/MCI can cope with their cognitive impairments and maintain fluid conversation (Davis & Maclagan, 2014; Guendouzi & Pate, 2014; Wray, 2014).

¹⁰ The authors do not specify that this is also a problem for people with MCI.

Subsequently, they enable PwD/MCI to meet social expectations of conversation and 'maintain face' when they encounter difficult questions (Guendouzi & Pate, 2014; Wray, 2014). Thus, exerting a level of control over the conversation (Davis & Maclagan, 2014). Moreover, conversational style interviews enable PwD to talk around or avoid questions that they find difficult to answer (Guendouzi & Pate, 2014).

These strategies can be frustrating for researchers (Hubbard et al, 2003) and, in conjunction with other effects of individuals' cognitive impairments such as disjointed or disordered speech, can make it difficult for researchers to make sense of conversations with PwD/MCI (Hubbard et al, 2003; Sixsmith et al, 2006). Thus, researchers may feel that they have not been able to acquire the information that they need from research encounters (Guendouzi & Pate, 2014). Importantly, these problems can introduce a risk of researchers imposing their own views and interpretations upon the data (Lloyd et al, 2006); or over emphasising the significance of some of PwD's talk (Hendriks et al, 2014).

A reported problem with open-style questioning used in qualitative interviewing is that it can make communication difficult for PwD because they are given too much choice or have to think up answers by themselves (Powell, 2007). Moreover, discussion of abstract concepts in the context of participatory research to develop ALT has been found to be very challenging (Sävenstedt & Karlsson, 2010; Hendriks et al, 2014). Thus, whilst indirect questioning has the benefits of placing less stress on memory and being potentially more empowering because it lets participants steer and develop interviews; too little structure can also be daunting and uncomfortable for some participants (Hubbard et al, 2003). Interviewers will need to be conscious of all these issues and remain flexible to adapt their approach accordingly to meet the requirements of individual research encounters. It is advised that researchers need to develop a "reflexive practice" to understand and be aware of the potential differences in researcher and participant perspectives (Pratt, 2002 pg. 177).

Key points:

- Qualitative interviewing is conversational enabling researchers and PwD/MCI flexibility in their talk, although there are also some challenges posed by this approach.
- Research has found that PwD utilise certain strategies to maintain conversation and deal with difficult questions.
- It can be difficult for researchers to gain the information they need from qualitative interviews with PwD.

5.3.3.1 Adapting interviews for PwD/MCI

There are a number of ways reported in the literature in which researchers can adapt interviewing approaches to maximise research encounters with PwD/MCI and, develop good research relationships with participants. An important technique in conducting interviews with PwD/MCI is that researchers need to be extremely flexible with regards to time (Nygard, 2006). PwD/MCI may struggle to remember words or questions and formulate sentences, therefore, researchers need to be patient since placing further time-pressure on individuals can make matters worse and create a stressful experience (ibid). It is advised that interviews are conducted at a pace and duration dictated by participants to prevent them from becoming overly tired or stressed by their participation (Clarke & Keady, 2002). Thus, regular pauses to allow participants time to understand or remember words can be helpful (Nygard, 2006; Powell, 2007). Moreover, depending on their judgement of each research encounter, interviewers may interpret a need to take breaks with informal chat in long interviews where required, or conduct multiple short interviews upon different occasions to facilitate an individual's participation (Pratt, 2002; Nygard, 2006). Both verbal and non-verbal communication cues are important factors in these decisions, and indeed, this is part of the on-going consent process (Clarke & Keady, 2002; Hellstrom et al 2007). Multiple interviewing with PwD/MCI can be particularly helpful because the impact of their impairments can vary from day-to-day (Pratt, 2002). Some days individuals are far more able to participate than others, making their contribution more informative for the researcher (ibid). Furthermore, it may take time to develop rapport so that a participant feels able to trust and share information with a researchers (ibid).

It is important to be flexible and, for researchers to creatively adapt qualitative interviews to meet to particular needs of individual participants, because interview methods and content are influential to participants' responses (Lloyd et al, 2006). This can be done by drawing on a range of tools and techniques to facilitate individuals' engagement and ability to convey relevant information (Clarke & Keady, 2002). Adopting good basic communication skills taking into consideration general strategies for talking with PwD (listed above, Powell, 2007) is fundamental. Moreover, to maintain communication with PwD/MCI, it is important to be aware of how one reacts to speech. As such, it is recommended that interviewers demonstrate that they are actively listening to reassure participants and, encourage them to continue talking (Davis & Maclagan, 2014; Murphy et al, 2015). Indeed, useful indicators of listening for PwD that have been found to encourage talking include providing "recipient tokens such as *Mmmm* or *Mhmm*" which demonstrate that the listener is engaged with what an individual is saying (Davis & Maclagan, 2014 pg. 96, emphasis in original). And, "emotive or evaluative assessments" which suggest affiliation with what a person is saying (Davis & Maclagan, 2014 pg. 97).

In terms of modes of questioning, simple open-ended questions can be a useful way to gather the views of PwD without leading their response (IPWD Reference Group [no date]). However, as mentioned above, open questioning has both benefits and drawbacks that require careful consideration for each research encounter. When adopting an open-ended approach it is advised that questions posed are particularly clear and relevant (DEEP, 2013d). Interviewers may work from a semi-structured topic guide to ensure that specific areas of interest to the researchers are covered in interviews. It is prudent to think carefully about sort of questions that should be included on the interview schedule, such as the phrasing of questions and prompts or cues and, keeping questions clear and direct (Murphy et al, 2015). It has been found that questions involving abstract issues can be confusing to PwD/MCI, so focussing on more concrete everyday issues may be more productive (Nygard, 2006). Also, choice can be particularly daunting and confusing to PwD/MCI (Powell, 2007; Hendriks et al, 2013). Therefore, researchers need to be careful in this respect and it is advised that choice is simplified where possible (Hendriks et al, 2013).

Interview schedules can be piloted to check their usability (Murphy et al, 2015). However, in practice interviewers may need to make adaptations for individual participants. For

example, when posing questions verbally, it may be necessary to rephrase them in different ways or simplify sentences spoken in order to make them understandable to different people (Nygard, 2006; Lloyd et al, 2006). During interviews, participant memory problems may make it necessary for interviewers to offer reminders to keep participants on track or repeat questions posed as required (Nygard, 2006). Researchers also need to strike a fine balance when interrupting PwD's flow of speech, since whilst it may be required to gently bring participants back on track, intervention may also inhibit participants' responses (ibid). Certainly, it is advised that interviewers should yield to participants if they both start to talk simultaneously, as PwD/MCI can easily lose their train of thought (McKillop & Wilkinson, 2004). Furthermore, it may be useful to provide a means by which participants can contact the interviewer after the interview if they have information to share that they forgot to mention, such as a stamped addressed envelope (McKillop & Wilkinson, 2004).

One of the challenges of conducting research with PwD/MCI is whether they can be considered reliable informants (Meiland et al, 2012; Hendriks et al, 2014). PwD/MCI may contradict themselves in the accounts they provide, however, researchers should remember that they might have just changed their mind about an issue (McKillop & Wilkinson, 2004). Furthermore, in exploring contradictory information, researchers should refrain from adopting a challenging approach (ibid). Sensitivity is also required when discussing 'problems' with PwD/MCI who may find being reminded of the cognitive difficulties they face distressing (Hawkey et al, 2005). Indeed, people may not accept their diagnosis of dementia, or may still be coming to terms with it, making questioning them about being affected by dementia difficult and potentially sensitive (ibid). Importantly, people who have a diagnosis of MCI may be concerned about the potential for this to develop into a type of dementia. Hellstrom et al (2007) caution against using the word 'dementia' unless it is introduced by participants themselves. And certainly, researchers should not use negative terminology to describe and talk about dementia with participants as this can be both upsetting and offensive (DEEP, 2013c; Hare, 2015). These and other potential sensitivities means that researchers need to be prepared to deal with difficult questions that may be posed by interviewees themselves, but also prepared for participants becoming distressed (Pratt, 2002).

