

## **Definition and recommendations for advance care planning: An international consensus**

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## **Abstract**

Advance care planning (ACP) is increasingly implemented in oncology and beyond, but a definition of ACP and recommendations concerning its use are lacking. We conducted a formal consensus procedure to develop these. 109 experts (82 from Europe, 16 from North America, and 11 from Australia) rated ACP definitions and 41 recommendations. The panel's agreement per definition or recommendation was 68%- 100%. ACP was defined as "enabling individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate". Recommendations include adapting ACP to one's readiness, targeting its content as one's health condition worsens, and trained non-physician facilitators to support the ACP process. We present a list of outcome measures to enable pooling and comparing ACP study results. Our set can provide guidance for clinical practice, ACP policy and research.

## Introduction

Advance care planning (ACP) enables individuals to make plans about their future healthcare. Robust evidence from systematic reviews shows that ACP increases completion of advance care directives and occurrence of discussions about future healthcare in clinical practice, and improves consistency of care with patients' goals among a variety of patient populations, including oncology.<sup>1,2</sup> ACP can improve the quality of patient-clinician communication, reduce unwanted hospitalisations, increase the use of palliative care, and increase patient satisfaction and quality of life.<sup>1,2</sup> Recent evidence suggests a broad support for ACP among cancer patients and their healthcare providers.<sup>3</sup> Interest in ACP continues to grow, as indicated by a rising number of scientific publications, programmes, laws, and public awareness campaigns. At the same time, several challenges in ACP require greater consensus.

First, the concept and content of ACP varies considerably. Originally, ACP was conceptualised as the mere completion of an advance care directive to be used when the individual's capacity to indicate preferences had been lost. Recently, ACP has increasingly been considered as a complex process that includes personal reflection on one's wishes, the appointment of a healthcare representative, discussions with clinicians about one's wishes, completion of an advance care directive, and healthcare system changes. This has resulted in growing interest in ACP beyond geriatric populations, such as in oncology.<sup>3</sup> Prior initiatives to define ACP have limited generalisability as they are mostly restricted to North America or the UK,<sup>4-7</sup> or to specific patient groups or disciplines.<sup>6,8</sup> Secondly, there is a need for guidance regarding the timing of ACP. Introducing ACP too early may lead to reluctance to engage in ACP. However, engaging in ACP in the face of a crisis or shortly before dying may be too late.<sup>9</sup> A third challenge in ACP is that differences in patients' preferences, knowledge, and health literacy may complicate healthcare professionals' navigation of ACP.<sup>10</sup> Lastly, there is an urgent need to determine the most relevant outcome measures for evaluating ACP.

To date, there is no consensus regarding the definition of ACP, nor are there practice recommendations that are applicable to a variety of cultural settings and personal values. This hinders the development of ACP programmes and the evaluation of ACP's effectiveness. Therefore, we aimed to: (1) Develop a consensus definition of ACP; (2) Present recommendations for ACP that can be used by healthcare providers, policy makers and researchers across a broad spectrum of patient populations, disease categories, and cultures.

## Methods

An international taskforce consisting of 15 recognised experts from eight countries (BE, CAN, DE, IRL, IT, NL, UK, USA) conducted a five-round Delphi study to build a systematic consensus on ACP. The European Association for Palliative Care (EAPC) Board commissioned this consensus project and invited JR and IK to chair the taskforce, based on their expertise in ACP and interdisciplinary and international comparative prior work. They invited to the taskforce well-known experts in ACP with the aim to comprise an international and interdisciplinary group, including experts from a range of regional areas, experts with clinical experience and those with research experience, experts from oncology, palliative care, geriatrics and ethics. These experts were identified either through their publication and citation track record or through contacts from the professional network of JR and IK or that of the EAPC Board. Rounds 1 and 5 used a qualitative approach, while Rounds 2, 3 and 4 were structured. As defined by the standard Delphi process, the structured rounds were characterised by anonymity (protecting the Delphi results from the influences of group conformity), iteration (allowing for change of opinions), and controlled feedback (communicating the results of the previous round).<sup>11,12</sup>

