**Online Supplement**

**Table 1.** Delphi study methods and the process of achieving of consensus

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| **Round** | **Design** | **Input and participants** | **Timeline** | **Criteria for evaluating consensus and result** |
| 1 | Qualitative | Evidence and expertise  -literature  -core group of 12 experts from 6 countries | April 2011 – March 2012 | **Criteria:**  No formal or external evaluation.  **Result:**  input for round 2. |
| 2 | Quantitative online survey with qualitative component (open-ended feedback) – first phase | Expert panel; 64 of 89 (72%) responded, and evaluated:  -11 domains  -57 recommendations  -statements about applicability in dementia stages (1), best practice and a Figure on care goals,  -provided demographics and other characteristics (descriptive) | -19 April–28 May 2012 (initial deadline: April 30; in total: 40 days open for feedback)  -during this period, 3 general and 2 personal reminders to non-respondents  -June 2012: revisions with core group. | **Criteria:**  -for domains and an overall rating, we required a minimum mean of 8 on the 0-10 importance scale.  -for recommendations, based on median, IQR and % agreement on the 5-point agreement scale, we distinguished very high, high, moderate, low, no (dis)agreement.\*  **Result:**  -*accepted* 10 of 11 domains  -*accepted* recommendation as consensus which was defined as very high or high agreement or disagreement (51 recommendations)  -*fed back* recommendation to panellists in round 3 with moderate or low agreement or disagreement (6 recommendations and Figure on care goals  -*rejected* recommendation with no agreement (0)  -statement on applicability in care goals only important in severe dementia: low disagreement (van der Steen, EAPC *et al.*, 2014).  -revisions in explanatory text based on feedback |
| 3 | Quantitative online survey with qualitative component (open-ended feedback) – second phase | Expert panel; 59 of the 64 responded  -2 domains (***1, applicability accepted but revised*,** and 5, prognostication)  -6 recommendations (***1.2, 1.4***, 5.1, 5.2, 6.4, 6.5)†  -a revised Figure on care goals  -2 other statements about applicability in dementia stages  -prioritized domains for research agenda (descriptive) | 15 June–22 August 2012 (69 days) open for feedback; longer because of summer  -during this period, 2 general and 4 personal reminders | **Criteria**: same as above  **Result:**  -*accepted* the domains  -*accepted* recommendation if consensus which was defined as very high or high agreement or disagreement (2; recommendations ***1.4*** and 5.1)  -*fed into next round* with moderate or low agreement or disagreement (4, and the explanation of the Figure)  -*rejected* with no agreement (0)  -noted that no consensus was achieved on the applicability through dementia stages (low and no agreement; van der Steen, EAPC *et al.*, 2014).  -revisions in explanatory text based on feedback |
| 4 | Quantitative email round | Core group: 5 of 12 members developed an alternative based on the feedback in round 3; the other 7 members, blinded for the version of the recommendations that fed into round 3, indicated their preference.  -4 recommendations (***1.2****,* 5.2, 6.4, 6.5)†  -explanation of Figure on care goals | Late August – mid October 2012 | **Criterion:**  to be adopted, we required at least 5 of 7 (the others of the core group) preferring the alternative.  **Result:**  - *accepted* as consensus (2 recommendations: ***1.2*** and 5.2)  - *no further revisions* but noted moderate consensus only was achieved (recommendations 6.4 and 6.5)  - *further improvement* of explanatory text with Figure on care goals based on feedback, and noted moderate consensus only was achieved  -revisions in explanatory text based on feedback |
| 5 | Qualitative | EAPC Board and national member organizations | -Late October – December 2012 input from EAPC Board and national member organizations  -January 2013, last adaptations with core group  -February 2013, Board approval | Revisions in explanatory text only. |

IQR = interquartile range. EAPC = European Association for Palliative Care

\* Response options of the agreement scale were coded as: strongly disagree’ (1), ‘moderately disagree’ (2), ‘neither agree, nor disagree’ (3), ‘moderately agree’ (4) and ‘strongly agree’ (5). Criteria: very high agreement = a median of 5 and an IQR of 0 and ≥80% scoring a 4 or 5; high agreement = a median 5 and an IQR ≤1 and ≥80% scoring a 4 or 5; moderate agreement = a median of 4–5 and an IQR ≤2 and ≥60% scoring a 4 or 5; low agreement = a median of 4–5, and an (IQR ≤ 2 or ≥ 60% scoring a 4 or 5); no agreement = median 4-5 otherwise, median >2 and <4. In parallel, we defined, for example, very high disagreement with median 1 and IQR = 0 and ≥80% scoring 1 or 2 (full consensus on very high disagreement) (van der Steen, EAPC *et al.*, 2014).

†Numbers refer to recommendations in the domains of ***Applicability of palliative care*** (***domain 1*;** see also Table 3), Prognostication and timely recognition of dying (5), and Avoiding overly aggressive, burdensome or futile treatment (6) (van der Steen, EAPC *et al.*, 2014).

**Box 1. Delphi study background**

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| Delphi studies   * A Delphi study provides a “process gain” (groups perform better than their best member), and is based upon “human experience and agreement as the basis for truth” (Powell, 2003). * Typical of Delphi studies are its   -anonymity: protecting results from undue influence of group conformity, prestige, power, and politics;  -iteration: allowing for change of opinions;  -controlled feedback: results of previous rounds are communicated; and  -group statistical response (De Vet *et al*., 2005).  Evaluation and defining consensus   * Delphi studies, including studies in palliative care, employ different formats for evaluation, for example, level of agreement (Jünger *et al*. 2012), relevance (Pigni *et al*., 2010), importance (de Vos *et al.,* 2008) and usefulness (Engels *et al*., 2005). * There are also no strict rules regarding consensus levels for Delphi studies (Powell, 2003; Steele et al., 2008) and different cut offs for consensus have been used.   -Proportions of consensus or agreement defined in different ways may range between 51% and 100% (Hasson *et al*., 2000; Powell, 2003; Steele *et al*., 2008).  -Some incorporate a measure of deviation (Froud *et al*., 2011)  -Others have defined consensus as less dispersion over time (Holey *et al*., 2007; Steele *et al*., 2008).  The panel   * In Delphi studies, panellists should be knowledgeable to provide information for the consensus-building process (Powell, 2003; Gordon, 1994). * The panel may form a heterogeneous group and minority perspectives may be actively recruited (Iqbal and Pipon-Young, 2009) * Representativeness in numbers is not needed (Powell, 2003). * The size of the panel may vary from just a few to several thousands of participants (Iqbal and Pipon-Young, 2009). |

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