Being flexible and creatively adapting interviewing strategies appears to be central to conducting successful qualitative interviews with PwD/MCI (Nygard, 2006; Murphy et al, 2015). Several researchers describe that in their research with PwD, it has been useful to talk to individuals informally, during ethnographic observations or whilst they are doing everyday things, rather than formalised interviews because it can facilitate communication (Hubbard et al, 2003; Nygard, 2006). Indeed, many researchers advocate supplementing verbal interview data with observational information such as field notes documenting non-verbal behaviour and other contextual nuances to develop a more holistic understanding of participants' lived experiences (Hubbard et al, 2003; Nygard, 2006; Murphy et al, 2015). Researchers may find it beneficial to literally move about and follow participants whilst conducting interviews, since context can be useful in research involving PwD, where the research environment can help trigger memories and facilitate discussion relevant to the environment around them (Dewing, 2002; Nygard, 2006). Subsequently, it may be conducive for researchers to ask certain questions in specific locations: for example, questions about cooking routines may be best posed on location in a participant's kitchen. Certainly, during home testing of the COGKNOW system, Sävenstedt et al (2010) found it useful to pose open questions about the technology whilst PwD/MCI were using the equipment because it helped participants to focus and they were able to discuss issues as they arose.

The creative use of props have been documented in the literature as useful ways of facilitating qualitative data collection with PwD/MCI. Specifically, tools such as pictures or photographs, can help develop understanding and facilitate communication (Clarke & Keady, 2002; Lloyd et al, 2006). Indeed, pictures can be used to map out key topics of interviews or photographs used as a reference to significant individuals in participants' lives (Clarke & Keady, 2002). These can be placed in front of participants during interviews serving as a 'memory board' to aid communication (ibid). When choosing pictures to aid communication it is advisable to pick ones that are simple and clearly depict what is meant to be represented, avoiding 'artistic' or 'cartoon' images that may confuse or patronise participants (DEEP, 2013a). A specific method called "Talking Mats" has been developed as a means of facilitating interviewing people who have communication difficulties by using a visual framework with pictures to enable participants to respond to simple research

questions (Murphy et al, 2005). This method helps researchers access views about likes/dislikes and quality of life from PwD/MCI, including those with little or no verbal communication (Murphy et al, 2005; IPWD Reference Group [no date]). It is also a useful method for individuals who may have trouble concentrating or thinking, by helping them to focus or to think things through (Murphy et al, 2005). And, useful in assisting the verbal communication of individuals who have or confused and unstructured speech (ibid).

In a participatory design project, Hendriks et al (2013) adapted a pre-existing participatory method “MAP-it” (Schepers, 2013 in Hendriks et al, 2014 pg. 34) for investigating participants’ daily routines using icon stickers (simple pictures and words) and maps and devising a “Mr Fixit” character to problem solve and explore solutions (Hendriks et al, 2013; 2014 pg. 34)¹¹. This tool helped researchers clarify and remind participants which facilitated their response and communication (Hendriks et al, 2013). Although the abstract, fantasy nature of “Mr Fixit” did cause some confusion amongst participants (Hendriks et al, 2014). Depending on the requirements of the interview, researchers may find it fruitful to adopt some of the techniques that have been utilised in group sessions with PwD/MCI in other assisted living projects. These include construction of case studies or scenarios, or the presentation of objects to facilitate discussion with participants (see below).

Finally, the involvement of both formal and informal carers can also facilitate interviews with PwD/MCI in a number of ways: carers can be helpful in contributing to interviews by assisting communication of PwD/MCI (Pratt, 2002), or even providing proxy answers where individuals have severe communication difficulties (Sixsmith et al, 2006). Furthermore, carers may also introduce ideas or questions that have not previously been considered by the researcher (Pratt, 2002). However, whilst the involvement of carers in interviews is in many ways beneficial, there are also problems reported with caregivers dominating discussions (Lindsey et al, 2012; Hendriks et al 2013), and their presence not allowing PwD/MCI the privacy to talk freely (Alzheimer’s Disease International (ADI)). Thus, it is important to recognise the different perspectives and experiences of PwD/MCI and their caregivers, and to balance these when interpreting data (Lindsey et al 2012; Hendriks et al 2013). Researchers will have to decide what to do in the case of discrepancies between

¹¹ Indeed, other researchers have also utilised fictional characters to explore routines and scenarios with participants in group sessions (see Mayer & Zach, 2013 below).

accounts (Nygard, 2006). Furthermore, using caregiver accounts as validation for those of PwD/MCI would not be consistent with a person centred approach. Rather, these accounts should be viewed as coming from different perspectives (ibid). Indeed it may be decided that interviews with carers and PwD/MCI should be conducted separately (Meiland et al, 2012); or at least to make sure that some interviews with PwD/MCI are conducted without caregivers being present (Pratt, 2002).

Ultimately, it is down to the judgement of individual researchers to decipher the best mode of questioning and techniques used for participants on a case-by-case basis (Hubbard et al, 2003; Murphy et al, 2015). However, some general guidelines for interview questioning can be summarised from the reported experiences of other researchers working with PwD/MCI (see below). These should be combined with an awareness of advice regarding skills for verbally communicating with PwD/MCI (see Powell, 2007 above). In addition to developing good research relationships and good communication skills, attention to practical issues in conducting interviews is another important issue that will be explored next.

Summary of do's and don'ts for qualitative interview questioning:

Do:

- Be flexible and adaptive to the abilities of each participant
- Be patient and have a flexible time scale – be willing to take breaks or conduct multiple interviews
- Use of pauses after each sentence – give participants time to understand and think
- Use of repetition – reminding about questions or last words spoken, helping to keep on track
- Use of props – photographs, surroundings, objects
- Rephrasing questions and information in different ways to help participants understand
- Use of indirect questioning (e.g. third person examples)
- Use questions exploring concrete everyday life
- Be prepared to deal with difficult questions or distress
- Consider documenting non-verbal communication and other contextual observations in field notes to supplement verbal information

Don't:

- Present abstract questions
- Give too much choice
- Use specific questioning that can put stress on long-term or short-term memory
- Use negative terms in talking about dementia and be careful about using the word 'dementia'

5.3.4 Practical considerations

Practical and logistical considerations are an important part of conducting successful interviews with PwD/MCI (McKillop & Wilkinson, 2004). Indeed, some of the benefits of conducting individual interviews with PwD/MCI are that they enable researchers to be flexible to fit in with participants' individual availability (Hendriks et al, 2013). Allowing PwD/MCI to choose the time of day for interviews is also helpful because individuals can set a time when they are at their best (McKillop & Wilkinson, 2004). When organising interviews, if the researcher is present at the time, it can be helpful if they encourage PwD/MCI to enter the appointment in their diary or calendar and provide timely written reminders (McKillop & Wilkinson, 2004). Researchers may be less successful making appointments over the telephone because PwD/MCI may forget to write the details down (McKillop & Wilkinson, 2004). However, it is helpful to confirm appointments with participants by telephone close to their scheduled dates, although this does not guarantee

that individuals will remember them (Nygard, 2006). Indeed, in scheduling interviews it may be useful to do this with the help of carers as well as PwD/MCI (McKillop & Wilkinson, 2004).

The location of interviews is another very important practical consideration (McKillop & Wilkinson, 2004). It is advised that PwD/MCI should be allowed to set the time and place of interviews (Clarke & Keady, 2002). However, conducting interviews in people's homes is reportedly preferable for a number of reasons: First, the home of research participants can be an ideal location from which to conduct one-to-one interviews because it is likely to be a comfortable and non-threatening environment for them (McKillop & Wilkinson, 2004; Hendriks et al, 2013). Second, conducting interviews in a person's own home, also makes participation in the research easier and potentially less stressful for them, since they do not have the hassle and anxiety of travelling to another location (Hawkey et al, 2005; Hendriks et al, 2013). Indeed, this can also be beneficial for researchers since participants may be at home even if they have forgotten their appointment¹². Third, as previously mentioned, the home environment of participants enables PwD/MCI to draw upon familiar objects in their surroundings, in response to questions about their lives and daily routines, which can be particularly helpful in ALT participatory design projects (Hawkey et al, 2005; Hendriks et al, 2013). Nevertheless, the home of a participant may not be suitable or preferable in all instances. Thus, if interviews are to be conducted at a location outside of a person's home researchers need to ensure that it is 'dementia-friendly' and accessible¹³ (DEEP, 2013e).