### Round 1

In June 2014, during a two-day meeting at the Netherlands Institute for Advanced Study in Wassenaar (the Netherlands), the taskforce established 2 draft definitions and 5 core domains of

ACP: elements, roles and tasks, timing, policy and regulation, and evaluation. We opted to establish an extended definition to be used in, for instance, research and education of health care staff, and a brief definition for practical use. To address each domain in detail, working groups were set up which consisted of four to five taskforce members. Within each domain, recommendations were developed, based as much as possible on evidence derived from the literature and on expert opinion. We studied the literature (in 2014 and updated in 2016) in three ways. First, we conducted a meta-review.<sup>13</sup> We searched PubMed for publications with the term “advance care planning” and included reviews and meta-analyses. The search was limited to title or abstract search fields. Reviews could include quantitative and qualitative studies. This resulted in 89 reviews and one meta-analysis that we studied, including all the publications in the respective reference lists. The studies were used to support the recommendations. Second, we searched for existing guidelines of position papers, by searching PubMed for publications with the term “advance care planning” combined with “guideline” or “position paper”. We performed a comparable search in Google, and additionally checked all identified reviews (including their references) for references to guidelines or position papers. This yielded five clinical practice guidelines.<sup>5-8,14</sup> Third, each working group conducted a specific PubMed literature search for each domain (definition, core elements, roles and tasks, timing, policy and regulation, and evaluation), combining the term “advance care planning” with relevant keywords for their section. For instance, the definitions formulated were based on 25 definitions derived from the literature, and we were able to leverage the work on the definition of ACP and outcomes ratings as conducted predominantly in North America.<sup>4</sup> The draft definitions and recommendations were discussed and improved eight times within the taskforce (by email and in face-to-face meetings and tele-meetings) over the course of one year. This process resulted in extended and brief definitions of ACP, along with 37 draft recommendations.

## **Round 2**

In September 2015, the extended and brief definition and the draft recommendations were presented to an expert panel through an online questionnaire using LimeSurvey software (<https://www.limesurvey.org/>). In a separate Word document, we provided the panellists with the definitions and recommendations including the supporting literature references to allow the panellists to study these as well. An overview of this literature, including the update in 2016, can be found in the table. Potential panel experts (including patient representatives) were identified through their publication and citation track record or through the professional networks of the members of the taskforce and that of the EAPC Board. In the selection, we aimed for an international and interdisciplinary group of ACP experts. The invited panellists were experts in ACP research, practice, and policy, with backgrounds in medicine, nursing, palliative care, psychology, ethics, law, and policy. Panellists also included nine patient representatives who were trained members of the “Expert Voices Group” of Marie Curie and who had first-hand experience with end-of-life care as a relative or friend, for instance, a 19-year old student who was closely involved in the provision of care for three close family members. To establish a multinational perspective, we invited experts from multiple countries (US, Canada, Australia, and different European regions). We invited 144 experts, of whom 124 agreed to participate (86%) and received the online questionnaire. Of these, 109 completed the questionnaire (response: 109/144=76%). The most common reason for declining participation was “lack of time”. The Appendix presents the characteristics of the expert panel. They originate from 14 countries. Of the 124 panellists, 83 indicated to work in clinical practice, mostly as a physician or a nurse. Of the 51 physicians, 34 were in the field of oncology or palliative medicine. The number of years that panellists worked in ACP was not asked.

