

The University of Bradford Institutional Repository

<http://bradscholars.brad.ac.uk>

This work is made available online in accordance with publisher policies. Please refer to the repository record for this item and our Policy Document available from the repository home page for further information.

To see the final version of this work please visit the publisher's website. Available access to the published online version may require a subscription.

Link to original published version: <http://dx.doi.org/10.1111/hsc.12191>

Citation: Sinclair J B, Oyebode J R and Owens R G (2015) Consensus views on advance care planning for dementia: a Delphi study. *Health & Social Care in the Community*. [Online before print]. <http://dx.doi.org/10.1111/hsc.12191>.

Copyright statement: © 2015 Wiley. This is the peer reviewed version of the article above, which has been published in final form at the link above. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving.



Consensus Views on Advance Care Planning for Dementia: A Delphi Study

James B Sinclair, M. Res. (Clinical Psychology)¹, Jan R Oyeboode, Ph.D.², R Glynn Owens,
D.Phil.³

¹*North East London NHS Foundation Trust, London, UK*

²*Bradford Dementia Group, University of Bradford, UK*

³*School of Psychology, University of Auckland, New Zealand*

Running title: Advance Care Planning for Dementia

Address for correspondence:

Professor Jan R Oyeboode, Bradford Dementia Group, University of Bradford, BD7 1DP, UK.
Phone +44-1724-233669; e-mail j.oyeboode@bradford.ac.uk

Consensus Views on Advance Care Planning for Dementia: A Delphi Study

Abstract

The uptake of advance care planning (ACP) is particularly low amongst people with dementia. This may reflect barriers to communication between professionals, patients and families in the face of lack of consensus about the process. This study aimed to methodically investigate consensus views of how ACP should be explained and carried out with people with dementia. A three round Delphi study explored views of how and when ACP should be addressed, what should be covered, who should be involved and why rates of ACP are low. Seventeen participants took part comprising family members, old age psychiatrists and policy-makers. Thirty-two items reached consensus. The panel agreed on 11 different areas for discussion. They concurred that ACP was best addressed after the person has come to terms with the diagnosis when the individual feels ready to do so. There was a consensus view that the process should be couched in terms of 'certain possibilities'. Consensus items emphasised personal choice and autonomy, whilst also prioritising the need to discuss financial aspects and to include spouses. There was no consensus that professionals should be involved, although the panel viewed them as carrying some responsibility for low uptake. It is suggested that ACP should include general discussion of values as well as coverage of specific points. Professionals need to offer discussion and information on ACP but also make clear that the patient has the right to choose whether to pursue ACP or not.

Key words: Alzheimer's disease, advance care planning, patient care planning, Delphi technique, consensus.

What is known about this topic

- The aim of advance care planning (ACP) is to protect patient choice beyond loss of capacity
- There is some limited evidence to support the view that ACP facilitates positive outcomes for those with dementia
- Uptake of advance care planning is low among people with dementia

What this paper adds

- There is consensus between relatives, professionals and policy-makers that ACP is important
- There is strong support for patient choice and self-determination regarding when and how ACP should be discussed, as well as for the process to include family members
- Professionals may best assist patients by touching on ACP routinely during ongoing consultations rather than setting aside appointments specifically for ACP

Consensus Views on Advance Care Planning for Dementia: A Delphi Study

Introduction

The prevailing ethos of patient involvement and patient-centred care (Hogg, 2007; Institute of Medicine, 2001), coupled with advances in medicine which increasingly extend life beyond an individual's ability to be involved in treatment decisions, has resulted in legislation, policy and procedures designed to protect patient choice beyond loss of capacity. For those with life-limiting conditions, the UK National Health Service (NHS) recommends care planning as the primary way of embracing person-centred care (National Health Service, 2011). This involves dialogue through which an individual's needs, goals and preferences are established and requires that the patient's 'best interests' are at the core of any decision made. If the patient has lost capacity to participate then their views, beliefs and preferences may be gleaned from care planning which took place when they did have capacity, i.e. Advance Care Planning (ACP; National Health Service, 2011). ACP can lead to any of three formalised outcomes (Mental Capacity Act (2005), all of which only come into effect when the individual loses capacity to make decisions: An Advance Statement which can be used to inform 'best interest' decisions, an Advance Decision to Refuse Treatment (ADRT) which is legally binding but only in relation to the treatments specified or the appointment of legally binding Lasting Powers of Attorney (LPA) over either 'health and welfare' or 'property and affairs' in which an elected other can make decisions on the person's behalf in the specified area.