The interview environment is important and it is advisable to shape this where possible. Ideally interviews should be conducted in a quiet place where there is no background noise or distractions, since this can distract participants and can be make it harder for PwD/MCI to concentrate (McKillop & Wilkinson, 2004). Indeed, researchers are likely to want to audio or video record interviews (with participant's permission), therefore a quiet research environment is also highly beneficial to producing good quality recordings that will be easier to transcribe. Additionally, the interview space needs to be comfortable, thus, thinking about things like room temperature, seating, lighting and privacy are important in this

¹² Of course in adopting an on-going, process approach to consent, researchers must not assume that an interview can go ahead just because it has been pre-arranged.

¹³ See below for further details about choosing a 'dementia-friendly' space.

regard (McKillop & Wilkinson, 2004). Finally, the duration of interviews is another important consideration that needs to be flexible to accommodate for participants' abilities (Nygard, 2006). Researchers will need to provide an estimate to participants as to how long interviews may take, however, these vary widely in the literature. For example, Sixsmith et al (2006) report interviews with PwD lasting from 15 minutes to 1.5 hours, whereas, Murphy et al (2015) report them taking between 15-30 minutes. This variation shows that in practice, researchers will need to adapt to individual participants and make judgements according to individual needs rather than any preconceived research ideals. Importantly, researchers need to be conscious of not just verbal, but non-verbal, behavioural cues such as tiredness, agitation and distress, indicating that an interview should perhaps be drawn to an end (Nygard, 2006).

Key points:

- Interviews enable researchers to fit in around individual participants' schedules.
- Location of interviews is important: it needs to be somewhere safe, comfortable and 'dementia-friendly'.
- Researchers need to be aware of participant fatigue and distress and bring interviews to an end if necessary.

5.4 Group work

The ALT project proposes to conduct group work with stakeholders through conducting a series of dialogue conferences. Dialogue conferences are an approach initially developed in Norway for workplace development (Gustavsen et al, 2008; Forsberg, 2014), and subsequently, these conferences are frequently used in action research development projects, from initiation stages to evaluation (Ekman Philips & Huzzard, 2007). Dialogue conferences are devised to provide a forum for democratic dialogue (Gustavsen et al, 2008). Central to this are democratic principles such as "freedom of speech" and "the right to be heard before authorities who are making decisions pertaining to the individual" (Gustavsen et al, 2008 pg.70). The aims of these conferences are to include a broad range of stakeholders and enable all their voices to be heard (Ekman Philips & Huzzard, 2007;

Ronnerman et al, 2016). Thus, providing a platform for marginalised voices is one of the aims of the process (Forsberg, 2014).

The broad inclusion of participants means that different experiences and perspectives can be brought together to explore an issue in different ways (Ronnerman et al, 2016).

Whereby, experiences are considered as important as expert knowledge (Ekman Philips & Huzzard, 2007). Hierarchies between participants are temporarily put aside to promote discussion and ideas creation and develop agreed outcomes (Gustavsen et al, 2008; Forsberg, 2014; Ahmad et al, 2015). And, a number of strategies may be adopted to promote equality amongst participants. Importantly researchers need to establish ground rules amongst participants, outlining the democratic goals of the meeting and remind participants of this where necessary (Ekman Philips & Huzzard, 2007; Ahmad et al, 2015). Furthermore, dialogue needs to be facilitated and encouraged amongst all.

The role of researchers in constructing dialogue conferences is to “establish the arenas for such dialogue and provide discursive tools to facilitate it” (Ekman Philips & Huzzard, 2007 pg. 9). Indeed successful communication is of central importance in democratic dialogues (Ekman Philips & Huzzard, 2007). Thus, when involving PwD/MCI as stakeholders, the potential challenges that they may face as participants in this sort of research is a vital planning consideration. In reviewing the ALT literature, whilst some adopt participatory approaches, there appear to be no examples cited of research and development involving PwD/MCI that utilise dialogue conferences. However, group approaches to data collection have been adopted amongst studies taking a participatory approach to developing ALTs for PwD/MCI, where focus groups (Mayer et al, 2012; Lindsey et al, 2013) and workshops (Meiland et al, 2010; 2012) are reported. Therefore, these discussions of ALT research combined with information developed by dementia groups promoting the involvement of PwD/MCI for research and care planning, will be drawn upon to explore the particular methodological considerations for doing group work with PwD/MCI and, reflect specifically upon the requirements of conducting dialogue conferences.

Key points:

- Dialogue conferences are based on democratic principles and aim to promote discussion, sharing of ideas and the development of agreed outcomes.
- No other ALT participatory design projects specify the use of dialogue conferences.
- Careful planning of dialogue conferences is essential to maximise successful communication during events.

5.4.1 Benefits and challenges of group work involving PwD/MCI

PwD/MCI can work together in groups (DEEP, 2013d; Bamford & Bruce, 2002), and researchers have reported successfully using group sessions such as focus groups or workshops as a means to involve PwD/MCI in participatory design and ALT development projects (Meiland et al, 2010; Lindsey et al, 2012; Mayer et al, 2013; Branco et al, 2015).

Focus groups have been found to be a useful tool to explore people's views and experiences on particular issues and, unlike individual interviews, the adoption of a deliberative approach (facilitated by researchers) enables participants to interact with each other (Bamford & Bruce, 2002). These interactions can be positive, where fellow group members have been observed to help one another, such as explaining questions to individuals who struggle to hear or understand (ibid). Importantly the sharing of similar experiences in these group interactions may help participants to recall pertinent information or feel empowered and encouraged to contribute, but also empowered to contribute to a lesser extent if they want to (ibid). Furthermore, group interactions enable participants to ask each other questions, rather than being completely led by researchers, which can be particularly valuable because this can introduce issues that have not been previously envisaged by the research team (Lindsey et al, 2012).

Group work with PwD/MCI does pose a number of challenges that are important to consider when planning these types of research sessions (Bamford & Bruce, 2002; Mayer et al, 2013; Hendriks et al, 2013). Communication can be particularly challenging in group sessions with PwD/MCI because the 'focus' of discussion can be lost for a number of reasons (Bamford & Bruce, 2002; Hendriks et al, 2013). Examples provided in the literature include that individuals may get easily distracted and go 'off track', which can be disruptive to the rest of

the group (Hendriks et al, 2013). Furthermore, groups can become fragmented where multiple conversations may occur (Bamford & Bruce, 2002).

Group dynamics are also an important challenge which are affected by communication problems but also, dominant contributors have been reported as particularly problematic in focus groups with PwD (Bamford & Bruce, 2002). PwD/MCI have also been observed as occasionally appearing to be rude to other group members (ibid), and impatient regarding others cognitive impairments (Hendriks et al, 2013). This can undermine confidence in affected group members and can lead to problems with group cohesion, which are arguably detrimental to the research and potentially harmful to individuals' concerned (Bamford & Bruce, 2002; Hendriks et al, 2013). However, where group work has been conducted in the development of ALT, this problem has not been widely highlighted.

It has been reported that PwD/MCI may talk in terms of "idealised accounts", and seem less willing to discuss the difficulties and needs arising from their cognitive impairments in focus group sessions (Bamford & Bruce, 2002 pg. 157). This can be tricky for researchers to negotiate and, challenging accounts provided by participants could have potentially detrimental ramifications (Bamford & Bruce, 2002; IPWD Reference Group [no date]). This is because it involves broaching aspects of participants' lives that may be particularly sensitive, difficult or embarrassing for them to reflect on and talk about (ibid). These issues emphasise how important it is that group facilitators are aware of group dynamics and potentially sensitive issues, as well as keeping discussions focussed and on track (Bamford & Bruce, 2002).