For the definitions and each of the recommendations, panellists were asked to indicate the extent of their agreement on a 7-point Likert scale (answering categories: 1=strongly agree; 2=agree; 3=agree somewhat; 4=undecided; 5=disagree somewhat; 6=disagree; 7=strongly disagree). In addition, they could provide their feedback on the definitions and on each recommendation in text boxes, and specify whether there were important omissions. The panellists’ responses were used to calculate levels of agreement and consensus.<sup>15, 16</sup> Agreement is indicated in two ways: by the percentage of

respondents either agreeing or strongly agreeing with a definition or recommendation, and by the median score, which represents the 50th percentile value of opinions. A smaller median indicates more agreement; a median of 1 indicated very strong agreement, and a median of 2 indicated strong agreement.<sup>17</sup> Consensus was calculated by the interquartile range (IQR), which represents the distance between the 25th and the 75th percentile value of ratings. A smaller IQR indicates more consensus; an IQR of 0 or 1 indicated very strong consensus, and an IQR of 2 indicated strong consensus.<sup>18</sup> Open comments were all analysed line by line by the respective working group as well as by JR and IK, and recommendations were revised if appropriate. Recommendations that received very strong agreement and very strong consensus were accepted (or underwent small textual edits only). All other recommendations were adapted with respect to their content, wording, and/or ordering, or were eliminated (to reduce redundancy). Proposals for adaptations were discussed several times within the working groups and within the taskforce.

### **Round 3**

To maintain conformity between rounds, only those panellists who responded in Round 2 were asked to respond to revised recommendations in Round 3. In the third round (May 2016), Round 2 respondents (n=109) were provided the original set of two definitions and recommendations including median and IQR scores, as well as the revised set. Again, panellists could indicate the extent of their agreement on a 7-point Likert scale and provide their feedback. If recommendations had received very strong agreement and very strong consensus in the second round, experts were presented a choice between selecting the default option (that is, the median score of that recommendation in the previous round) or, alternatively, to rate the recommendation again. Of the 109 panellists from Round 2, 103 responded in Round 3 (94%).

### **Round 4**

Recommendations that received very strong agreement (a median of 1) and very strong consensus (an IQR of 0 or 1) were accepted (or underwent small textual edits only). The other recommendations were adapted by JR and IK, based on the panellists' comments. The revised set was sent to the 15 members of the taskforce in August 2016, who each independently indicated whether they agreed with the suggested changes per adapted recommendation (yes/no), and if not, whether they could suggest further improvements.

### **Round 5**

The set was adapted according to the final feedback of the taskforce. The full set was then sent to the EAPC Board of Directors.

### **Role of study sponsors**

The study sponsor had no role in the study design, in the collection, analysis, and interpretation of data, in the writing of the report or in the decision to submit the paper for publication. The corresponding author (JACR) confirms that she had full access to all data in the study and had final responsibility for the decision to submit for publication.

## **Results**

### **Summary of the rounds**

The flowchart in Figure 1 presents an overview of the five rounds. In Round 2, the extended definition was rated with a median of 2 and an IQR of 1, and the brief definition with a median of 2 and an IQR of 2. Furthermore, 28 of the 37 recommendations (78%) received very strong agreement and very strong consensus (a median of 1 and an IQR of 0 or 1). In Round 3, the extended definition was rated with a median of 2 and an IQR of 1, and the brief definition with a median of 2 and an IQR of 1. For 36 of the 44 recommendations (78%), agreement and consensus were very strong. In Round 4, twelve of the taskforce's 15 members rated the remaining set of eight recommendations.

Four recommendations received agreement by all members, the other four by 7 to 11 of the 12 members. The provided feedback mainly concerned small textual changes. These changes were made eventually resulting in a final set that reached consensus of the full taskforce. The full final set comprised of a brief definition, an extended definition, and 41 recommendations (including 14 ACP outcome measures). These are listed in the Table. The full final set was reviewed by the EAPC board members, who were unanimous in their support and had no suggested revisions.

### **Definition**

The box shows the extended and brief consensus definitions of ACP.

### **Box: Consensus definitions of advance care planning**

**Extended definition:** Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and healthcare providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they at some point be unable to make their own decisions.

