Original Article

Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel

Rebecca L. Sudore, MD, Hillary D. Lum, MD, PhD, John J. You, MD, Laura C. Hanson, MD, MPH, Diane E. Meier, MD, Steven Z. Pantilat, MD, Daniel D. Matlock, MD, MPH, Judith A.C. Rietjens, PhD, Ida J. Korfage, MSc, PhD, Christine S. Ritchie, MD, MSPH, Jean S. Kutner, MD, MSPH, Joan M. Teno, MD, MS, Judy Thomas, JD, Ryan D. McMahan, BS, BA, and Daren K. Heyland, MD, MSc

Division of Geriatrics, Department of Medicine (R.L.S., C.S.R., R.D.M.), University of California, San Francisco; San Francisco Veterans Affairs Medical Center (R.L.S.), San Francisco, California; VA Eastern Colorado Geriatrics Research Education and Clinical Center (GRECC) (H.D.L., D.D.M.), Denver, Colorado; Division of Geriatric Medicine, Department of Medicine (H.D.L., D.D.M.), University of Colorado School of Medicine, Aurora, Colorado, USA; Departments of Medicine (J.J.Y.) and Clinical Epidemiology and Biostatistics (J.J.Y.), McMaster University, Hamilton, Ontario, Canada; Division of Geriatric Medicine (L.C.H.), University of North Carolina at Chapel Hill, Chapel Hill, North Carolina; Brookdale Department of Geriatrics and Palliative Medicine (D.E.M.), Icahn School of Medicine at Mount Sinai, New York, New York; Palliative Care Program, Division of Hospital Medicine, Department of Medicine (S.Z.P.), University of California, San Francisco, California, USA; Department of Public Health (J.A.C.R., I.J.K.), Erasmus University Medical Center, Rotterdam, The Netherlands; Division of General Internal Medicine (J.S.K.), Department of Medicine, University of Colorado School of Medicine, Aurora, Colorado; Division of Gerontology and Geriatrics (J.M.T.), University of Washington, Seattle, Washington; Coalition for Compassionate Care of California (J.T.), Sacramento, California; and Department of Critical Care Medicine (D.K.H.), Queen's University; Clinical Evaluation Research Unit, Kingston General Hospital, Kingston, Ontario, Canada

Abstract

Context. Despite increasing interest in advance care planning (ACP) and previous ACP descriptions, a consensus definition does not yet exist to guide clinical, research, and policy initiatives.

Objective. The aim of this study was to develop a consensus definition of ACP for adults.

Methods. We convened a Delphi panel of multidisciplinary, international ACP experts consisting of 52 clinicians, researchers, and policy leaders from four countries and a patient/surrogate advisory committee. We conducted 10 rounds using a modified Delphi method and qualitatively analyzed panelists' input. Panelists identified several themes lacking consensus and iteratively discussed and developed a final consensus definition.

Results. Panelists identified several tensions concerning ACP concepts such as whether the definition should focus on conversations vs. written advance directives; patients' values vs. treatment preferences; current shared decision making vs. future medical decisions; and who should be included in the process. The panel achieved a final consensus one-sentence definition and accompanying goals statement: "Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness." The panel also described strategies to best support adults in ACP.

Conclusions. A multidisciplinary Delphi panel developed a consensus definition for ACP for adults that can be used to inform implementation and measurement of ACP clinical, research, and policy initiatives. J Pain Symptom Manage 2017;53:821–832. *Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

Key Words

Advance care planning, consensus, Delphi technique, policy making

Address correspondence to: Rebecca L. Sudore, MD, University of California, San Francisco School of Medicine, SFVAMC 4150 Clement Street, #151R, San Francisco, CA 94121, USA. E-mail: rebecca.sudore@ucsf.edu

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Introduction

Initiatives to improve advance care planning (ACP) are increasing in the clinical, research, and public sectors. Because ACP programs have been shown to result in improved value-aligned medical care,[1,2] policy makers are increasingly taking notice. For example, the Centers for Medicare and Medicaid Services (CMS) recently approved reimbursement to health care providers for ACP counseling.[3] As ACP initiatives, clinical demonstration projects, and system-based programs are implemented into health care systems and as reimbursement is dependent on whether ACP occurred, a common definition of ACP is needed.