Another challenge of conducting group work involving multiple stakeholders is how to deal with differences in needs and priorities expressed, including differences in opinion that may occur between potential users (PwD/MCI or caregivers) and the designers (Lindsey et al, 2012). Here, it is important to ensure that the voices of PwD/MCI and their caregivers are not side-lined or misinterpreted by the research and design team (ibid). Certainly, the action research approach of dialogue conferences have the potential to overcome these barriers because they involve a democratic process where all the stakeholders work together to construct outcomes (Gustavsen et al, 2008; Forsberg, 2014; Ahmad et al, 2015). However, the cognitive impairments of PwD/MCI puts them at a disadvantage to the other stakeholders in this process, because it is more difficult for them to understand and

communicate effectively and, they may feel less confident. It will be interesting for the AL Project to explore the implications that these difficulties have on the democratic aims of the dialogue conference methods utilised.

Finally an important consideration for conducting group sessions involving PwD/MCI and their caregivers are practical considerations, in terms of finding an appropriate location and organising times and dates for sessions that are suitable for everyone involved. These issues can be exacerbated by the health status of individuals, since researchers will need to accommodate for a diversity of needs, but also, PwD/MCI may have good and bad days. The involvement of many different people in multiple singular events can be quite challenging, an issue that is particularly relevant when research relies upon the on-going involvement of individuals across the different stages of the project (Galliers et al, 2012 in Hendriks et al, 2013). Indeed, controlling the number of focus group participants has been reported as difficult when doing research with PwD (Lindsey et al, 2012). These difficulties associated with group sessions can lead researchers to conclude that individual research meetings may be more effective (Hendriks et al, 2013).

Key points:

- Group discussions amongst PwD/MCI can be a successful research method but there are several challenges that require consideration.
- It can be hard to maintain the research focus in discussion and manage group dynamics.
- PwD/MCI will be at a communicative disadvantage in multiple stakeholder groups.
- Organising times/dates of group research sessions can be complicated and participant numbers can be difficult to manage.

5.4.2 Establishing groups

Researchers utilising group methods can either tap into established groups or create research groups by inviting individuals to group sessions specifically designed for research purposes. There are of course benefits and challenges to adopting either option. A variety of established dementia groups, such as support or social groups may already exist in the community that researchers can approach, some of whom may be experienced in providing their views for research, policy or care purposes (DEEP, 2013d). Utilising established groups

can be a useful method of recruiting PwD/MCI to research projects since groups are ready made, providing practical benefits for researchers in terms of recruitment and organisation of sessions. Furthermore, group members will already be familiar with each other and the location (DEEP, 2013d). Thus, it is likely that established groups can offer a trusted environment where individuals can support each other to remember things, articulate thoughts and communicate (Lindsay et al, 2012). This means that they may feel able to safely discuss sensitive topics (Bamford & Bruce, 2002; Lindsay et al, 2012; DEEP, 2013d). Moreover, there may also be support workers present to facilitate the meetings (DEEP, 2013d). However, a disadvantage of established groups is that there are established hierarchies and social relationships within a group, which can be detrimental to free and open participation of all individuals (Bamford & Bruce, 2002). Also, it may be difficult for researchers to fit in around the normal business of the group and have the research tasks prioritised (DEEP, 2013d).

The alternative is that researchers create and organise groups for the specific purpose of the research. There are several benefits of this approach. First, group sessions can be designed to focus on the research topic and provides a clear reason for the meeting to group members (DEEP, 2013d). Second, research organised sessions can bring PwD/MCI from different locales together to discuss issues (DEEP, 2013d). And finally, hosting a specific event can be a special and enjoyable occasion for PwD/MCI, where they can socialise and have a change to their daily norm (DEEP, 2013d). Nevertheless, researcher organised sessions have several potential disadvantages. First, in not using established group meetings, researchers will need to carefully plan and organise the practicalities of the meeting, including careful consideration of the location so that it is 'dementia-friendly' (DEEP, 2013e). Second, the unfamiliarity in terms of both the location and other group members, may be a source of anxiety for some individuals (IPWD Reference Group [no date]; DEEP, 2013d). And, furthermore, some individuals may be confused as to the purpose of group sessions because of the unfamiliarity (DEEP, 2013d). Finally, if people have to travel to attend, this could be tiring for them (DEEP, 2013d).

Since the Assisted Living Project proposes to utilise dialogue conferences, where multiple stakeholders will participate, it is likely that the research will need to organise specific meetings for these ends. This may be possible by inviting members of an established group

or separate individuals with MCI/D to attend. Either way, careful consideration will need to be paid to planning so that the location of sessions is accessible and held in a 'dementia-friendly' environment. But also, that the format of these conferences are accessible, so that the agenda for the event, discussions and tasks are mindful of the potential needs of PwD/MCI and, devised in such a way that is inclusive as possible. The advice regarding these issues that is provided in the literature reviewed will be presented below.

Key points:

- Researchers can either tap into established groups or create special research groups.
- There are advantages and disadvantages to either option that require contemplation.

5.4.3 Planning and invitations

It is important that PwD/MCI find participating in the dialogue conferences an enjoyable experience, therefore, minimising causes for stress are an important consideration in the planning of these events. Guidelines developed by dementia groups to promote the involvement of PwD/MCI in research or care planning, advocate the involvement of PwD in the set-up and planning of group sessions to help develop materials and make sure that venues are 'dementia-friendly' (DEEP, 2013e; Alzheimer's Disease International (ADI) [no date]). Thus, the Assisted Living Project may wish to invite representatives of key stakeholders (PwD/MCI and informal and formal caregivers) to join the organising committee of the dialogue conferences.

It is advisable that the dialogue conferences are planned well in advance. This means that plenty of notice can be given to PwD/MCI so that they have time to organise their transport and support from a caregiver if needed (DEEP, 2013f; IPWD Reference Group [no date]). Furthermore, good notice will enable other stakeholders such as relatives of PwD/MCI greater opportunity to organise their schedules to attend. It is important to be aware that some PwD/MCI may be more isolated than others, and therefore may require a greater level of support to attend, as well as during the event (IPWD Reference Group [no date]). Thus, the research will need to have some provision to support these individuals so that they are not unnecessarily excluded from participating. Indeed, some studies report using

trained dementia experts, such as specially trained nurses and formal carers or relatives to facilitate and encourage participation (Hanson et al, 2007; Robinson et al, 2009; Branco et al, 2015). This promotes an inclusive, person centred approach to the research (Hanson et al, 2007; Robinson et al, 2009).

As with interviewing, it may be helpful for researchers and designers involved in running the dialogue conferences to meet participants in advance to introduce themselves and the project (IPWD Reference Group [no date]). This entails a number of benefits: It provides PwD/MCI with a point of reference and contact if they want to ask questions or clarify information in advance of the research sessions. Indeed, for research involving multiple meetings (as in many participatory design approaches where individuals are often involved in a three stage design process), Lindsay et al (2012 pg. 523) advise that the research offers a “consistent point of contact” with whom participants can communicate and deal with across research sessions. Furthermore, it is helpful for PwD to be able to liaise with the same person because this can help to reassure participants, fostering familiarity and trust and, hopefully making them feel more comfortable regarding their involvement (IPWD Reference Group [no date]; DEEP, 2013f). Finally, prior communication gives the research team an opportunity to ask potential participants about any particular support needs they have so that these can be accounted for in the planning of research sessions (ADI [no date]).

It is important to remember that attending group sessions (such as dialogue conferences), may not be desirable for everyone (IPWD Reference Group [no date]; ADI [no date]). Some people may prefer to participate on an individual basis, so flexibility to allow people to choose their own means of participation could be helpful and takes a person centred approach. Indeed allowing individual choice in engagement is advocated in some dementia group advisory documents (IPWD Reference Group [no date]; ADI [no date]). For those individuals who do wish to participate, it is advisable that regular reminders are sent in good time of the event (DEEP, 2013f; IPWD Reference Group [no date]). It may also be useful to send information about the events prior to the date to enable people to bring notes with them (IPWD Reference Group [no date]). If participants are to receive reimbursement for transport and expenses, procedures need to be simple and clearly spelt out to participants (IPWD Reference Group [no date]). All the written documentation and verbal communication with PwD/MCI should follow the recommendations (outlined previously) to

maximise accessibility and cultivate good communication between participants and the Assisted Living Project team. Finally, due to the varied way in which individuals may be affected by their dementia or MCI on a day-to-day or even moment-by-moment basis, the research cannot assume consistent attendance of PwD/MCI. Therefore, it is prudent to have a contingency plan in place to be able to flexibly deal with these eventualities (DEEP, 2013f).

