Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care

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Advance care planning (ACP) is increasingly implemented in oncology and beyond, but a definition of ACP and recommendations concerning its use are lacking. We used a formal Delphi consensus process to help develop a definition of ACP and provide recommendations for its application. Of the 109 experts (82 from Europe, 16 from North America, and 11 from Australia) who rated the ACP definitions and its 41 recommendations, agreement for each definition or recommendation was between 68–100%. ACP was defined as the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate. Recommendations included the adaptation of ACP based on the readiness of the individual; targeting ACP content as the individual's health condition worsens; and, using trained non-physician facilitators to support the ACP process. We present a list of outcome measures to enable the pooling and comparison of results of ACP studies. We believe that our recommendations can provide guidance for clinical practice, ACP policy, and research.

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Introduction

Advance care planning (ACP) enables individuals to make plans about their future health care. Robust evidence from systematic reviews shows that ACP increases the completion of advance care directives and occurrence of discussions about future health care in clinical practice and improves consistency of care with patients' goals in various patient populations, including oncology.[1,2] ACP can improve the quality of patient–clinician communication, reduce unwanted admission to hospitals, increase the use of palliative care, and increase patient satisfaction and quality of life.[1,2] In 2016, a systematic review[3] suggested broad support for ACP among patients with cancer and their health-care providers. Interest in ACP continues to grow, as indicated by an increasing number of related scientific publications, programmes, laws, and public awareness campaigns on the topic. However, several challenges in ACP require greater consensus before its potential can be fully realised.

First, the concept and content of ACP substantially varies. Originally, ACP was conceptualised as only the completion of an advance care directive, to be used when the individual's capacity to indicate preferences had been lost. More recently, ACP is increasingly considered to be a complex process that includes personal reflection and discussion with clinicians about the patient's wishes, the appointment of a health-care representative, completion of an advance care directive, and changes to the health-care system. These developments have resulted in growing interest in ACP beyond geriatric study, such as in oncology.[3] Previous initiatives to define ACP have poor generalisability because they are mostly restricted to North America or the UK,[4–7] or to specific patient groups or disciplines.[6,8] Second, there is a need for guidance regarding the timing of ACP. For example, introducing ACP too early could lead to a reluctance to engage in ACP, whilst engaging in ACP in the face of a crisis or shortly before dying could be too late.[9] A third challenge in ACP is that differences in patient preference, knowledge, and health literacy could complicate navigation of ACP by health-care professionals.[10] Finally, 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 any practice recommendations that are applicable to various cultural settings and personal values. This lack of agreement hinders the development of ACP programmes and the evaluation of ACP's effectiveness. Therefore, we aimed to develop a consensus definition of ACP and present recommendations for ACP that can be used by health-care 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 (Belgium, Canada, Germany, Ireland, Italy, Netherlands, UK, and USA) designed 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 JACR and IJK to chair the taskforce on the basis of their expertise in ACP and previous interdisciplinary and international comparative work. JACR and IJK invited well-known experts in ACP to the taskforce with the aim of forming an international and interdisciplinary group that included experts from a range of regions, with clinical experience and with research experience, in the fields of oncology, palliative care, geriatrics, and ethics. These experts were identified either through their

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publication and citation record, or through contacts from the professional network of JACR and IJK or that of the EAPC board. Rounds 1 and 5 used a qualitative methodological approach, whereas rounds 2, 3, and 4 required quantitative assessment. The figure shows the number of participants and how the recommendations were adapted at each stage. As defined by the standard Delphi process, the structured rounds were characterised by anonymity (protecting the Delphi results from the effects of group conformity), iteration (allowing for a change of opinion), and controlled feedback (communicating the results of the previous round).[11,12]