Despite its importance, no unifying formal definition of ACP exists across the medical, legal, or policy literature. Previous descriptions of ACP have been published[4–11] and were incorporated in the Institute of Medicine (IOM) Report *Dying in America*.[12] CMS billing instructions for ACP have also been published.[3,13] Common elements across these descriptions included discussing patient's values, documenting plans for medical treatments, and continuing ACP as a process over time through conversations with clinicians, families, and surrogate decision makers. However, several health care organizations recommend measuring the quality of ACP without using standard metrics, suggesting different conceptualizations of ACP and the absence of shared quality standards.[14–16]

Furthermore, ACP experts still disagree on a formal ACP definition. We convened a large, multidisciplinary Delphi panel of ACP experts who were initially tasked to identify and rank patient-centered ACP outcomes. It was assumed that the IOM description of ACP was widely accepted and, therefore, sufficient for use by this expert group. However, it became clear in the first round of the Delphi panel that several panelists disagreed with the IOM ACP description and a unifying definition of ACP did not actually exist. Several panel members disagreed on the purpose, goals, and key components of ACP. Thus, the panel decided to halt the initial study and focus its efforts on first creating a unifying ACP definition.

Without a consensus definition, it is difficult to implement consistent quality standards, incentives, and systems support to promote effective ACP. To address the need for a unifying consensus ACP definition to guide research and clinical initiatives, we leveraged the expertise of our large, multidisciplinary panel of ACP experts to address "What is the definition of ACP?"

Methods

Study Design

We assembled a panel of clinicians, researchers, legal experts, and policy makers with expertise in ACP to participate in a consensus panel to define ACP using a modified Delphi method.[17,18] The Delphi process occurred between February and November 2015 and was determined to be exempt by the Institutional Review Board at the University of California, San Francisco.

Selection and Qualification of Participants

Based on a literature review of ACP studies and references from the IOM report, we identified 18 ACP research experts for the Delphi. We then used snowball sampling (i.e., referred by initial invitees) to recruit an additional 37 members with clinical, research, or policy expertise in ACP. To be included, participants had to have either published a peer-reviewed manuscript concerning ACP or have been involved in ACP research, teaching, clinical, or policy programs.

Delphi Methods

In an area that lacks certainty, the Delphi method uses multiple rounds of structured feedback to achieve consensus.[18] Panels from five to 60 participants have shown equal validity and reliability.[19] Self-selection is anticipated, resulting in participants who are well informed and engaged in the purpose of the research.[18] The figure outlines the 10 Delphi rounds involving the full panel ($n = 52$), a subgroup ($n = 15$), and a patient/surrogate advisory committee. We used serial rounds of edits and consensus building to reach a unifying definition of ACP and a statement of the goal of ACP and strategies to support adults in ACP in clinical practice. All rounds involving the full panel were anonymous, as is often standard in Delphi panels.[20] For the subgroup and patient/surrogate advisory committee, we used a modified Delphi method created for groups. In the modified method, the group comments are not anonymous; however, other tenets of the Delphi method are adhered to such as iterative, ongoing reviews of information and feedback.[21]

As described earlier, the Delphi panel was originally convened to identify and rank ACP outcomes. For the ranking study, we presented the IOM description of ACP (Supplemental Table 1) to the 52-member Delphi panel because this description had been recently published and was based on several previous descriptions.[12] Although the Delphi members were not asked to comment on the IOM ACP description, several panelists made comments that highlighted the absence of a unified understanding of ACP. In addition, several panelists were ranking ACP outcomes based on varying purposes and goals of ACP than what was described in the IOM report. Based on an initial set of identified discrepancies and lack of consensus for several topics, we halted the original ACP outcome

ranking Delphi panel and turned the panel's attention to reaching a consensus on the definition of ACP. Delphi rounds continued until consensus was reached. Consensus was considered to have been reached when all panelists had no further substantive comments and approved that version of the definition for publication.

In Round 1, the full Delphi panel was asked to review the IOM description and suggest changes based on their conceptualization of ACP to be used for clinicians, researchers, and policy makers. In rounds 2 and 3, the full panel was asked to establish a consensus for ACP definition concepts; we also identified concepts for which consensus could not be reached.[17] For these rounds, we used a modified Delphi process where the panel could respond by e-mail to the full panel or directly to the facilitator (R. S.). Open-ended comments regarding the conceptualization of ACP or direct edits could be made to the definition. When panel members e-mailed comments to the full panel, other panelists iteratively responded and often emphasized areas of agreement or disagreement within each round. All comments were summarized for each round and presented back to the panel for review.