There is some limited evidence to support the view that ACP facilitates positive outcomes for those with dementia (Chen *et al.* 2006, Engel *et al.* 2006, Monteleoni & Clark

2004) and there are in existence several sets of brief guidelines on how to address ACP with people with dementia (Conroy, *et al.* 2009, Dying Matters Coalition 2012, National Health Service 2011). In practice, however, uptake of ACP is particularly low amongst people with dementia (Australian Government 2004; Exley *et al.* 2009, Taylor & Cameron 2002). ACP for people with dementia has been argued to be more effective as a process of discussion (in line with current NHS policy) rather than simply completion of a form, in that this increases uptake and makes end-of-life care more compliant with patients' wishes (Karel *et al.* 2004). That these discussions are not taking place may reflect barriers to communication between professionals, patients and families in the face of lack of consensus about the process. Considering these issues, the aim of this study was to explore views of ACP for people with dementia in the following areas: What should be discussed, who should be involved, when it should be done and how it should be explained. Reasons why uptake is so low amongst people with dementia were also investigated.

Method

The Delphi method

A method was required which would allow equal input from principal stakeholders, in order to gain consensus across those who are involved in and affected by the process (Powell 2003). A method which allows this equal involvement, whilst achieving 'consensus in a given area of uncertainty or lack of empirical evidence' (Powell 2003) is the Delphi method, which has principles of multiple rounds of consultation, structured feedback and anonymity at the heart of its approach to achieving consensus (Hasson *et al.* 2000).

Delphi methodology has been used since the 1970s to assess goals, generate ideas and guide policy development, mostly within education and health research (Hasson *et al.* 2000, Linstone & Turoff 1975). The conventional Delphi approach, employed in this study, involves establishing a panel of experts who are consulted individually, with their identity not known to other panel members. Members of the panel generate ideas on the topic in question and these ideas are re-presented to the panel with the aim of establishing those which hold general consensus or demonstrating that consensus cannot be reached (Clayton 1997). In this process, the researcher acts a facilitator for what may essentially be thought of as an anonymous, remote, staggered focus group.

Panel of experts

The aim was for the 'panel of experts' to be composed of representatives of four groups of participants: Healthcare professionals, policy-makers in the area of ACP, people with dementia and family members who also act as carers. People with dementia and their family members were judged to be experts by virtue of living with dementia. Old age psychiatrists and GPs were considered to be expert if they had been involved in one or more disclosures of dementia over the past year, and policy-makers were considered to be expert if they had had direct involvement in forming policy documents at a national and/or regional level relating to dementia, ACP and/or end-of-life care. Professionals were therefore judged to be expert through a demonstration of professional experience, and service users through lived experience.

There is no official sample size calculation for a Delphi Study: Previous studies have employed as few as 5 and up to more than 60, with little evidence that this has any effect on validity or reliability (Powell 2003). There is a conservative rule of thumb which suggests

that studies using a heterogeneous sample should have a sample size of at least 5 (Clayton 1997). These participants need not be representative of their populations, as representativeness is instead judged through the quality of the panel. As the process is an intensive one there is likely to be a large element of self-selection in any Delphi study with individuals most interested in the area being most likely to participate (Hasson *et al.* 2000). This is an unavoidable consequence of the method, and may be positive rather than negative through increasing the likelihood that participants will be people who are already well-informed about the relevant issues.

First round questionnaire design

The first questionnaire of a Delphi study typically consists exclusively of open-ended questions in order to generate information about an under-researched area. The first questionnaire of this study contained five such open-ended questions which general and intended to cover all relevant aspects. These were specifically: What should be discussed, who should be involved, when should it be done, how should it be explained and why is it not being done? Three closed response items were also included to establish general attitudes to ACP. These were: "Advance Care Planning is important to the future care of a person with dementia", "All people with dementia should have an ACP", and "Telling a person they have dementia is essential before a discussion about their future care needs can take place." Participants were asked to indicate the degree of their agreement with these on a five-point Likert scale from strongly disagree to strongly agree.

A draft of the first round questionnaire was reviewed by one person from each potential participant group. The carer and person with dementia had no issues with questions or wording. The policy-maker suggested some minor changes to the wording for

the sake of clarity. The psychiatrist had concerns which mainly focussed around the asking of questions which they felt would provoke only agreement due to legality. These concerns resulted in it being made clear on the instructions that the study was asking about the participants' thoughts and opinions not their knowledge of, or compliance with, legislation.

Ethics

This study was given a favourable ethical opinion by a local Research Ethics Committee and management permission was obtained from the research and development departments of one primary care trust and two foundation trusts.

Recruitment

Thirty-seven policy-makers were e-mailed an invitation and a participant information sheet through contact details that were sourced from the 'acknowledgements' section of national policy documents relating to ACP. If they expressed an interest they were then posted a consent form to be completed and returned. Three policy-makers consented to take part. Seventeen old age psychiatrists were emailed an invitation to participate and a participant information sheet, through a collaborator at their NHS site. If they expressed an interest they were then posted a consent form to be completed and returned. Six psychiatrists consented to take part. As it was not possible to gain direct access to GPs' contact details, all GP practices within a primary care trust were faxed an invitation to participate. Sixty-seven GP practices were faxed. No GPs responded to the invitation. Six people with dementia and fourteen family members were given a presentation about the study by the researcher at social meetings organised by charitable bodies and a carers' support group. Those interested in taking part were invited to discuss the study with the researcher, were

given a participant information sheet and a time was arranged for the researcher to visit them in their own home to answer any questions and to obtain consent. Seven carers and one person with dementia consented to take part.