Round 1

In June 2014, during a two-day meeting at the Netherlands Institute for Advanced Study (Wassenaar, Netherlands), the taskforce established two draft definitions and five core domains: core 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 that consisted of four to five taskforce members. Within each domain, recommendations were developed based as much as possible on evidence derived from the medical literature and on expert opinion. Done in 2014, and updated in 2016, we studied the literature in three ways. First, we did a meta-review.[13] This meta-review was conducted by searching PubMed for publications with the term "advance care planning", and only included reviews and meta-analyses. The search was limited to the title and abstract search fields. This search resulted in 89 reviews and one meta-analysis, of which their respective reference lists were also reviewed. These studies were used to support the initial 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 did a similar search in Google, and checked all identified reviews (including their reference lists) for references to guidelines or position papers. This search found five clinical practice guidelines.[5–8,14] Third, each working group did a specific PubMed literature search for each domain (ACP definition, core elements, roles and tasks, timing, policy and regulation, and evaluation), combining the term "advance care planning" with relevant keywords for their section.

The definitions of ACP were formulated based on 25 definitions derived from the literature search. Additionally, the working groups were able to use a previous study on the definition of ACP and outcomes ratings that was predominantly done in North America.[4] The draft definitions and recommendations were discussed and improved eight times by each working group and the taskforce (by email and in face-to-face and telephone meetings) over the course of a year. This process resulted in an extended and a brief definition of ACP and 37 draft recommendations.

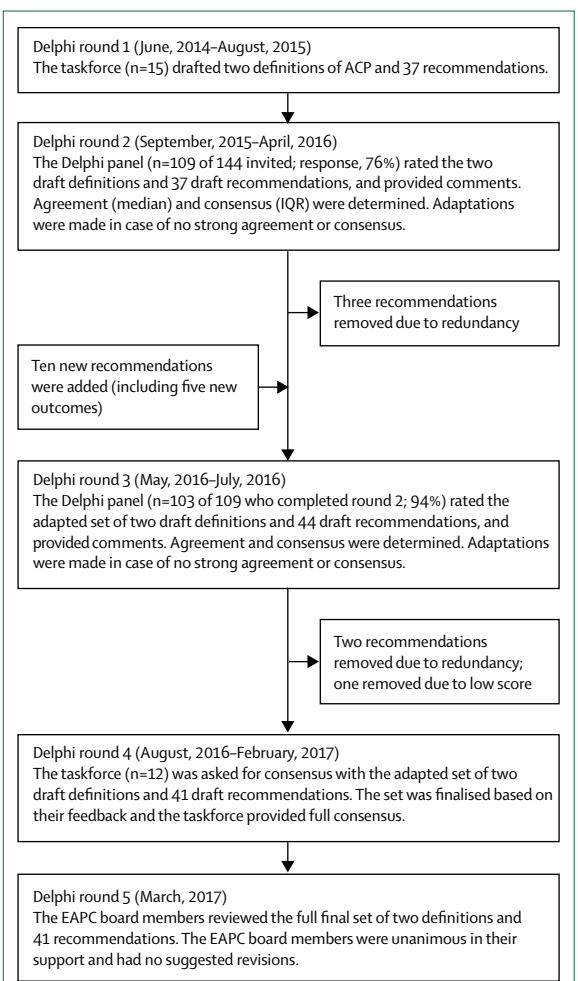

***Figure*: Delphi consensus process on the definition and recommendations of ACP**
ACP=Advance care planning. EAPC=European Association for Palliative Care.