Because the full panel identified several ACP concepts lacking consensus, a subgroup of 15 experts were invited to serve on a Delphi-panel subgroup to review these ACP concepts. The subgroup included individuals who demonstrated significant engagement beyond the standard requests for Delphi input and/or who suggested that a subgroup be created to resolve discrepancies and offered their expertise. This subgroup participated in an e-mail round (Round 4), a phone conversation (Round 5), two additional e-mail rounds (rounds 6 and 7), and are co-authors on this article. The revised definition was then discussed by a 13-member patient/surrogate advisory committee comprising individuals who had received care or had been a surrogate of a patient in an intensive care unit (Round 8) with the purpose of reviewing the definition from a layperson's perspective.[22] This revised version was reviewed by the subgroup (Round 9) and then the full panel to achieve a final consensus definition (Round 10) (Fig. 1).

Data Collection and Analysis

Electronic document versions, e-mail correspondence, and meeting audio-recordings were collected and archived for each round. Comments, recordings, transcripts, and notes were collated by the Delphi moderator (R. S.), iteratively summarized for each round, and presented back to the Delphi panel for further comment and revision of the definition. All comments were further analyzed by R. S. and H. L. using content analysis to identify overarching themes concerning key tensions, along with illustrative quotes.

Results

The characteristics of the full 52-member Delphi panel, and the 15-person subgroup, are listed in Table 1. The panel includes multidisciplinary experts from four countries in the fields of medicine, law, nursing, and epidemiology. Both the full Delphi panel and the subgroup had similar expert types and gender. Three individuals from the U.S., who were initially identified from the literature search, declined to participate due to time constraints (96% response rate).

Table 2 presents Delphi panel comments that demonstrated a lack of consensus concerning the IOM description and resulted in halting the original ACP outcomes ranking study and necessitating this ACP definition study. Discrepancies included whether to focus on advance directives vs. conversations, treatment preferences vs. patient's values, and future decision making vs. current shared decision making.

Through 10 Delphi panel rounds, panelists identified and resolved key tensions using the Delphi process. Table 3 presents the final consensus definition for ACP and includes a statement describing the goal of ACP. Panelists also felt strongly that a definition and goals statement should be accompanied by clinical and policy strategies to optimally support adults in ACP. The panelists felt that the definition, goal, and strategies should not be disentangled. The key tensions are described in subsequent paragraphs, and illustrative quotes are listed in Table 4.

Key Tensions

Population

What Populations Should be Included in This ACP Definition? Although vitally important, the Delphi panel determined that the resultant definition is not specific enough to deal with legal issues related to ACP for children and/or a parent or guardian who may need to make decisions for a minor or an adult who lacks decision making capacity. Accordingly, the panel decided to focus this ACP definition only on adults who retain decision making capacity (i.e., before losing capacity).

Scope

Should the Scope of the ACP Definition Be Prescriptive or Broad? The panel decided to create a broad, one-sentence definition that could be used by clinicians and health care systems, researchers in grants and papers, and policy makers in policy briefs. Given the agreed-on importance of the goal of ACP, the panel developed a goal statement to immediately follow the definition. Nearly all panel members agreed that

the main goal is to help ensure that the medical care patients receive is aligned with patients' values and goals.

Should the ACP Definition Focus on Patient or Clinician Behaviors? The panel discussed that both patients' and clinicians' roles are important and interdependent. However, because clinicians cannot guide patients in medical decision making without input from the patient and because the panel noted the importance of focusing the definition on respecting an individual's choices, the panel decided to focus the one-sentence ACP definition statement on the patient. However, given the importance of the clinician's role, the panel created an associated section focused on strategies clinicians can use to optimally support adults in ACP (Table 3).

Should the ACP Definition Include Surrogates, Family and Friends? Because many people may lack a suitable surrogate, some panel members felt that identification of a surrogate should not be included in the definition. However, most panel members felt that, where appropriate, preparing the surrogate decision maker is a key component of ACP. A consensus was reached to include a statement about surrogates following the definition statement. A related tension was whether to include family and friends in addition to a surrogate. The panel observed that for many cultures, family inclusion is critical and that discussion of a person's wishes with both the surrogate and the family may prevent conflict. The panel discussed the need to be sensitive to individuals who choose "trusted" persons who are not necessarily related. The term "trusted person or persons" was decided on to broadly encapsulate surrogate decision makers, family and friends.