Data collection and analysis

The study consisted of three rounds of questionnaires. The first round questionnaire was posted or e-mailed to policy-makers and psychiatrists and hand delivered to family members and the person with dementia. They were either given two weeks in which to complete and return it, or an arrangement was made for the researcher to return and collect the questionnaire within two weeks. The questions in this round were presented as interrogative statements with a free text box underneath.

Interim analysis was performed on all the returned questionnaires. This involved performing 'minimal semantic-thematic synthesis' on all open-ended answers that were given for each question; i.e. in line with thematic analysis (Braun & Clarke 2006), the comments were coded on the basis of their explicit meaning without looking for any deeper meaning; they were then 'synthesised' by condensing similar comments into one comment. No interpretation was performed. All comments were considered and comments were only collapsed together if close to identical. The participants' words were always retained. Triangulation between the first and second authors was carried out on 20% of the comments as a validity check, and very little difference was found. In rare cases of disagreement synthesis was abandoned and the separate statements were retained.

The statements produced in this way were then re-submitted to the participants along with a five-point Likert scale on which they were asked to indicate their level of

agreement ('strongly disagree' to 'strongly agree'); respondents were also invited to make any comments they wished under each statement. The five questions and their accompanying statements and scales made up the second round questionnaire. Round two was posted to all psychiatrists and policy-makers (due to their being much easier to complete by hand than on a computer) and was hand delivered to family members (the person with dementia withdrew at this stage finding the demands too high). Again, they were given two weeks in which to complete the questionnaire.

After collection all the Likert responses were entered onto the data analysis software SPSS and any questions where 80% of respondents chose 'agree/strongly agree' or 'disagree/strongly disagree' or 'neither agree nor disagree' were judged to have reached consensus and were not included in the subsequent round, with the proviso that at least one member of each participant group contributed to any consensus. There is no set definition of 'consensus' in the Delphi methodology with some studies using 'more than half' the participants agreeing on a statement and others requiring 100% agreement (Powell 2003). 100% agreement for consensus is relatively rare and therefore this study's 80% rule for consensus is relatively stringent.

As part of the Delphi method, the central tendencies and distributions of participants' scores on those questions not reaching consensus are fed back to the participants in the next round of questionnaires. This was done by feeding back the number of participants who indicated each choice along with any comments made (which were subjected to the same minimal synthesis described above) and each participant's own previous response (see figure 1). This was felt to be more understandable for a lay population than the presentation of means or medians (Clayton 1997) and also, because a

number of the statements showed binomial distribution and descriptive statistics, it would have been misleading. Participants were asked to reconsider the statements in light of the group response and comments; they could then change their score if they wished and make any further comments.

FIGURE 1 ABOUT HERE

Due to a high number of 'neither agree nor disagree' responses on a number of statements in round two, in order to gain clarity about participants' responses, this point on the Likert scale was divided into two options: 'It depends on the person' (mentioned in comments by a number of participants) and 'I have no strong opinion about this statement'.

The individualised round three questionnaires were sent out and collected in the same manner as the round two questionnaires, and after two weeks all the Likert responses were entered into SPSS. Items reaching consensus were identified. For those not still reaching consensus the scores given were broken down by participant group, and the comments were examined, to gain insight into why they had failed to reach consensus.

Results

Demographics and attrition

The first round questionnaire was completed and returned by 17 participants; one person with dementia (female), seven carers (one daughter, one wife, two sons, one son-in-law and two husbands), six psychiatrists (one female) and three policy-makers (two female).

Thirteen identified themselves as white (British), two as white (other), one as Pakistani and one as Other Asian (non-Chinese). The policy-makers and psychiatrists all had more than 10 years of experience of dealing with dementia and/or related issues, whereas the carers and

person with dementia had three to five years of experience of having been diagnosed with dementia or caring for someone with such a diagnosis.

The second round was completed and returned by 15 participants, an attrition rate of 12%.

The person with dementia did not complete this round and neither did one of the carers.

The third round was completed by 13 participants. One psychiatrist and one policy maker did not return this round. Thus there was an overall attrition rate of 23.5%.