Round 2

In September 2015, the extended and brief definition of ACP and the draft recommendations were presented to an expert panel through an online questionnaire using LimeSurvey. In a separate document, we provided the panellists with the definitions and recommendations, including the supporting literature references. Potential panel experts (including patient representatives) were identified through their publication and citation record or through the professional networks of the members of the taskforce and that of the EAPC board. In the selection process, we aimed for an international and inter-disciplinary 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, one participant was a 19-year-old student who was closely involved in the provision of care for three close family members. We invited 144 experts (from USA, Canada, Australia, or Europe), of whom 124 (86%) agreed to participate. Of these experts, 109 (76%) completed the questionnaire. The appendix presents the characteristics of the Delphi panellists, who were from 14 different countries. Of the 109 panellists, 83 worked in clinical practice, mostly as a physician or as a nurse. Of the 51 physicians, 34 worked in oncology or palliative medicine. The number of years that panellists had 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 (1=strongly agree; 2=agree; 3=agree somewhat; 4=undecided; 5=disagree somewhat; 6=disagree; 7=strongly disagree). The panellists could also provide their feedback on the definitions and on each recommendation and specify whether there were any important omissions by writing their remarks in text boxes. The panellists' responses were used to calculate the levels of agreement and consensus.[15,16] Agreement was indicated in two ways: by the percentage of respondents either agreeing or strongly agreeing with a definition or recommendation; and, by a median score, which represents the 50th percentile value of opinions. A smaller median indicated more agreement—a median of 1 indicated very strong agreement, and a median of 2 indicated strong agreement.[17] Consensus was calculated using the IQR. The smaller the IQR, the greater the consensus: an IQR of 0 or 1 indicated very strong consensus, whilst an IQR of 2 indicated strong consensus.[17] Open-text comments were analysed in detail by the respective working group of each domain, and by JACR and IJK. Recommendations were revised if appropriate. Recommendations that received very strong agreement and very strong consensus were accepted or underwent minor edits only. All other recommendations were adapted with respect to their content, wording, or ordering, or a combination of these, or were eliminated to reduce redundancy. Proposals for adaptations were discussed within the working groups and within the taskforce.

Round 3

To maintain conformity between rounds, only those panellists who responded to the online questionnaire 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 given the original set of two definitions and recommendations, including median and IQR scores, and the revised set of definitions and recommendations. Again, panellists could indicate the extent of their agreement on a 7-point Likert scale and give their feedback. If recommendations had received very strong agreement and very strong consensus in the second round, experts were presented with 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 who responded in round 2, 103 (94%) responded in round 3.

Round 4

See Online for appendix

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

Round 5

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

Findings

The panel and table present the definitions and final recommendations of ACP. In round 2, the extended definition was given a median rating of 2 (strong agreement) and an IQR of 1 (very strong consensus), and the brief definition was given a median of 2 (strong agreement) and an IQR of 2 (strong consensus). In this round, 28 (76%) of the 37 recommendations received very strong agreement and very strong consensus (a median of 1 and an IQR of 0 or 1).

In round 3, ten recommendations were added and three were removed because of redundancy (figure). The extended definition was rated with a median of 2 (strong agreement) and an IQR of 1 (very strong consensus), and the brief definition was given a median score of 2 (strong agreement) and an IQR of 1 (very strong consensus). For 36 (82%) agreement and consensus were very strong.

In round 4, two recommendations were removed—one for redundancy and one because of a low score (figure). Of the taskforce's 15 members, 12 members rated the remaining set of eight recommendations that did not reach agreement or consensus in round 3. Of these eight recommendations, four received agreement by all members, whilst the other four received agreement from seven to 11 of the 12 taskforce members. Feedback mainly concerned minor changes to the phrasing. These changes were made, eventually resulting in a final set of recommendations that reached consensus by the full taskforce. The full final set comprised a brief definition of ACP, an extended definition, and 41 recommendations (including 14 ACP outcome measures). The full final set

***Panel*: 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 health-care 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

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 health-care providers, and to record and review these preferences if appropriate.

was reviewed by the EAPC board members, who were unanimous in their support and had no suggested revisions.