Key points:

- Dialogue conferences need to be an enjoyable and positive experience for PwD/MCI and their caregivers.
- It may be helpful to involve PwD/MCI and caregivers in organising dialogue conferences.
- Providing a consistent point of contact to participants can be reassuring for participants.
- Advance notice and regular reminders to participants about the events are essential.

5.4.4 Location and environmental considerations for Dialogue Conferences

Careful consideration needs to be given to situation, access and nearby facilities when choosing a suitable location to conduct the dialogue conferences with PwD/MCI and their caregivers or relatives. It is important that buildings utilised for conducting research sessions with PwD/MCI are 'dementia-friendly' (DEEP, 2013e). This means that a meeting space should be:

- Easy to find
- Easy to get into
- Not confusing
- Friendly and welcoming

(DEEP, 2013e pg.1)

Finding and creating a 'dementia-friendly' space in which to hold the dialogue conferences will require some advance planning and an understanding of the needs of PwD/MCI (DEEP, 2013e). Therefore, it may be helpful to involve someone with dementia and/or caregivers or dementia experts in this process (ibid). Indeed, asking a person with dementia to help

conduct a 'dementia-friendly audit' of a building is advisable, to assess the suitability of the building and identify any potential problems that can be improved upon (DEEP, 2013e pg.2). Certainly, collecting information from participants about access requirements before each conference will help the Assisted Living Project meet participant needs.

Previous studies involving PwD in the design of ALT, report that it might be preferable to hold meetings, focus groups or design workshops within the same community as participants are based (Hanson et al, 2007; Robinson et al, 2009). This means that people do not have to travel far and surroundings are more likely to be familiar (ibid), making buildings 'easy to find' (DEEP, 2013e). It is thought that unfamiliar surroundings or having to venture somewhere new may make some individuals anxious (Hendriks et al, 2013). Where research is conducted outside of the homes of participants, it is advised that locations should be well known and centrally based so that there are good access and public transport connections and local amenities (Hanson et al, 2007; IPWD Reference group [no date]). It is also helpful for participants if researchers can provide information or advice regarding transport options in advance of research sessions (DEEP, 2013e). Furthermore, the social status of a building may also be an important consideration (Hanson et al, 2007). For example, a community setting rather than hospital environment may be more reassuring to participants because it distinguishes the research from care interactions (IPWD Reference Group [no date]). However, if group sessions are to occur in the same building that participants live in, it is recommended that 'ritual' (e.g. fragrance the room with a particular essential oil) can distinguish research group sessions from other non-research activities (Bamford & Bruce, 2002).

In addition to location, the layout and design of the interior of buildings needs attention. Buildings that are inviting and accessible to disabled people, with adequate facilities, such as no step access, ramps, elevators and disabled toilets will be best, since participants with MCI/D may have physical as well as cognitive and perceptual impairments (Hendriks et al, 2013). The entrance to the building needs to be obvious and simple to negotiate (DEEP, 2013e). For example, revolving doors or buzzer entry can be confusing to PwD/MCI (ibid). Subsequently, it may be particularly helpful if there is a reception area and someone to welcome and direct people when they arrive (ibid). Reflective surfaces, poor lighting or certain design features can also be confusing to PwD/MCI with perceptual difficulties and

may be best avoided (DEEP, 2013e). Furthermore, if the building is busy with people or other events, this can also be disorientating to PwD/MCI (ibid). It may be possible to overcome some difficulties by having friendly and helpful people on hand to assist participants (ibid). Certainly, the use of plenty of clear signs especially those indicating meeting rooms, exits and toilets can also be invaluable (DEEP, 2013e). Providing clear information to participants in advance of the dialogue conferences, detailing where to go and how to access the building will be particularly useful and may help alleviate any anxieties.

It is advised that signs are:

- Clear and bold text with good contrast between text and background
- Positioned at eye level and well lit
- Positioned on doors they refer to rather than next to them
- Use of arrows positioned at key decision points in the building
- Include directions to and from the carpark where necessary

Paraphrased from: DEEP, Guide to Choosing a Meeting Space (2013e)

Finally researchers will need to be mindful of the ‘dementia-friendliness’ of the room(s) utilised for the dialogue conferences. The structure of the dialogue conferences will obviously dictate the size and number of rooms required as well as the style of room layout. Rooms need to be big enough and furniture laid out so that people are able to freely move about (DEEP, 2013e), potentially this includes allowing sufficient space for wheelchairs. The purpose of the dialogue conferences are to promote democratic communication and discussion to develop ideas and outcomes (Ahmad et al, 2015). The physical layout of the meeting space is an important aspect in achieving these aims (DEEP, 2013e). If these conferences involve more than twelve people, a round table discussion, ‘boardroom’ style, will probably not be practical (DEEP, 2013e). Being sat around one large table can be useful to encourage group discussion (ibid). However, it may also make it difficult for participants to hear one another (ibid), although participants may help one another (Bamford & Bruce, 2002).

Larger groups of participants will obviously require larger room space. Depending on the needs of the dialogue conference, individuals could be seated ‘theatre style’, where

everyone faces the same way; therefore, a handy set-up for presentations, but not so beneficial for group discussion (DEEP, 2013e). Alternatively, large groups of individuals could be seated 'cabaret style', creating lots of tables of small groups of around five to six people within one large room (ibid). The advantage of this is that it promotes discussion amongst participants, enabling more people the opportunity to voice their views (ibid). However, multiple conversations in one room can become very noisy (ibid), which could be confusing and distracting for some participants, particularly those affected by language cognition problems (Hendriks et al, 2013). Thus, ideally it may be helpful to have a large main meeting room for the purposes of presentations or overall group feedback and discussions; combined with 'break-out' rooms for small group-work (DEEP, 2013e). The use of 'break-out' rooms minimises distraction from background noise and may also provide more privacy for participants to discuss issues. This may be particularly useful if the AL project decide to conduct some separate sessions for with PwD/MCI and their caregivers or relatives. DEEP (2013e) also suggest that an area near to the main meeting room(s) can be useful if people want a quiet space to escape to during the event. Moreover, if conferences extend over lunch, a separate area where people can informally sit and eat can be a pleasant break from the main business of the conference (DEEP, 2013e). It is important that adequate signage is present to direct participants to-and-from the different rooms and facilities used for the dialogue conference within the building.

Finally, an important consideration for researchers is how group sessions will be recorded. Audio or video recordings of meetings are a possibility, but are contingent upon permissions of group attendees and the suitability and any constraints of the physical environment. Another means of capturing the results of group sessions which has been utilised in focus group research for another project developing AL technologies is employing individuals to act as rapporteurs, keeping records of group sessions through taking notes (Sixsmith et al, 2006). Furthermore, writing up an overall analyses of sessions is also advised (ibid).

Key points:

- The location and physical environment of dialogue conferences is a significant concern that will impact upon the success of the dialogue conferences.
- Care needs to be taken to maximise the dementia-friendliness of events to ensure that they accessible, functional and comfortable.

5.4.5 Structuring group sessions

The Assisted Living Project dialogue conferences may draw upon pre-defined procedures to structure them (for example, Engelstad's (1995) three stage process, adopted in a project by Ahmad et al, 2015)¹⁴. Nevertheless, attention to the reported experiences of other types of group work involving PwD/MCI, and advice from dementia groups, are a valuable and relevant source of information to draw upon and incorporate into any pre-defined dialogue conference formats.