Closed questions

There was consensus that ACP is important to the future care of a person with dementia (82%, agree or strongly agree) and that telling a person they have dementia is essential before a discussion about their future care needs can take place (82% agree or strongly agree) but only 61% agreed or strongly agreed that all people with dementia should have an ACP. Those agreeing included all but one carer but only a minority of the psychiatrists. The psychiatrists' responses were divided between the possible categories. Four participants added comments. Two of these supported the importance of ACPs, one cited the need to give choice and one wrote: "Many patients show no interest in this and are happy for the family and professionals to make these decisions on their behalf."

Overall consensus

Following the minimal thematic synthesis of suggestions made in response to the open-ended questions on the first round questionnaire, the open-ended questions which focused on the *what*, *when*, *how* and *who* of ACP, produced 41 statements to be rated in the second round. After the second round 21 (51%) of these statements reached consensus and were removed. After the third round a further five statements reached consensus. Overall

twenty-six (63%) of the participants' statements about what, who, how and when, reached consensus. The question asking *why* few people with dementia take part in ACP produced 19 statements; just two (10%) of these reached consensus after the second round and a further four after the third round, giving an overall consensus on 31% of the statements generated by this question.

Consensus and non-consensus items

The statements linked to the four questions (what, who, how, when) which reached consensus are presented in table 1. This lists the responses to each question in descending order of strength of consensus from strongest to weakest. 'Strength' is defined primarily as the percentage of participants selecting that option (with consensus being 80% or above) and is secondarily defined as the percentage of participants choosing 'strongly' agree or disagree. Items reaching consensus after the second or third round are ordered separately.

Due to the attrition between the second and third round the definition of consensus remained at 80% of those responding but reflected agreement of 11/13 participants rather than 12/15. It is therefore possible that items reaching consensus after the third round may only have done so due to the non-response of the two panel members who dropped out.

Therefore, any item which reached consensus after round three which would have done so even had the two non-responders not been in the consensus group, is indicated with (x).

Items not reaching consensus are shown in table 2. Space precludes a comprehensive listing of the comments made in relation to these. The statements which reached consensus in response to the question on why so few people with dementia take part in ACP are shown in table 3, and those not reaching consensus are shown in table 4.

TABLES 1,2,3 AND 4 ABOUT HERE

Discussion

The responses to the three closed questions included in the study show consensus that a person with dementia should be given their diagnosis before they participate in ACP and that ACP is considered important to future care of those with dementia. These views are in line with current policy which stresses the importance and benefits of ACP and which promotes discussion of future care needs (National Health Service 2011). Yet, although a majority of respondents agreed that all people with dementia should have an ACP, this item failed to achieve the level of 80% consensus. Those who did not agree argued that this should be at the discretion of the person with dementia, disagreed or held no strong view. Thus, although ACP may be thought valuable there is a case for respecting the patient's choice about whether to discuss it. Indeed, the items generated and endorsed by the Delphi panel strongly support the prevailing ethos of person-centred care, with statements relating to patient choice and individualised communication reaching consensus after the second round in each of the four open-ended sections. Tailoring to the person with dementia's wishes and needs achieved the strongest degree of consensus of all the statements in the sections on *when* ACP should be discussed and *how* it should be explained.

Nonetheless, the results do not represent a full consensus that patient choice is the absolutely fundamental aspect of ACP, as some items reached stronger consensus than those relating to patient choice. In particular, financial considerations showed stronger consensus in the section on *what* ACP should include, than 'whatever the person wants it to include.' This might imply that financial planning and LPA for property and financial affairs takes priority over and above the patient's wishes, or may simply reflect a view that such practical matters should not be forgotten. In addition, in the section on *who* should be

involved, the strongest consensus was for the inclusion of spouses, with consensus on this being stronger than the item on patient choice. The view seems to be, therefore, that the presence of the spouse should override the person with dementia's wishes about whether they should be present. Given that recruitment of people with dementia to the panel was unsuccessful, these views represent consensus from family members, psychiatrists and policy-makers only. These items would seem to reflect the urgency these stakeholders perceive to address material issues whilst the person with dementia still retains capacity, ensuring the spouse is fully involved, presumably as they are the key person affected by financial matters. It is of course unfortunate that the one patient who agreed to take part was unable to see the project through to the end, since one might intuitively expect that patients would be the ones most likely to argue for their own wishes having priority.

The overall consensus on issues such as ACP covering a broad range of topics and being value-based might reflect a real acknowledgement of the uniqueness of individual cases with such a broad base permitting a judgement call to be made should unexpected scenarios arise. Previous research however (Kolarik *et al.* 2002) has shown that specific, rather than value-based ACP was viewed as providing a better sense of control over future treatment, suggesting here a potential conflict. Moreover it has been found, in a systematic review, that surrogates are poor at accurately predicting patients' treatment preferences, particularly when scenarios involve dementia and stroke (Shalowitz *et al.* 2006). The consensus about the value of discussion across a wide range of areas along with that on understanding the general principles by which the person makes decisions, combined with support for respect for the person with dementia's wishes suggests that the most suitable

way of ensuring 'attorney' knowledge of the person's wishes would be for conversations to include general discussion of values as well as coverage of specific points.