Can the ACP Definition Be Used for a Health Care Audience and the General Public? The panel made significant efforts to keep the language at an easy-to-read level. However, doing so created confusion around the precise meaning of nuanced concepts, such as medical care aligned with values (see "Should ACP address personal life goals and values or medical treatments" section), readiness, and prognosis. Panelists concluded that using easy-to-read phrasing may be too vague and open for interpretation. Therefore, the panel and a patient advisory group decided that this definition, in its current form, should be for a health care audience.

Purpose—What Constitutes ACP?

Is ACP on a Continuum Over Time or a One-time Event, such as Completion of an Advance Directive or Medical Order? The panel decided that ACP should be described as a process that occurs on a continuum. Given that a patient's situation changes over time, ACP is described as a process that should change with patient's changing health states, including becoming more specific about medical care and treatment preferences when needed. Revisiting a person's

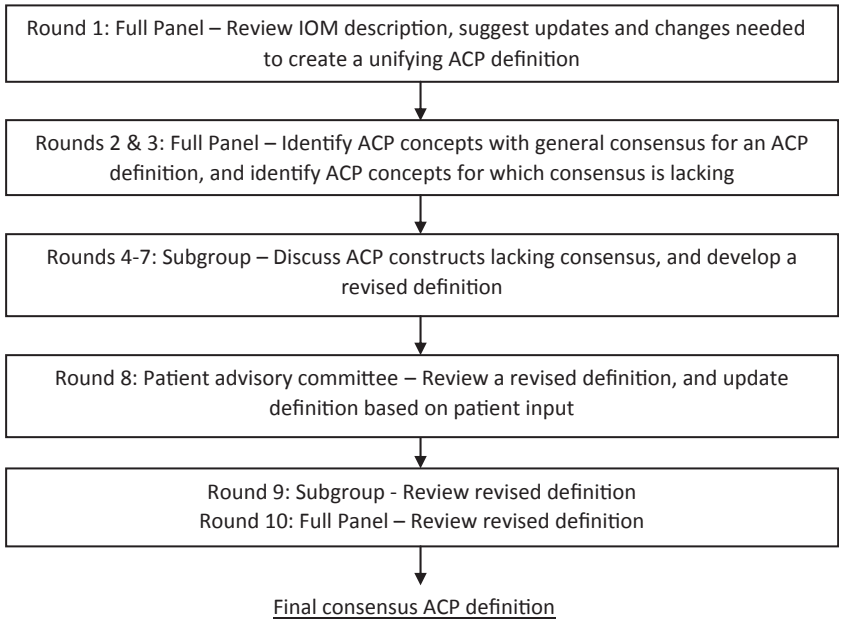

Fig. 1. Modified Delphi method flowchart. The development of a consensus definition for advance care planning by an international expert panel, using Delphi method rounds. IOM = Institute of Medicine.

Table 1
Characteristics of Delphi Panelists

Characteristics	Full Delphi, $n = 52$, n (%)	Delphi Subgroup, $n = 15$, n (%)
Type of expert		
Research	38 (71)	10 (66)
Clinician/policy/program expert	13 (25)	4 (27)
Law	2 (4)	1 (7)
Primary discipline		
Physician (MD) researcher	38 (73)	11 (73)
Nurse (RN) researcher	4 (8)	0 (0)
Lawyer	2 (4)	1 (7)
PhD/other	8 (15)	3 (20)
Country of origin		
United States	42 (80)	11 (73)
Canada	6 (12)	2 (13.5)
Netherlands	2 (4)	2 (13.5)
Australia	2 (4)	0 (0)
Gender		
Women	33 (63)	10 (66)

wishes over time, and especially during times of transition, is critical to this process.

Is ACP Appropriate When Healthy or Only During Serious Illness and at the End of Life? There were some concerns that having ACP occurs before a person experiencing serious illness is "not reliable as preferences change with one's life conditions and circumstance." Other members commented that ACP should also play a role in healthy adults and individuals with chronic illness and disabilities. The panel decided that it would be important to broaden ACP to prepare people in varying health states for medical decision making, not just at the end of life. The panel compromised and included "at any age and stage of health" in the definition statement and included decisions for both "serious and chronic illness" in the goals statement.

Should ACP Focus on Preparing a Surrogate or the Individual for Their Own Decision Making? Some panelists felt that the main ethical reason for ACP was to prepare surrogate decision makers for a potential time when the patient becomes incapacitated. The panel recognized that many patients retain their decision making capacity at the end of life.[1] Therefore, patient preparation, through self-reflection and communication of values and goals, helps to clarify care preferences both for the patient as they subsequently face important decisions and the surrogate as the surrogate may become more involved in helping with decision making or if the patient becomes incapacitated.[8,22] Therefore, the definition focuses on preparing the patient through engagement in ACP and the strategy section recognizes the role of preparing both the individual and their trusted person(s) for medical decision making.