Definition

The panel shows the extended and brief consensus definitions of ACP. 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 that includes the identification of values and defining goals and preferences for future medical treatment and care and discussion of these factors with the patient's family and health-care providers. ACP can include the documentation of preferences and 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 can include concerns across the psychological, social, and spiritual domains. Furthermore, ACP is not limited to specific patient groups but should concern individuals with decisional capacity. Both final definitions were rated with a median of 2 (strong agreement) and an IQR of 1 (very strong consensus) in round 3. Overall, 91 (88%) panellists (versus 90 (83%) in round 2) indicated that they agreed or strongly agreed with the extended definition, and 92 (89%) (versus 71 [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 comments 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 shows the 41 consensus recommendations for ACP, along with their respective agreement and median scores, IQRs, and the number of comments provided by the panellists. The appendix provides an overview of agreement and consensus scores of the 41 recommendations, indicating that median scores and IQRs were skewed towards very strong agreement and consensus ratings. Of the 41 recommendations, 36 (88%) received very strong consensus and very strong agreement, three (7%) received strong agreement and very strong consensus, and two (5%) received strong agreement and strong consensus. Of the five domains of ACP: 12 recommendations were related to elements of ACP, six on the roles and tasks, three on timing, five on policy and regulation, and 15 on evaluation.

Recommendations that received very strong agreement and very strong consensus

Recommendations relating to the elements of ACP concern the exploration of the individual's current understanding of ACP and the adaptation of the process to a patient's readiness to engage in the ACP process. Furthermore, it is recommended that ACP should include the exploration of an individual's personal values and goals for future care. Where appropriate, ACP should include the provision of medical information (eg, about diagnosis and prognosis) and the clarification of goals and preferences for future medical treatment and care (including a discussion of whether these are realistic). Additionally, 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 health-care professionals with a copy of the advance care directive.

With regards to the roles and tasks domain, it was recommended that health-care 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 show openness to discuss ACP and to provide individuals and their families with clear and coherent information. Furthermore, it is recommended that a trained facilitator who is not a physician supports an individual in the ACP process and that the initiation of ACP can occur within or outside of a health-care setting. 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), health-care providers are needed.

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

For policy and regulation, it was recommended that advance care directives have both a structured (ie, checkbox) and an open-text format. Health-care 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 a patient's medical

	Agreement		Inter-quartile range‡	Comments that were written by the panel in rounds 2 and 3 (n)
	Percentage*	Median†		
Recommended elements of ACP				
(1) The ACP process includes an exploration of the individual's understanding of ACP and an explanation of the aims, elements, benefits, limitations, and legal status of ACP	91	1	1	53
(2) ACP should be adapted to the individual's readiness to engage in the ACP process[3,10,18–20]	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[21–23]	99	1	0	28
(4) ACP includes exploring goals for future care[21]	100	1	0	34
(5) Where appropriate, ACP includes information about diagnosis, disease course, prognosis, advantages and disadvantages of possible treatment, and care options[9,24]	96	1	0	33
(6) ACP might include clarification of goals and preferences for future medical treatment and care; if appropriate, ACP includes exploration of the extent to which these goals and preferences are realistic[21,24,25]	83	1	1	55
(7) ACP includes discussing the option and the role of the personal representative, who might act on behalf of the individual when they are unable to express their preferences, as per local legal jurisdiction[26]	94	1	1	50
(8) ACP includes an exploration of the extent to which the individual allows their personal representative to consider their current clinical context in addition to their previously stated preferences when expressing preferences on their behalf[27–29]	74	2	2	31
(9) ACP might include the appointment of a personal representative and documentation thereof[2,26,30]	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 the individual is unable to express their preferences), as per local legal jurisdiction[26]	95	1	0	37
(11) ACP might include the completion of an advance care directive[2,26,31–33]	94	1	0	25
(12) ACP includes encouraging an individual to provide family and health-care professionals with a copy of the advance care directive	82	1	1	23
Recommended roles and tasks				
(13) Health-care professionals should adopt a person-centred approach when engaging in ACP conversations with individuals and, if the individual wishes, their family; this approach requires tailoring the ACP conversation to the individual's health literacy, style of communication, and personal values[15,16,34–38]	100	1	0	25
(14) Health-care professionals need to have the necessary skills and show an openness to talk about diagnosis, prognosis, death, and dying with individuals and their families[6,21,34,37,39–42]	99	1	0	34
(15) Health-care professionals should provide individuals and their families with clear and coherent information concerning ACP[43]	99	1	0	21
(16) A trained non-physician facilitator can support an individual in the ACP process[1,44–51]	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 within or outside of health-care settings[52,53]	98	1	0	31
(18) Appropriate health-care 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 discussion in the medical file of the patient[54]	68	2	2	39
Recommended timing of ACP				
(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[9,55–57]	96	1	0	39
(20) As values and preferences might change over time, ACP conversations and documents should be updated regularly, such as if the individual's health condition worsens, their personal situation changes, or as they age[15,21,55,58–60]	99	1	0	18
(21) Public awareness of ACP should be raised, including the aims and content of ACP, its legal status, and how to access it	96	1	0	17