**Brief definition of ACP:** Advance care planning enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate.

The brief consensus definition contains all the key elements of the extended consensus definition. A central element of the definitions is that ACP is considered to be a process which includes identifying values and defining goals and preferences for future medical treatment and care, and discussing these with family and healthcare providers. It may include the documentation of preferences or the appointment of a proxy decision maker. These preferences should be regularly reviewed. Other key points are that the scope of ACP is broader than the physical domain alone (and may include concerns across the psychological, social, and spiritual domains) and that ACP is not limited to specific patient groups (yet should concern individuals with decisional capacity). Both final definitions were rated with a median of 2 and an IQR of 1 in Round 3. Overall, 88% of panellists (versus 83% in Round 2) indicated that they agreed or strongly agreed with the extended definition, and 89% (versus 65% in Round 2) with the brief definition. In total, the panellists provided 97 comments with suggestions for improvement regarding the extended definition, and 88 regarding the brief definition. Adaptations of the extended and brief definitions predominantly concerned the addition that individuals must have decisional capacity to engage in ACP, the inclusion of the social domain, and the importance of reviewing preferences.

### **Recommendations**

The table presents the 41 consensus recommendations for ACP, along with their respective agreement and median scores, IQRs, and the number of comments provided by the panellists. Of the 41 recommendations, 36 (88%) received very strong consensus and very strong agreement, three (7%) strong agreement and very strong consensus, and two (5%) strong agreement and strong consensus.

The recommendations concern five domains of ACP: elements (12 recommendations), roles and tasks (six recommendations), timing (three recommendations), policy and regulation (five recommendations), and evaluation (15 recommendations).

### **Recommendations that received very strong agreement and very strong consensus**

Elements of ACP

Recommended elements of ACP concern the exploration of the individual's current understanding of ACP and the adaptation to one's readiness to engage in it. Furthermore, it is recommended that ACP should include the exploration of the individual's personal values and goals for future care. Where appropriate, ACP should include the provision of medical information (e.g. about diagnosis and prognosis) and the clarification of goals and preferences for future medical treatment and care (including an exploration of whether these are realistic). In addition, ACP should involve discussing the option of completing an advance care directive and of appointing a personal representative, along with determining their role, as per local legal jurisdiction. ACP should also encourage individuals to provide family and healthcare professionals with a copy of the advance care directive.

#### Roles and tasks

It is recommended that healthcare professionals tailor the ACP conversation to the individual's health literacy, style of communication, and personal values. Health care professionals need to have the necessary skills and display openness to discuss ACP and to provide individuals and their families with clear and coherent information. Furthermore, it is recommended that a trained non-physician facilitator can support an individual in the ACP process, and that the initiation of ACP can occur both in healthcare settings and non-healthcare settings. For medical elements of ACP (such as discussing diagnosis and exploring the extent to which goals and preferences for future medical treatment and care are realistic), healthcare providers are needed.

#### Timing of ACP

It is recommended that individuals can engage in ACP at any stage of their life, but that the ACP content can be more targeted when the individual's health condition worsens or as ageing progresses. In these circumstances, ACP conversations and documents should be updated regularly, as values and preferences may change over time. It is further recommended that public awareness of ACP should be raised.

#### Elements of ACP policy and regulation

It is recommended that advance care directives have both a structured (i.e. checkbox) and an open text format. Healthcare organisations are encouraged to develop triggers for the initiation of ACP, and set up reliable and secure systems to store copies of advance care directives in the patient's medical file. Governments, health insurers, and healthcare organisations are advised to secure appropriate funding and organisational support for ACP, and laws should recognise the results of an ACP process as legally binding guidance for medical decisions.

#### Evaluation of ACP

Depending on the study or project aims, we recommend a list of constructs to be assessed and high-quality outcome measures to be identified or developed, so that results can be standardised, pooled, and compared.