It is also noted that in this section, the weakest consensus item, on Advance Directives for the Refusal of Treatment (ADRT), is actually the major area enshrined in UK law (National Health Service 2011), the aspect of ACP most usually employed (Hughes *et al.* 2007) and the aspect with the largest evidential basis (Caplan *et al.* 2006). In the present study, although there was an 80% consensus, only 8% (one person) *strongly* agreed with the statement. The panel's views on this may be weaker because in dementia it is hard to predict the eventual cause of death and therefore also the treatment that one needs to discuss or refuse. On the other hand, it could be felt that being concrete and specific in this regard would be uncomfortable for the person with dementia.

The consensus around leaving ACP until the person has been diagnosed and "when they wish to have the discussion" may reflect the notion that it would be difficult for a person with dementia to make rational plans for the future when they are still responding emotionally to a devastating diagnosis. It is notable that two of the items that did not achieve consensus were suggestions that ACP should take place at the point of diagnosis. There was a division of opinion here; all carers agreed that ACP should be addressed as soon after diagnosis as possible, but all professionals and policy-makers, except for one of each group, disagreed. This division of opinion may stem from the different pressures of the respective positions, with carers being keen to get matters sorted out but professionals wary of causing the patient, and perhaps themselves, undue stress. Professionals' preference for postponing ACP, alongside the slightly weaker consensus about ADRT may reflect the understandable desire of health professionals to avoid confronting mortality for

fear of causing distress to the patient or the self. This has been proposed by others as a barrier to ACP (Taylor & Cameron 2002) and may be particularly cogent for medical personnel given their professional commitment to recovery. Although not the object of this study, theories of death anxiety, salience and avoidance (Neimeyer 1994, Peck 2009, Tomer & Eliason 2000) may give some useful psychological insight into the results obtained. It was also noted that comments made about some of the items which did not reach consensus suggested a degree of misunderstanding of the legal context. For example, in response to the statement that ACP should be explained by letting the patient know “that it will ensure their wishes and preferences will always be considered during any care planning/treatment process”, one respondent commented “we can’t be unrealistic and state that we can ensure things are carried out”, indicating confusion about ‘best interests’ decisions.

The points of consensus on timing suggest that it is important to ensure that information on ACP is readily available to those with dementia well beyond the point of diagnosis, for example, via voluntary agency websites, since many of those diagnosed may not be in contact with health professionals in the period following diagnosis. This does not necessarily imply that there is a point when a person with dementia has completely adjusted to the diagnosis or that they or others involved would realise it was an appropriate moment to discuss the future; there may indeed be a risk being that such discussions are indefinitely postponed. Robinson *et al.* (2005), in their qualitative study of psychological reactions to a diagnosis of dementia found that couples who were interviewed on average 11 months after diagnosis were still continuing to adjust. It may be that discussions about the future, labelled as ACP or more informally, contribute to adjustment; and as with other difficult communications (e.g. the disclosure of a terminal diagnosis) discussions may need

to continue over a relatively extended period while the patient remains able to make their wishes known.

Concerning *how* the issue of ACP should be explained to someone with dementia, aside from tailoring the way it is explained to the individual, several items contained elements that emphasised the control the patient can gain from ensuring others know their wishes whilst others framed it as 'dealing with possibilities', thus softening the notion that what is discussed is necessarily going to happen. Such discussion, it was agreed, should involve the spouse, children, primary carers, close friends and whoever else the patient wishes, but with no consensus regarding other specific individuals such as clinicians, lawyers and advocacy services.

The fifth open-ended question enquired about possible reasons *why* so few people with dementia have ACPs. This generated 19 items in total, showing the variety of opinion and the many possible explanations. Those reaching consensus support previous research into the reasons for low uptake of ACP amongst the elderly (Australian Government 2004, Taylor & Cameron 2002).

A number of items that reached consensus placed the responsibility, openly or by implication, on clinicians, i.e. 'It isn't being offered', 'the belief that it is someone else's job' and 'the time required'. In combination with the consensus items on choice, timing and who should be involved, this demonstrates strong support for patient choice and self-determination and for the process to include primarily family members; yet on the other hand, ACP is also being viewed as a process to be initiated by a professional. Since the introduction of the Mental Capacity Act (2005), it has become important for care providers in the UK to ensure they address advance statements and follow ADRT. In turn ACP has

become recognised as the way for those with illness to ensure they put these measures, as well as LPA, in place. Services may increasingly be expected to show that they are contributing to ACP and yet the panel indicated a consensus view that this is a matter for the person concerned, not for professionals. It may be that the solution is to promote ACP as important for people with dementia and their families to address, but to take responsibility within health and social services, as well as in the third sector, for ensuring that material about ACP is widely disseminated in user-friendly, readily understandable formats. A second group of consensus items links to a related but different issue, that of postponing ACP due to focus on other current crises and a failure to appreciate the urgency of facing the future. Again, this may emphasise the need for professionals both to initiate discussion and to encourage further discussion as appropriate as long as the patient remains competent. It is suggested that one way to promote a sense of urgency in a non-threatening way would be through the use of vignettes, illustrating for example, financial matters, as suggested by Conroy *et al.* (2009).