It is helpful at the beginning of group sessions, for researchers to clearly explain to participants, in a manner that is easily understood, what will happen during the session and what their role is in the research (Hendriks et al, 2013). Indeed, the IPWD Reference Group advise providing participants with an agenda for the event so that they are aware of its structure. Agendas need to be devised that are realistic and achievable. It is important that research sessions allow sufficient time for PwD/MCI to be able to think things through and express themselves and, allow time for tasks or information to be clearly understood (Hanson et al, 2007). Concentration can be difficult for PwD/MCI and, both caregivers and PwD/MCI may find long meetings tiring; therefore, plenty of time should be included for refreshments and breaks (IPWD Reference Group [no date]). It may be realistic to set twenty minutes for each task so that maximum concentration is maintained (IPWD Reference Group [no date]), although some research has reported sessions lasting up to an hour (Inns et al, 2009).

¹⁴ These three stages as reported by Ahmad et al (2015 pg. 6-7) are:

“(1) conference organisers provide briefings with respect to theme, group composition and work/discourse procedures; (2) participants spend a majority of the time within small discussion groups; and (3) each group selects a reporter to make presentations to the plenary session.”

It is advised that group sessions may benefit from incorporating some time for participants to engage with each other and socialise, making their participation a more rewarding and positive experience (Hanson et al, 2007). Group sessions need to create a friendly environment (Branco et al, 2015). It is advisable to include time for 'meet-and-greet' where it may be helpful to provide people with name badges so that everyone in the group are more approachable, facilitating conversation between participants (IPWD Reference Group [no date]; Wu, 2004 in Hendriks et al, 2013). Devising an icebreaker task to start off the session so that people can relax and get to know one another is also recommended (IPWD Reference Group [no date]). For example, Bamford & Bruce found it useful to begin focus groups with PwD with "sweets and singing" (Bamford & Bruce, 2002 pg.153). Informally beginning of group sessions, has been reported as particularly beneficial for individuals affected by speech difficulties (Hendriks et al, 2013). Other opportunities for people to socialise informally during sessions is if lunch is provided, indeed, this is described as being popular with PwD/MCI involved in events and it also provides a welcome break from the main tasks of the sessions (DEEP, 2013e).

Once group members have been informally introduced, it is important to remind participants about the purposes of the group session and the research (Bamford & Bruce, 2002). Indeed the IPWD Reference Group have devised a set of ground rules for group sessions involving PwD based on fostering mutual respect and a safe and supportive environment (detailed below).

Establishing ground rules for group sessions:

(Quotation from: IPWD Reference Group [no date] section 4, pt.11)

Listen and respect We all have a different knowledge base and life experiences as a starting point. Be aware that some of the areas covered may be sensitive for some participants.

Listening skills These have to take priority in any exercise which includes patience and understanding. Maintain eye contact and listen to every answer no matter how 'off the wall' it may seem at first. This can turn out to be very relevant. Give time.

Support Create a supportive environment that will allow each participant to feel comfortable asking questions; provide opportunities for participants wishing to discuss any issues in private.

Equality Each participant has an equal opportunity to be involved at their own pace and to feel their views and opinions are respected and valued.

Time out Each participant should feel free to take 'time out' if they feel uncomfortable at any time. Do this by being explaining this at the beginning of the session.

Confidentiality All participants must respect the confidentiality of any personal information shared.

Be open minded Always treat people with dementia equally and on a par with carers.

Differences Recognise that people see things differently.

Topics of interest Plan the sessions for discussion and include breaks every 20 minutes or so.

Finally in terms of drawing group sessions to a close, similar to qualitative interviewing, it is advised that they finish on a positive with time for feedback and informal talk, ensuring that people leave feeling happy and have a sense of achievement from participating (Hanson et al, 2007; Branco, 2015).

Key points:

- It is helpful to start and finish group sessions informally to allow participants to relax and socialise.
- It is important to be clear about the purpose of sessions and establish ground rules at the beginning of sessions.

5.4.6 Managing groups

A difficulty reported in conducting group research with PwD/MCI is keeping them focussed and 'on track' during sessions (Lindsay et al, 2012; Hendriks et al, 2013), which can be

disruptive to the rest of the group and the aims of meeting (Hendriks et al, 2013). Also, it is reported that in focus group research involving individuals at different stages of dementia, tasks may be received differently by members of the group, some finding things more difficult than others (Mayer & Zach 2013). Indeed, Ryan et al (2014) highlight that variation in abilities between PwD/MCI is so extensive that researchers will need to be aware of this and adopt a flexible approach. Nevertheless, individuals with different cognitive abilities within a group can help each other to remember things and contribute (Ryan et al, 2014).

Group facilitators can support participants and, it is advised that there should be at least two facilitators per group to maintain group focus and provide assistance where necessary (Bamford & Bruce, 2002; Ryan et al, 2014). The IPWD Reference Group recommend ten facilitators to thirty PwD/MCI. Facilitators should have experience of dealing with PwD, or they can be caregivers accompanying participants with MCI/D (IPWD Reference Group [no date]). What is important is that they have the skill and understanding required to effectively deal with the potential challenges posed in research sessions (ibid). Certainly, where family members are present in sessions, they can be helpful in trying to keep PwD/MCI 'on track', however, it is also noted that assisting a relative with MCI/D in research sessions can be frustrating for informal caregivers (Hendriks et al, 2013).

The strategic positioning of facilitators within the group is an important consideration because they can help to limit distractions (Ryan et al, 2014). Facilitators may also need to support and encourage participants, since some PwD/MCI may feel nervous or embarrassed about speaking openly in a group because of their cognitive difficulties (Ryan et al, 2014). However, other participants may talk too freely, requiring facilitators to tactfully direct participants to wait their turn (Ryan et al, 2014). It is also important that facilitators and family members do not unduly influence participants in their answers (IPWD Reference Group [no date]).

Another issue encountered is that it can be challenging for PwD/MCI and their relatives to be confronted with, and have to discuss their impairments, diagnoses and problems that they might be facing (Mayer & Zach 2013; Hendriks et al, 2015). Thus, researchers need to have supportive techniques to help deal with situations where participants may become distressed or agitated, and to mitigate participants' feelings of anxiety (Hubbard et al, 2003). Indeed a number of strategies have been reported by researchers as useful tools to help

avoid these problems. One such strategy is to use a fictional character so that PwD/MCI can discuss problems they face indirectly, through the character, rather than referring to themselves (Mayer & Zach, 2013). Skilled facilitators can help comfort and support participants if they do become distressed or agitated. Indeed, Bamford & Bruce (2002) mention that if focus groups are conducted without caregivers being present, it is useful to have some background information about participants to enable facilitators to respond to questions and concerns posed by participants. Finally, Hendriks et al (2013) report that they made participants aware that they can pause or stop sessions at any time if they need to.

Another factor in managing group dynamics is group size. It is advised that smaller groups than might normally be utilised for group work are better for working with PwD (Robinson et al, 2009; Hanson et al, 2007). This is because smaller groups enable more opportunity for people to express their views and, if the research involves the same participants longitudinally, small groups also allow participants to become familiar with each other, facilitating group dynamics (Hanson et al, 2007). Larger groups are more difficult to manage because they provide a greater prospect of disruptions, and can make discussions less accessible to individuals who have hearing or visual impairments because of the greater dispersal of participants from one another (Ryan et al, 2014).

Key points:

- Variation between participants with MCI/D means that researchers will need to maintain an awareness of individual group members and adopt a flexible approach.
- Skilful facilitation of groups can help overcome many challenges, such as communication difficulties, keeping the group focussed and managing participants.
- Small group work is advisable when involving PwD/MCI.

5.4.7 Group research strategies

As described above, the democratic aims of dialogue conferences means that ideally hierarchies between participants will be broken down so that all attendees are considered to be equally important to the development process (Ekman Philips & Huzzard, 2007; Gustavsen et al, 2008). Since, dialogue conferences may involve multiple stakeholders, including researchers and designers, it will be important for communication to remain at a

level that is understood by all, even at points when experts are talking to each other (Ekman Philips & Huzzard, 2007). Lindsay et al advise that in research developing ALTs with PwD/MCI, a “*common frame of reference*” (Lindsay et al, 2012 pg. 523) needs to be developed to facilitate communication between designers and PwD/MCI. However, this common frame of reference needs to derive from the language of PwD/MCI rather than utilising design jargon and terminology (Lindsay et al, 2012). The use of jargon should definitely be avoided to maximise the potential for involvement from all participants, otherwise the research risks alienating and annoying PwD/MCI and their relatives or caregivers (Aveyard et al, 2015).