#### *Recommendations that received strong agreement and (very) strong consensus*

For 36 of 41 recommendations, agreement was very strong. For five recommendations, agreement was strong (a median of 2). These five concern ACP which includes an exploration of the extent to which the individual allows their personal representative leeway in decision-making (Recommendation #8), the need for healthcare providers with regard to clinical elements of ACP (Recommendation #18), the format of the advance care directive (Recommendation #22), and two recommended constructs to be assessed, i.e. self-efficacy and healthcare utilisation (Recommendations #27B and #27M).

## **Discussion**

For the first time, a unifying, transcultural, international consensus definition of ACP and recommendations for its application have been drafted through a rigorous, large international Delphi study. The recommendations guide the way in which ACP should be conducted and

integrated into healthcare, and suggest outcome measures of ACP. Most recommendations received full consensus from our multi-disciplinary panel, which also included patient representatives: the majority achieved this in one round, while others did so in subsequent rounds. This suggests that our recommendations are appropriate for a variety of healthcare settings, patient populations, and cultures. The high response rate from panellists implies that the issue is topical and of high relevance to clinical practice. We used hundreds of qualitative comments from panellists to improve the recommendations. The final definitions and recommendations provide important guidance for the delivery of high-quality ACP. We recommend their use in future studies and clinical programmes in order to facilitate the comparison and synthesis of findings across studies.

Our international consensus study offers wider generalisability than earlier initiatives to define ACP and previously published guidelines or position papers, as these were limited to specific patient groups<sup>6,8</sup> or to certain countries or cultures.<sup>4-7,14</sup> The definitions and recommendations resulting from this study highlight how the focus of ACP is shifting from eliciting treatment instructions to be used when an individual's decisional capacity has been lost, towards communication about goals and preferences for future medical care across the age and illness spectrum.<sup>18,19</sup> Other important elements are that the scope of ACP is broader than the physical domain alone (and may include concerns across the psychological, social, and spiritual domains) and that ACP is not limited to specific patient groups (yet should concern individuals with decisional capacity). With this new focus, the concept of ACP has become increasingly relevant for many patient populations, such as those in the areas of oncology, chronic diseases, and multi-morbidity, and both for patients and healthcare providers. However, recent evidence suggests that in oncology, ACP tends to be limited to the completion of documents.<sup>3</sup>

The definitions and recommendations reflect the value of ACP in providing care to people in different stages of their illness. Worldwide, the extent to which healthcare providers, patients, and relatives are willing and able to discuss issues related to disease progression and end-of-life care differs considerably, as does the extent to which such discussions are integrated into the healthcare system. Our recommendations therefore encourage an individualised approach to ACP, e.g. one that is tailored to whether or not people want to engage in ACP, to disease stage, and to local legal and cultural circumstances. Finally, the results reflect the reality that in many countries patients can express their preferences for care, but have different degrees of authority to refuse treatments and limited authority to request treatments themselves.

This study has a number of strengths. First, the resulting recommendations owe their credibility to the rigorous use of the Delphi technique. We followed the reporting standard for Conducting and Reporting of Delphi Studies (CREDES).<sup>20</sup> This included, for instance, the appointment of independent researchers to coordinate the study, the presence of a clear consensus criterion, clear descriptions of how the synthesis of responses in one survey round was used to design the subsequent round, and the review and approval of the final draft by an external board before publication and dissemination. Second, where possible, we built our definitions and recommendations on the available evidence about ACP by studying 90 published reviews about ACP and their respective references. Third, the Delphi methodology allowed the involvement of a network of 109 geographically dispersed experts from 14 countries. These participants represented various professional backgrounds and work settings. In the expert panel, we also included nine patient representatives, an approach which is increasingly considered to add relevance to study results. Our response rate of 76% indicates that the risk of selection bias is fairly limited. Fourth, while Delphi studies aim to determine the extent to which experts agree about a construct (agreement) and the degree to which they agree with each other and resolve disagreements (consensus), firm rules regarding sufficient consensus and agreement levels are lacking. We used conservative cut-off levels (median of 1 indicating very strong agreement and an IQR of 0 or 1 indicating very strong consensus), adding robustness to our study outcomes. Fifth, the high degree of consensus and agreement among panel members contributes to the validity of our findings. Finally, the hundreds of



comments that were provided by panel members were systematically studied and used to improve the definitions and recommendations.