Limitations

A major limitation of this study was the lack of participation from people with dementia, with the result that the consensus lacks input from the very group most directly affected. In addition the number of policy-makers was small although the definition on consensus adopted ensured that at least one of the policy-makers was in the 80% consensus group.

Reflections on Delphi method

This study set out to explore methodically the subject of ACP with people with dementia with the aim of discovering consensus that could be used to inform practice. The use of the

Delphi method allowed for the inclusion of a range of stakeholders, the generation of data from those directly involved rather than this being dominated by academic ideas, the gathering of a large amount of data, and the ability to deconstruct the reasons why some of the suggestions made by members of the panel could not be agreed upon. The main insight gained from the latter is that there is a distinct lack of knowledge about the policy and legal issues which exist around ACP in the UK.

Implications for practice

The consensus items reflect approval of autonomy and patient choice with regard to ACP noting particularly the involvement of spouses and the importance of financial issues. Although ACP is endorsed as important, the panel's view appeared to be that patient-choice should over-ride this such that ACP should only take place if and when the person with dementia wishes. It is therefore concluded that, rather than adopting the strategy of training and expecting staff to carry out ACP with people with dementia, or starting to count the proportion of patients with an ACP as an indicator of success, a more valid strategy would be to ensure that user-friendly accurate information is readily available and delivered whether this be through professionals or third sector organisations. The hint of professional reluctance to make decline and death more salient, the recognition that ACP may require discussions over time, and the need for ACP to be timed to suit the patient, combine to suggest that professionals may best assist patients by touching on ACP routinely in the course of ongoing patient consultations rather than setting aside appointments separately and specifically for ACP, ensuring information is readily available but making it clear it is the patient's decision whether, how and with whom to pursue ACP.

Panel members suggested a number of ways to introduce ACP that play to its strengths and benefits and these could readily be included in information provided; these include the value of discussing a breadth of areas under the umbrella of ACP as well as ensuring the general principles by which the person makes decisions are understood by the 'attorney' or key others. Thus materials would need both to suggest specific areas for discussion and the utility of supplementing these with values-based approaches. Indeed it may be argued that for dementia in particular, for which long-term care beyond a point of capacity may go on for some time, the process of discussion itself may be at least as important to adjustment and care as any written ACP.

References

- Australian Government Department of Health and Ageing. (2004) *Guidelines for a Palliative Approach in Residential Aged Care*. Canberra: Australian Government Department of Health and Ageing
- Braun V. & Clarke V. (2006). Using thematic analysis in Psychology. *Qualitative Research in Psychology* **3**, 77-101. doi: 10.1191/1478088706qp063oa
- Caplan G. A., Meller A., Squires B., Chan S. & Willett W. (2006). Advance care planning and hospital in the nursing home. *Age And Ageing* **35** (6), 581-585.
- Chen J., Lamberg J., Chen Y.C., Kiley D., Page J., Person C.J. & Mitchell S. (2006). Occurrence and Treatment of Suspected Pneumonia in Long-Term Care Residents Dying with Advanced Dementia. *Journal of the American Geriatrics Society* **54**, 290-295. doi: 10.1111/j.1532-5415.2005.00524.x
- Clayton M. (1997). Delphi: a technique to harness expert opinion for critical decision-making tasks in education. *Educational Psychology* **17**, 373-386. doi: 10.1080/0144341970170401
- Conroy S., Fade P., Fraser A. & Schiff R. (2009). Advance care planning: concise evidence-based guidelines. *Clinical Medicine* **9** (1), 76-79.
- Dying Matters Coalition (2012) Time To Talk? Starting end of life care conversations with people affected by dementia [leaflet]. Available at http://www.dyingmatters.org/sites/default/files/user/Leaflet%2011_WEB.pdf
- Engel S., Kiely D. & Mitchell, S. (2006). Satisfaction with End-of-Life Care for Nursing Home Residents with Advanced Dementia. *Journal of the American Geriatrics Society* **54**, 1567-1572. doi: 10.1111/j.1532-5415.2006.00900.x
- Exley C., Bamford C., Hughed J. & Robinson L. (2009). Advance care planning: An opportunity for person centred care for people living with dementia. *Dementia: The International Journal of Social Research and Practice* **8**, 419-424. doi: 10.1177/14713012090080030702