Despite the democratic approach of the dialogue conferences, best practice guidelines drawn up by Alzheimer’s Disease International (ADI) highlight that PwD and their caregivers may find it difficult to talk freely and openly in front of each other (ADI, [No Date]). Indeed, this is an issue that has been observed in other research involving these participant groups (Bamford & Bruce, 2002; Meiland et al, 2012). Moreover, several studies (including participatory research) involving both PwD/MCI and their caregivers participating in group discussions, report that carers can interfere by leading the talk of PwD/MCI (Hendriks et al, 2013), or dominate discussions (Inns et al, 2009; Lindsey et al, 2012; Hendriks et al, 2013), limiting the opportunities for PwD/MCI to contribute (Inns et al, 2009). Thus it may be preferable that at least some sessions or tasks during conferences involve PwD/MCI and caregivers separately to overcome this (ADI, [No Date]).

Researchers may need to take a more supportive role in the research than they perhaps would normally; through communication and encouragement of PwD/MCI in their participation of research tasks. Participants who are PwD/MCI can be supported by carefully planning and structuring research sessions and, adopting practical research solutions to make sessions more inclusive (Hendriks et al, 2013). If there are any presentations to be given in group sessions it is advisable that presenters are supported so that talks are as widely accessible as possible to the audience (DEEP, 2013f). Furthermore, like qualitative interviewing, group work involving PwD/MCI needs to adapt modes of questioning and tasks so that they are accessible to PwD/MCI. It is advised that open, but simple questioning is utilised and that choice is minimised by including some yes/no answers (IPWD Reference Group [no date]). Thus it may be helpful for a semi-structured

question guide to be carefully devised with this in mind (Bamford & Bruce, 2002; Lindsay et al, 2012). Whilst researchers will need to stimulate and somewhat guide discussions, Lindsay et al highlight the value of “co-questioning” (Lindsay et al, 2012 pg.524); here, participants ask each other questions. “Co-questioning” is useful because participants can introduce questions and issues not previously thought of by researchers (Lindsay et al, 2012). Bamford & Bruce (2002) also advise that background information about participants is obtained because this can help researchers to pose questions that may be relevant to less dominant members of the group. Researchers may also need to provide reminders or repetition of information to facilitate understanding and communication (Hanson et al, 2007).

To maintain the focus of group members it may be useful to utilise visual props such as using a whiteboard or flip chart in addition to verbally facilitating group (Ryan et al, 2014). Furthermore, the use of different tasks in the course of group sessions that can help focus participants and, can be flexibly applied according to the dynamics of the group (Mayer & Zach, 2013). This means that facilitators need to remain open to the particular needs of each group and approach sessions without too many pre-conceived ideas about how sessions will run (Ryan et al, 2014). An array of research tools utilised to facilitate group sessions have been reported in the literature. Researchers need to rely on both verbal and non-verbal behaviour cues as an indication of whether participants are happy in the process of the research to gauge whether different approaches may be required (Hubbard et al, 2003).

The use of word-cards, pictures, stories and case-studies or scenarios can be useful tools to stimulate discussion (Bamford & Bruce, 2002; Robinson et al, 2009; Mayer & Zach, 2013; IPWD Reference Group [no date]). However, Bamford and Bruce (2002) have reported limited success with using a case-study in focus groups sessions, although they hypothesise that this could have been due to them utilising a male case-study with mainly female participants. Thus, gender neutral names that accommodate for both male and female participants may be beneficial. Photograph prompts are a useful way to encourage people to talk and reflect upon issues and can potentially introduce things to discuss that may not

be remembered without prompting (Bamford & Bruce, 2002)¹⁵. The use of “storyboarding”, has been found to be a useful means by which participants can discuss routines, enabling discussions about the ways in which technology may be a useful addition to these, as well as identifying potential problems (Robinson et al, 2009 pg. 496). Lastly, scenario work has been conducted by number of AL projects (Robinson et al, 2009; Mayer & Zach, 2013). Scenarios can involve exploring normal, best and worst-case scenarios that individuals would want the features of technology to support them with (Robinson et al, 2009). Or, scenarios can involve fictional characters that enable participants to talk about potentially sensitive issues in the third-person (Mayer & Zach, 2013).

Another successful method of promoting discussion that is pertinent to participatory design and development of AL technology is the use of objects or artefacts, such as old or existing technology or prototypes (Robinson et al, 2009; Lindsey et al 2012; Hendriks et al, 2013). This allows PwD/MCI to physically examine these objects which can facilitate remembrance and enable participants to talk about particular features, likes, dislikes of the technology, as well as any ethical issues raised (Robinson et al, 2009). Finally, it is advised that taking a playful approach to data collection is both conducive to stimulating participant responses as well as making sessions enjoyable (Mayer & Zach, 2013). Consequently, researchers can be creative in devising games and puzzles that can be flexibly incorporated into group discussions both helping to change topics or promote a positive atmosphere (Mayer & Zach, 2013). One caution here however, is that the varying abilities of participants can mean that some individuals may find games or puzzles more challenging than others (Mayer & Zach, 2013). Thus, it important to be able to alter the difficulty so that some people do not become frustrated or disheartened (Mayer & Zach, 2013).

¹⁵ However, as mentioned above, photographs or pictures utilised need to be simple to understand, not artistic or patronising (DEEP, 2013a).

Key points:

- A 'common frame of reference' needs to be developed between stakeholders during group sessions which is led by PwD/MCI and caregivers, and jargon-free.
- Researchers and designers need to adopt creative and flexible strategies to encourage group discussions and maintain focus.
- It is important to be aware of the differences in abilities between participants to ensure that individuals do not become excluded or distressed by tasks.

5.5 Testing and evaluation of technology prototypes

An important part of participatory design is the testing and evaluation of prototypes that are developed. There are a number of ways in which other ALT research involving PwD/MCI have conducted these phases of their projects. In preliminary stages some projects report using paper prototypes presented with scenarios (Mayer & Zach, 2013; Hwang et al, 2015), or pictures and a video of prototypes (Wolters et al, 2015), to obtain feedback from end-users regarding perceived benefits and limitations. However, a drawback of using these types of early paper prototype testing stages is that they may be challenging for PwD/MCI because of the abstract nature of the task. Indeed, early prototype testing has been reported as particularly difficult for individuals who are affected by aphasia due to their MCI/D, because it requires individuals to be able to verbalise their thoughts out loud (Moffat et al, in Hendriks et al, 2013). Thus, to facilitate understanding amongst participants in general, it is advised that researchers move quickly to more "high-fidelity" prototypes that are more easily understood (Mayer & Zach, 2013 pg. 543).

Several projects developing ALTs report conducting prototype testing in a laboratory, for example the TEBRA system (Peters et al, 2014), Boman et al (2014), who tested a video-phone mock-up in a laboratory setting, and some stages of testing the COGKNOW system (Sävenstedt et al, 2010). However, the Assisted Living Project proposes that prototype testing and evaluation will involve installation of technology into the homes of some of the participants involved in the research. Installation in the homes of PwD has been done by other ALT initiatives, for example COGKNOW (Davies et al, 2009), NOCTURNAL (Martin et al, 2013) and explorations of the usability of the "Companion" (Kerssens et al, 2015). Home installation can be successful, however, Martin et al (2013) report that moving the

technology from the laboratory to a home environment is challenging. An important consideration is that prototypes can be confusing or at worst distressing to PwD if they do not work well (Orpwood et al, 2005; Mayer & Zach, 2013).