(Table continues on next page)

file. Governments, health insurers, and health-care 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.

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.

	Agreement		Inter-quartile range‡	Comments that were written by the panel in rounds 2 and 3 (n)
	Percentage*	Median†		
(Continued from previous page)				
Recommended elements of policy and regulation				
(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[54,61]	80	2	1	57
(23) Health-care organisations should develop potential triggers for the initiation of ACP including, but not limited to, age, degree of illness, and transitions in care[9,21,60,62–65]	95	1	0	31
(24) Health-care organisations 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[18,66–68]	97	1	0	29
(25) Governments, health insurers and health-care organisations should secure appropriate funding and organisational support for ACP[58,69,70]	100	1	0	20
(26) Laws should recognise the 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
Recommended evaluation of ACP				
(27) Depending on the study or project aims, we recommend the following constructs be assessed:				
(A) Knowledge of ACP (rated by individuals, family, and health-care professionals)	91	1	1	..
(B) Self-efficacy to engage in ACP (rated by individuals, family, and health-care professionals)	84	2	1	..
(C) Readiness to engage in ACP (rated by individuals, family, and health-care 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 health-care 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 health-care professionals)	96	1	0	..
(K) Quality of ACP conversations (rated by individuals, family, and facilitators or health-care professionals, or both)	90	1	1	..
(L) Satisfaction with the ACP process (rated by individuals, family, and health-care professionals)	94	1	1	..
(M) Use of health care	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 based on these constructs so that 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[71]	89	1	1	37

ACP=advance care planning. *Of total participants (n=109), percentage of panellists who gave the Likert response options "agree strongly" or "agree"; answering categories: 1=strongly agree; 2=agree; 3=agree somewhat; 4=undecided; 5=disagree somewhat; 6=disagree; 7=strongly disagree. †Of scores on the Likert scale that were given by panellists, indicating agreement. ‡Of scores on the Likert scale that were given by panellists, indicating consensus.

Table: **Final set of recommendations on ACP with ratings, as provided by the panel in Delphi round 3**

Recommendations that received strong agreement and strong or very strong consensus

For five of the 41 recommendations, agreement was strong (median score 2) and consensus was very strong (IQR 0 or 1) or strong (IQR 2) (table). These five recommendations included: ACP should include an exploration of the extent to which the individual allows their personal representative leeway in decision making (recommendation 8; strong consensus); the need for the provision of health-care professionals for the clinical elements of ACP (recommendation 18; strong consensus); the format of the advance care directive (recommendation 22; very strong consensus); and two recommended constructs to be assessed—self-efficacy (recommendation 27B; very strong consensus) and use of health care (recommendation 27M; very strong consensus).

Discussion

To the best of our knowledge, we have drafted the first unifying, transcultural, international consensus definition of ACP and recommendations for its application through a rigorous, large international Delphi study. The recommendations guide the way in which ACP should be done and integrated into health care and suggest outcome measures of ACP. Most recommendations received full consensus from our multi-disciplinary panel, which also included patient representatives. Most recommendations achieved consensus in one round, whereas others did so in

subsequent rounds. This level of agreement suggests that our recommendations are appropriate for various health-care 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 also used numerous qualitative comments from panellists to improve recommendations. The final definitions and recommendations provide important guidance for the delivery of high-quality ACP and we recommend their use in future studies and clinical programmes to facilitate the comparison and synthesis of findings across studies.