- Hasson F., Keeney S. & McKenna H. (2000). Research guidelines for the Delphi survey technique. *Journal of Advanced Nursing* **32**, 1008-1025. doi: 10.1046/j.1365-2648.2000.t01-1-01567
- Hogg C. (2007). Patient and public involvement: What next for the NHS? *Health Expectations* **10**, 129-138. doi: 10.1111/j.1369-7625.2006.00427.x
- Hughes J., Jolley D., Jordan A. & Sampson E. (2007). Palliative care in dementia: Issues and evidence. *Advances in Psychiatric Treatment* **13**, 251-260. doi: 10.1192/apt.bp.106.003442
- Karel M., Powell J. & Cantor M. (2004). Using a Values Discussion Guide to facilitate communication in advance care planning. *Patient Education and Counselling* **55** (1), 22-31. doi: 10.1016/S0738-3991(03)00246-5
- Kolarik R., Arnold R., Fischer G. & Hanusa B. (2002). Advance Care Planning. *Journal of General Internal Medicine* **17**, 618-624. doi: 10.1046/j.1525-1497.2002.10933.x
- Linstone H. & Turoff M. (1975). Introduction. In H. Linstone & M. Turoff (Eds.), *The Delphi Method: Techniques and Applications* (pp. 3-12). Reading, Massachusetts: Addison-Wesley.
- Mental Capacity Act 2005: Code of Practice. (2007). Retrieved October 27, 2012, from <http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/mca-codepractice-0509.pdf>
- Monteleoni C. & Clark E. (2004). Using rapid-cycle quality improvement methodology to reduce feeding tubes in patients with advanced dementia: before and after study. *British Medical Journal* **329**, 491-494. doi: 10.1136/bmj.329.7464.491
- National Health Service, NHS End of Life Care Program (2011). Capacity, care planning and advance care planning in life limiting illness: A Guide for Health and Social Care Staff.
- Neimeyer R. (1994). The threat index and related methods. In R. Neimeyer (Ed.), *Death anxiety handbook: Research, instrumentation, and application* (pp. 61-101). Washington DC: Taylor & Francis.

- Peck M. (2009). Personal death anxiety and communication about advance directives among oncology social workers. *Journal of Social Work in End-of-Life & Palliative Care* **5**, 49-60. doi: 10.1080/1552425093173892
- Powell C. (2003). The Delphi technique: myths and realities. *Methodological Issues in Nursing Research* **41**, 376-382. doi: 10.1046/j.1365-2648.2003.02537.x
- Robinson L., Clare L. & Evans K. (2005). Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples. *Aging & Mental Health* **9**, 337-347. doi: 10.1080/13607860500114555
- Shalowitz D., Garrett-Mayer E. & Wendler D. (2006). The accuracy of surrogate decision makers: A systematic review. *Archives of Internal Medicine* **166**, 493-497. doi: 10.1001/archinte.166.5.493
- Taylor D. & Cameron P. (2002). Advance care planning in Australia: overdue for improvement. *Internal Medicine Journal* **32**, 475-480. doi: 10.1046/j.1445-5994.2002.00268.x
- Tomer A. & Eliason G. (2000). Attitudes about Life and Death: Towards a Comprehensive Model of Death Anxiety. In A. Tomer (Ed.), *Death attitudes and the older adult: Theories, concepts, and applications*. New York, US: Brunner-Routledge.

Figure 1: Extract from instructions and items from round 3 Delphi questionnaire showing those items concerning *how* ACP should be explained to a person with dementia which had not reached consensus by the end of round 2.

“ The number of participants who chose each option appears on the bottom row. The option you chose previously is highlighted in grey. If no box is highlighted then you did not previously respond to that statement but you may still do so in this round. For each statement please indicate your level of agreement by circling **one** of the responses (even if it remains the same as in the previous round).

If you “neither agree nor disagree” with a statement then please circle either “it depends on the person” or “I have no strong opinion about this statement” depending on which best represents your reasons for choosing the middle option.”

The issue of advance care planning should be explained to a person with dementia in the following way:

a) The explanation will be no different for a person with dementia than for any other person.

Strongly disagree	Disagree	It depends on the person	Agree	Strongly agree
		I have no strong opinion about this statement		
1	5	3	3	3

- Not sure as I think this would be dependent on cognition at the time of disclosure – I guess this could be the same for many diagnoses.
- This very much depends on the individual person and their level of cognitive function.