Consequently, prototypes need to be designed to a high enough level that they are robust and easy for people to use (Mayer & Zach, 2013). Moreover, it is important that participants are provided sufficient support in using prototypes; thus clear instructions need to be provided to individuals (ibid). A significant issue is that PwD/MCI and their caregivers are not fearful of breaking the technology, therefore they must be reassured that they can touch and interact with the technology to minimise any anxieties (Mayer & Zach, 2013). Despite these challenges, other projects have also observed that no distress was caused by unreliable prototypes (Robinson et al, 2009). And even, that PwD/MCI and their caregivers have accepted and enjoyed using prototypes (Astell et al, 2006; Martin et al, 2013). Although, Martin et al (2013) do report that some PwD did try to remove the NOCTURNAL technology on the day of installation. It is recommend that prototype testing with PwD is carried out once systems are reliable (Meiland et al, 2012; Mayer & Zach, 2013) and function well in terms of responsiveness to avoid PwD/MCI becoming frustrated or confused (Mayer & Zach, 2013).

Where technology has been installed in people's homes researchers have supported them in a number of ways: The COGKNOW project reported that they provided individuals with a training session and a manual, but also there was a helpline for technical support that individuals' could access (Meiland et al, 2012). Kerssens et al (2015), stated that they conducted an initial home visit by a member of their technical team to assess any potential user barriers. Moreover, on the day of installation, users were presented with scripted training protocol and given support and feedback until they had acquired a reasonable understanding and were able to utilise the basic functions of the system (Kerssens et al, 2015). Finally, Kerssens et al (2015) conducted telephone follow-ups once a week to monitor usage and any problems experienced by participants.

In both laboratory and at-home prototype testing a number of methods have been utilised to evaluate and test the technology. Some studies have reported adopting a quantitative approach to assessing the technology through providing participants with standardised questionnaires to assess usability (e.g. the MoBIS-Q scale utilised by Hervas et al, 2014) and

scales examining perceived ease of use and usability developed by Davis (1989) which were utilised by Kerssens et al (2015). Adopting a mixed-methods approach to evaluate prototypes is also beneficial and something that many studies report doing. Certainly combining observations and interviewing appears to be a common approach adopted by studies when evaluating prototypes (Astell et al, 2009; Sävenstedt et al, 2010; Boman et al, 2014). However, Sävenstedt et al (2010) have reported that technical problems with the equipment greatly distracted the PwD when answering questions about it at the same time. Other methods of capturing interactions and participants' views may also be implemented. For example, Sävenstedt et al, 2010 used mixed methods of structured questionnaires, qualitative interviews and observations, and "in situ measurements" (pg.204), which is software that effectively logs the technology use, to evaluate the COGKNOW system. Furthermore, Suijkerbuijk et al (2015) took an inventive approach by devising an "evaluation game" (which combined question cards along with an audio recorder and camera that participants could choose to use), to qualitatively explore the perspectives of both caregivers and PwD to lighting technology they developed and installed in people's homes for testing. The game was greatly enjoyed by participants and elicited rich data, although, it was found that some of the questions in the game were left unanswered (Suijkerbuijk et al, 2015). Finally, Kerssens et al (2015) report providing caregivers with a diary to document their experiences of using the technology installed in their home.

The involvement of caregivers is recommended in the prototype testing stages since they can support and encourage PwD/MCI in utilising developed ALTs (Hanson et al, 2007; Meiland et al, 2012; Mayer & Zach, 2013). One issue with developing technology for PwD/MCI is that they may find it difficult to learn to use new things or may forget to use the technology (Meiland et al, 2012). For example, the COGKNOW project noted that, whilst the technology may be developed for independent use by PwD/MCI, relatives/carers were often required to provide assistance, prompts and reminders to help PwD/MCI utilise the technology (Meiland et al, 2012). Furthermore, AL technologies may be directly used by, or at least supportive of the work of caregivers. Thus several studies have adopted dyads where both PwD and caregivers have been asked their opinions about the developed technology (Astell et al, 2009; Sävenstedt et al, 2010; Kerssens et al, 2015; Suijkerbuijk et al, 2015). Moreover, some studies have asked carers not just about their own experiences but

also to reflect upon their perceptions of how PwD have found the prototype (Astell et al, 2009). Therefore, including caregivers in the research enables researchers to supplement the information obtained from PwD evaluating the technology (Sävenstedt et al, 2010). However, despite valuing caregiver involvement, Suijkerbuijk et al (2015) did report that in their “evaluation game” caregivers did seem to take charge, although, they were unsure whether this affected the legitimacy of the evaluations made by PwD.

Key points:

- Early prototype testing and evaluation can be particularly difficult for PwD/MCI.
- Prototypes should be stable and reliable to minimise potential to distress PwD/MCI.
- PwD/MCI may find it hard to learn to use prototypes and need a lot of support and reassurance in using them.
- It can be helpful to question PwD/MCI about the technology whilst they are using it.
- Caregivers are also important users and facilitators of developed technologies.

6. Feedback & concluding the research:

As already mentioned above, literature advising best practice methods for involving PwD/MCI in research highlight the importance of ending research interactions on a positive and leaving the PwD/MCI with a sense of achievement regarding their participation (e.g. McKillop & Wilkinson, 2004; DEEP, 2013f; Murphy et al, 2015). Other important considerations when concluding research include: enabling participants to provide feedback regarding their experiences of involvement, as well as provision of feedback about the different research stages or the project as a whole (IPWD Reference Group [no date]; McKillop & Wilkinson, 2004). For example, participants may be interested to hear how the AL project has utilised the information that they have provided and the outcomes of the research (IPWD Reference Group [no date]). Here, it may also be important to clarify information provided from the start such as any agenda for commercialisation of the developed AL technology. This type of feedback could be provided in the form of regular newsletters and thank you cards for people’s involvement and a concluding document (McKillop & Wilkinson, 2004). Furthermore, researchers should be aware that due to the complex needs and potential vulnerability of PwD/MCI and their caregivers, participants

may need signposting to information and advice about support and local services that are external to the research (IPWD Reference Group [no date]; Hanson et al, 2007). Therefore it is advisable that the project investigates and gathers links to helpful organisations (e.g. local and national charities or government initiatives) or information sources (websites, leaflets, etc.) in advance of research sessions so that information is readily available to individuals.

Key points:

- It is important to conclude research positively, leaving PwD/MCI feeling valued and with a sense of achievement.
- Thanks and provision of feedback to participants about the research is appreciated.
- Researchers may need to signpost PwD/MCI or caregivers to external organisations for advice and support.

7. Conclusion:

From reviewing the literature regarding the involvement of PwD/MCI in research (including participatory design), it is apparent that an inclusive and flexible approach needs to be adopted by researchers. A 'one-size-fits-all' methodology will not work due to the complex and idiosyncratic ways that people are affected by dementia and MCI (Hendriks et al, 2013; 2015). It is important that researchers recognise and respect the limitations and boundaries to individuals' ability to participate because of their MCI/D (Hanson et al, 2007). This includes careful consideration of issues such as informed consent, where an on-going process approach is advised (Dewing, 2002; 2007; 2008). Furthermore, researchers should plan research sessions carefully, with attention to practical aspects of sessions, such as time and location, but also focus on the individual capabilities of participants. Appropriate communication and research tools will need to be utilised in the data collection, development and testing stages of the design process (Hubbard et al 2003; Hendriks et al 2015). It cannot be assumed that methods developed for PwD/MCI will not need further adaptation to meet specific requirements of individual participants or the project (Hendriks et al, 2015).

The involvement of other stakeholders (such as informal caregivers) as both informants and facilitators of the research can be very beneficial to researchers (Pratt, 2002; Sixsmith et al,

2006) however, it is important to reflect upon their potential influences upon the contributions of PwD/MCI (Pratt, 2002), so as not to undermine the inclusive aims of the participatory approach (Hendriks et al, 2013).

Finally, the Assisted Living Project needs to be aware that conducting research with PwD/MCI may progress at a slower rate than perhaps it would in other populations because of the variable and complex nature of MCI/D. Researchers should anticipate this when planning the project; in particular it is vital to be understanding and maintain good research relationships with participants and other individuals involved (Pratt 2002; McKeown et al, 2010).

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