Our international consensus study offers broader generalisability than earlier initiatives to define ACP and previously published guidelines or position papers, since these were limited to specific patient groups[6,8] or to certain countries or cultures.[4–7,14] The definitions and recommendations 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 spectrum of ages and illnesses.[72,73] Other important elements are that the scope of ACP is broader than the physical domain alone, and can include concerns across the psychological, social, and spiritual domains. Furthermore, ACP should not be limited to specific patient groups, but concern individuals with decisional capacity. With this new focus, the concept of ACP has become increasingly relevant to many patient populations, such as those in the areas of oncology, chronic diseases, and multi-morbidity, and for both patients and health-care providers. However, evidence suggests that, in oncology, ACP tends to be limited to the completion of documents.[3]

The definitions and recommendations in this study reflect the value of ACP in the provision of care to people at various stages of their illness. Worldwide, the extent to which health-care providers, patients, and relatives are willing and able to discuss issues related to disease progression and end-of-life care differs substantially, as does the extent to which such discussions are integrated into the health-care system. Therefore, our recommendations encourage an individualised approach to ACP—eg, one that is tailored to whether patients want to engage in ACP or not—and adapted to disease stage and to local legal and cultural circumstances. Finally, our findings reflect the reality that, in many countries, patients can express their preferences for care but have varying degrees of authority to refuse treatments and limited authority to request treatments themselves.

This study has several strengths. First, the resulting recommendations owe their credibility to the use of the Delphi technique. We followed the reporting standard for Conducting and Reporting of Delphi Studies (CREDES).[74] This standard 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 method 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. Our response rate of 76% indicates that the risk of selection bias is low. Fourth, although 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 for agreement, 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 comments provided by panel members were systematically studied and used to improve the definitions and recommendations produced.

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 methods. Additionally, the recommendations might need to be updated as more evidence becomes available. Furthermore, we acknowledge that the evidence from the scientific literature and expert views predominantly originate from resource-rich regions, 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 by members of the Delphi panel. In these cases, we recommend doing an additional Delphi study to determine recommendations that best represent these regions. Finally, 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 future steps, we recommend the translation, dissemination, and implementation of these definitions and recommendations for use in practice and policy-making. We also suggest evaluating the use of these recommendations in clinical practice and policy. Future work could also include the formal priority-setting exercises suggested in the recommendations.[75] We are continuing our work to define ACP outcome domains and constructs[4] by working on a separate Delphi study to develop a set of recommendations to standardise ACP constructs and instruments.[76,77] Furthermore, we encourage the identification of measurement tools for assessment of the

outcomes of ACP. Additionally, to enhance the broad applicability of our recommendations, we have aimed at providing general recommendations across disciplines. Future work could 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, since this was outside the scope of our study.

Conclusion

Our large international Delphi panel came to a consensus on an ACP definition and recommendations for its application. This Review 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 catalytic effect to further benefit patients and their relatives by facilitating the provision of care to patients with cancer, and others, that is aligned to their preferences and goals, thus contributing to improved quality of life.

Contributors

All authors made substantial contributions to the manuscript, including to the conception (JACR, RLS, JJvD, MAD, AvdH, DH, DJAJ, LO, SP, JS, RJJ, IJK) and design (JACR, RLS, MC, JJvD, MAD, AvdH, DKH, DH, DJAJ, LO, SP, JS, RJJ, IJK) of the study, to the literature search (JACR, IJK), collection of the data (JACR, IJK, MD), and to the draft and final revision of the manuscript (all authors). All authors provided final approval of the final version and its submission.

Declaration of interests

We declare no competing interests.

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