Table 1: Items achieving consensus across 80% Delphi panel members about what, when, with whom and how to address ACP with dementia

What do you think that an advance care plan for a person with dementia should include?			
	Consensus	% Agree	% Strongly Agree
Financial planning	93%	79%	21%
Power of attorney (financial)	93%	79%	21%
Whatever the person wants it to include	87%	46%	54%
Power of attorney (well-being)	87%	77%	23%
Planning for end-of-life care	87%	77%	23%
What care is available on the NHS	87%	77%	23%
Preferences for place of death	87%	85%	15%
Preferences for place of care	80%	75%	25%
Treatment/ medication preferences	80%	83%	17%
Advance directives for refusal of treatment	80%	92%	8%
<i>Items reaching consensus after Round 3</i>			
General principles by which they have made decisions throughout their lifetime	92% (x)	83%	17%
Religious views and beliefs	85%	64%	36%
At what point should advance care planning be discussed with a person with dementia?			
When they wish to have the discussion	80%	67%	33%
<i>Items reaching consensus after Round 3</i>			
After the person has come to terms with the diagnosis	85%	91%	9%

How should the issue of advance care planning be explained to a person with dementia?

The explanation has to be tailored to the individual	100%	47%	53%
That it is not known what their future will hold but that there are certain possibilities and if these were to occur how they would want them to be dealt with	93%	71%	29%
That we want to know what is important to them	93%	79%	21%
That, because of diminishing capacity, decisions are better made at an early stage	87%	85%	15%
That it makes it easier for families and health professionals to act in a way they would have wanted	80%	67%	33%
That the process enables some element of control to be retained	80%	75%	25%
By stressing that they might not need it but it would help if advance care planning was discussed	80%	83%	17%

Who should be involved in Advance Care Planning with a person with dementia?

Spouses	87%	54%	46%
Anyone the person with dementia decides they want to be involved.	80%	33%	67%
Children	80%	83%	17%
<i>Items reaching consensus after round 3</i>			
Primary carers	85%	91%	9%
Close friends	85%	82%	18%

Consensus = %age who agree/strongly agree; % agree = % of consensus group who agree; % strongly agree = % of consensus group who strongly agree. Bold type is used to indicate whether a majority agree or strongly agree with each consensus item.

Table 2: Items not reaching consensus, concerning what, when, how and who should be involved in ACP with people with dementia

What do you think that an advance care plan for a person with dementia should include?

The cost of care

Specific aspects of care (e.g. how often they like to have their hair washed, how they like their tea)

Any available medical trials

At what point should advance care planning be discussed with a person with dementia?

As soon after diagnosis as possible

Not at initial diagnosis

When they start to become a burden

How should the issue of advance care planning be explained to a person with dementia?

The need for it, particularly in terms of Lasting Power of Attorney over finance and property, needs to be explained.

That it will ensure their wishes and preferences will always be considered during any care planning/treatment process.

The explanation will be no different for a person with dementia than for any other person.

Who should be involved in Advance Care Planning with a person with dementia?

Siblings

GPs

Clinicians from psychiatric services

Any medical professionals who may be involved in implementing any future care

Advocacy services

A family lawyer

Table 3: Consensus items on why so few people with dementia take part in ACP

Very few people with dementia take part in advance care planning. A reason for this may be:	Consensus	% Agree	% Strongly Agree
The time required	87%	69%	31%
It is left too late until the person with dementia has lost the capacity to have the discussion	80%	75%	25%
<i>Items reaching consensus after Round 3</i>			
It isn't being offered	100% (x)	61%	39%
They do not realise the urgency of it	85%	82%	18%
The belief that it is someone else's job	85%	82%	18%
Not a priority for patient, carer and health professionals because of dealing with crises and current problems	85%	100%	0%

Bold type is used to indicate whether a majority agree or strongly agree with each consensus item.

(x) – Item would have reached consensus even if participants who left the study between rounds 2 and 3 had not been in consensus group.

Table 4: Items failing to achieve consensus regarding why so few people with dementia take part in ACP

Reluctance on the part of professionals to discuss it for fear of causing anxiety/distress.
Staff lack confidence and adequate communication skills
Professionals fear not being able to answer questions.
Paternalistic view
Clinicians and carers may be worried that a patient will make unrealistic demands that they will not be happy to implement
They feel they're coping anyway
They would rather deal with the situation in a crisis.
Families do not want the person to have to think about the future
A denial of future needs.
Neither patients nor clinicians think to discuss it
Most patients do not have a community psychiatric nurse and there are not enough resources for this.
They are not of much practical use apart from the areas covered by law (i.e. mental capacity act, and area overseen by the OPG)
Late diagnosis

Figure legends

Figure 1: Extract from instructions and items from round 3 Delphi questionnaire showing those items concerning *how* ACP should be explained to a person with dementia which had not reached consensus by the end of round 2.

Table titles

Table 1: Items achieving consensus across 80% Delphi panel members about what, when, with whom and how to address ACP with dementia

Table 2: Items not reaching consensus, concerning what, when, how and who should be involved in ACP with people with dementia

Table 3: Consensus items on why so few people with dementia take part in ACP

Table 4: Items failing to achieve consensus regarding why so few people with dementia take part in ACP