We acknowledge the following limitations of our study. Systematic literature reviews were not feasible given the plenitude of scientific articles published on the topic of ACP with varying concepts, research questions, and methodology. In addition, the recommendations may need updating as more evidence becomes available. Furthermore, we acknowledge that both the evidence from the scientific literature and the expert views predominantly originate from resource-rich countries such as Europe, North America and Australia. There were no Asian, South American or African representatives. It is likely that cultural adaptations will be needed if definitions and recommendations are to be applied in regions that were not represented in the Delphi panel. In that case we recommend conducting an additional Delphi study. Lastly, our definitions and recommendations need validation in different populations. Whether the use of the recommendations will in fact improve processes or outcomes of care is a matter that warrants further study.

As for future steps, we recommend the translation, dissemination, and implementation of these definitions and recommendations for use in practice and policymaking. We also recommend the evaluation of the recommendations' use in clinical practice and policy. Future work may also include formal priority setting exercises of the recommendations.<sup>21</sup> We are continuing our work to define ACP outcome domains and constructs.<sup>4</sup> For instance, we are currently working in a separate Delphi study to develop a set of recommendations to standardize ACP constructs and instruments.<sup>22, 23</sup> Furthermore, we encourage the identification of measurement tools to assess the outcomes of ACP as recommended. Additionally, to enhance the wide applicability of our recommendations, we have aimed at providing general recommendations across disciplines. Future work may further specify the recommendations for specific disciplines, health care systems and local legal jurisdictions. We recommend that further attention be paid to ACP in the context of patients with limited capacity, as this was outside the scope of our work.

## **Conclusion**

In conclusion, our large international Delphi panel was able to come to a consensus on an ACP definition and recommendations. This represents an important first step in providing clarity with a view to further policy and research in this field. We hope these recommendations will have a catalyst effect to further benefit patients and their relatives by facilitating the provision of care to oncology patients and others that is aligned to their preferences and goals, thus contributing to improved quality of life.

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## **Conflict of Interest Statement**

The authors declared no conflicts of interest.

## **Contributions**

All authors (J Rietjens, R Sudore, M Connolly, J van Delden, M Drickamer, M Droger, A van der Heide, D Heyland, D Houttekier, D Janssens, L Orsi, S Payne, J Seymour, R Jox, I Korfage) have made substantial contributions to the conception (JR, RS, JvD, MDri, AvdH, DHo, DJ, LO, SP, JS, RJ, IK) and design (JR, RS, MC, JvD, MDri, AvdH, DHe, DHo, DJ, LO, SP, JS, RJ, IK) of the study, to the literature

search (JR, IK), the data-collection (JR, IK, MDro), and to the draft and critical revision of the manuscript (JR, RS, MC, JvD, MDri, MDro, AvdH, DHe, DHo, DJ, LO, SP, JS, RJ, IK). All authors provided final approval of the final version and agree with submitting the final version to Lancet Oncology.

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### Appendix Characteristics of Delphi panelists (n= 109)

<b>Age</b>	
Mean (SD)	50.3 (10.3)
Age range	19-74 years
<b>Sex, n (%)</b>	
Female	68 (62%)
<b>Country of residence, n (%)</b>	
UK	19 (17)
USA	14 (13)
The Netherlands	14 (13)
Australia	11 (10)
Germany	10 (9)
Italy	9 (8)
Spain	9 (8)
Ireland	8 (7)
Other <sup>1</sup>	15 (15)
<b>Expertise<sup>2</sup>, n (%)</b>	
Medicine <sup>2,3</sup>	51 (47)
Researcher <sup>2,4</sup>	52 (48)
Ethics, Philosophy and Law	26 (24)
Nursing	24 (22)
Psychology	12 (11)
Patient representative	9 (8)
Policy	8 (7)
Social worker	2 (2)
Teacher	2 (2)
Other <sup>5</sup>	1 (1)

<sup>1</sup>. Other: Belgium, Denmark, Canada, Slovenia, France, Portugal

<sup>2</sup>. More than one option possible

<sup>3</sup>. Expertise included: Palliative medicine (n=32); Geriatrics (n=10); General practice (n=8); Critical care / intensive care medicine (n=6); Medical ethics (n=4); Internal medicine (n=3); Advanced illness medicine (n=2); Oncology (n=2); Psychiatry (n=2); Neurology (n=1); Pediatrics (n=1); Pulmonology (n=1); Legal medicine (n=1); Unknown (n=1).

<sup>4</sup>. Researchers were specialized in Palliative care (n=25); Advance care planning (n=12); Ethics (n=7); Health communication (n=6); End of life decision making (n=5); Social science (n=4); Psycho-oncology (n=3); Ageing (n=2); Dementia (n=2); Law (n=2); Qualitative research (n=2); Quality of life (n=1); Death (n=1), Epidemiology (n=1); Outcomes (n=1); Policy (n=1); Frailty (n=1); Pain management (n=1); and/or Services (n=1).

<sup>5</sup>. Other: ACP program coordinator

**Table Final set of recommendations and ratings as provided by the panel (n=103) in Delphi round 3**

	Agreement		IQR	No. of written comments by panel in Rounds 2 & 3
	% <sup>1</sup>	median		
<b>Recommended elements of ACP</b>				
1. The ACP process includes an exploration of the individual's understanding of ACP and an explanation of its aims, elements, benefits, limitations and legal status.	91	1	1	53
2. ACP should be adapted to the individual's readiness to engage in the ACP process <sup>3,10,24-26</sup> .	99	1	0	22
3. ACP includes the exploration of the individual's health-related experiences, knowledge, concerns and personal values across the physical, psychological, social and spiritual domains <sup>27-29</sup> .	99	1	0	28
4. ACP includes exploring goals for future care <sup>27</sup> .	100	1	0	34
5. Where appropriate, ACP includes information about diagnosis, disease course, prognosis, advantages and disadvantages of possible treatment and care options <sup>9,30</sup> .	96	1	0	33
6. ACP may include clarification of goals and preferences for future medical treatment and care. If appropriate, it includes exploration of the extent to which these goals and preferences are realistic <sup>27,30,31</sup> .	83	1	1	55
7. ACP includes discussing the option and the role of the personal representative, who may act on behalf of the individual when they are unable to express their preferences, as per local legal jurisdiction <sup>32</sup> .	94	1	1	50
8. ACP includes an exploration of the extent to which the individual allows their personal representative to take into consideration their current clinical context in addition to their prior stated preferences when expressing preferences on their behalf <sup>33-35</sup> .	74	2	2	31
9. ACP may include the appointment of a personal representative and documentation thereof <sup>2,32,36</sup> .	96	1	0	39
10. ACP includes information about the option and role of an advance care directive (which is a document to record values, goals and preferences to be considered when he or she is unable to express their preferences) as per local legal jurisdiction <sup>32</sup> .	95	1	0	37
11. ACP may include the completion of an advance care directive <sup>2,32,37-39</sup> .	94	1	0	25
12. ACP includes encouraging an individual to provide family and healthcare professionals with a copy of the advance care directive.	82	1	1	23
<b>Recommended roles and tasks</b>				
13. Healthcare professionals should adopt a person-centered approach when engaging in ACP conversations with individuals and, if the individual prefers so, their family. This requires tailoring the ACP conversation to the individual's health literacy, style of communication, and personal values <sup>24,25,40-44</sup> .	100	1	0	25
14. Healthcare professionals need to have the necessary skills and display an openness to talk about diagnosis, prognosis, death and dying with individuals and their family <sup>6,27,40,43,45-48</sup> .	99	1	0	34
15. Healthcare professionals should provide individuals and their family with clear and coherent information concerning ACP <sup>49</sup> .	99	1	0	21
16. A trained non-physician facilitator can support an individual in the ACP process <sup>1,50-57</sup> .	91	1	0	46
17. The initiation of ACP (that is, the exploration of the individual's experiences, knowledge, personal values, and concerns) can occur in healthcare settings or non-healthcare settings <sup>58,59</sup> .	98	1	0	31
18. Appropriate healthcare providers are needed for clinical elements of ACP, such as discussing diagnosis, prognosis, treatment and care options, exploring the extent to which goals and preferences for future medical treatment and care are realistic and documenting the	68	2	2	39



discussion in the medical file <sup>60</sup> .				
<b>Recommended timing of ACP</b>				
19. Individuals can engage in ACP in any stage of their life, but its content can be more targeted as their health condition worsens or as they age <sup>9,61-63</sup> .	96	1	0	39
20. As values and preferences may change over time, ACP conversations and documents should be updated regularly, e.g. as the individual's health condition worsens, their personal situation changes, or as they age <sup>24,27,61,64-66</sup> .	99	1	0	18
21. Public awareness of ACP should be raised. This concerns the aims and content of ACP, as well as its legal status and how to access it.	96	1	0	17
<b>Recommended elements of policy and regulation</b>				
22. Advance care directives need both a structured format to enable easy identification of specific goals and preferences in emergency situations, and an open text format so individuals can describe their values, goals, and preferences <sup>60,67</sup> .	80	2	1	57
23. Healthcare organizations should develop potential triggers for the initiation of ACP including but not limited to age, degree of illness, and transitions in care <sup>9,27,66,68-71</sup> .	95	1	0	31
24. Healthcare organizations need to create reliable and secure systems to store copies of advance care directives in the medical file so that these are easy to retrieve, transfer, and update <sup>27,72-74</sup> .	97	1	0	29
25. Governments, health insurers and healthcare organizations should secure appropriate funding and organizational support for ACP <sup>67,75,76</sup> .	100	1	0	20
26. Laws should recognize results of an ACP process (such as surrogate decision making and advance care directives) as legally binding guidance of medical decision making.	91	1	0	37
<b>Recommended evaluation of ACP</b>				
27. Depending on the study- or project aims, we recommend the following constructs be assessed:				
A. Knowledge of ACP (rated by individuals, family, and healthcare professionals)	91	1	1	
B. Self-efficacy to engage in ACP (rated by individuals, family, and healthcare professionals)	84	2	1	
C. Readiness to engage in ACP (rated by individuals, family, and healthcare professionals)	92	1	1	
D. Identification of goals and preferences	96	1	0	
E. Communication about goals and preferences with family	96	1	1	
F. Communication about goals and preferences with healthcare professionals	98	1	1	
G. Identification of a personal representative	92	1	1	
H. Documentation of goals and preferences	95	1	0	
I. Revision of ACP discussions and documents over time	96	1	0	
J. Extent to which ACP was considered meaningful and helpful (rated by individuals, family, and healthcare professionals)	96	1	0	
K. Quality of ACP conversations (rated by individuals, family, facilitators and/or healthcare professionals)	90	1	1	
L. Satisfaction with the ACP process (rated by individuals, family, and healthcare professionals)	94	1	1	
M. Healthcare utilization	83	2	1	
N. Whether care received was consistent with the individual's expressed goals and preferences	92	1	0	
28. We recommend identifying or developing outcome measures regarding the aforementioned constructs so results can be pooled and compared across studies or projects. These outcome measures should have sound psychometric properties, be sufficiently brief, and validated within relevant populations <sup>77</sup> .	89	1	1	37

<sup>1</sup> Sum of Likert response options 'Agree strongly' and 'Agree'