Should ACP Focus on Discussions or Documentation, such as an Advance Directive? Some panelists felt that conversations were the most important and others emphasized documentation. There was discussion that some individuals will want to document their wishes without having a conversation, whereas others may face issues related to mistrust of the health care system or have limited literacy or language proficiency preventing them from recording their wishes in a legal document. The panel decided that documentation of ACP conversations and/or completion of legal documents is needed to ensure that the medical care provided aligns with a patient's preferences. Given their importance, both on-going conversations and documentation were included as strategies for

Table 2
Delphi Comments Demonstrating a Lack of ACP Definition Consensus

Advance directives vs. conversations	"Documentation of an advance directive [is] not necessarily good or appropriate for all patients." "Conversations are more important than documentation. I do not conflate ACP with advance directives."
	"Documentation of directives in the medical record is essential for linking outcomes in the future and ensuring that the information is there when needed."
Treatment preferences vs. patient's values	"These are all important components of ACP but, documentation of treatment preferences [is] the most important."
	"DNR/DNI is only important in that it is an order - by itself it may say less about a patient's overall values than we want it to and thus is less informative overall than documented ACP discussions covering a range of values, preferences, and goals."
Future decisions vs. shared decision making	"ACP takes place BEFORE it's needed. These measures apply to real-time medical decision making, which is a part of the ACP continuum."
	"ACP and shared medical decision making are not the same and should remain separate."
Surrogates vs. not	"My bias about ACP is that the decision maker is the most important aspect"
	"The surrogate is only important if the patient becomes incapacitated."
Clinicians vs. not	"I'm struggling with the clinician/provider issue, as documentation is so poor and the clinical [situation] changes so quickly that it does not always help to have a conversation with 'Your Doctor.'"
	"It is most important for clinicians to encourage and engage in creating, reviewing ACP documents and … bring surrogates and patients together to discuss ACP."

Table 3
New Consensus Definition of Advance Care Planning for Adults

Consensus Definition of Advance Care Planning for Adults[a]:
Definition statement
(1) Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.
(2) The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness. (3) For many people, this process may include choosing and preparing another trusted person or persons to make medical decisions in the event the person can no longer make his or her own decisions.
Strategies for How to Optimally Support Adults in Advance Care Planning:
(4) Advance care planning should bring together the person, individuals they trust to include in decision making, and health care providers to support discussions about the person's preferences regarding medical care. (5) The discussions should match how ready the person is to talk about her or his medical care and how much information she or he wants to know about their health and prognosis. (6) Advance care planning should also be revisited over time and when health or life circumstances change.
(7) To begin, advance care planning should focus on overall goals regarding medical care and on preparing the person to make informed choices based on what is most important to her or him. (8) It may also focus on identifying another trusted person or persons to help make medical decisions in the event the person becomes unable to make her or his own decisions. (9) As the person's health condition changes over time, advance care planning can focus on a specific plan for future medical treatments.
(10) Decisions about treatment plans should include a healthcare provider, follow local healthcare laws, and be based on a shared understanding of the person's changing health and prognosis. (11) Recording the person's values and choices for medical care is important and should be done after talking with individuals whom the person trusts to be included in decision making and healthcare providers. (12) Recorded preferences for medical care should be saved in such a way that they can be found when they are needed and updated over time.

[a]Sentence numbers of the new ACP definition are listed and are referenced in Table 4.

supporting adults in ACP. It is specifically noted that conversations should be documented in the medical record to provide context about the patients' decisions, although different jurisdictions internationally have varying laws concerning the use of oral advance directives.[23]

Should ACP Address Personal Life Goals and Values or Medical Treatments? The panel recognized that discussions of life goals and values (e.g., comfort, independence, dignity), specific medical treatments (e.g., CPR), and individualized medical treatment plans are all important elements of ACP and should be addressed. Several panelists noted that the lay public defines "goals" as "personal life goals." Therefore, the panel defined values and/or goals as expressions of a person's overarching philosophies and priorities in life and include such things as wanting to see a grandchild graduate from school, adhering to religious beliefs, and an overall desire to focus on comfort or life extension. Panelists discussed that health care providers should elicit and apply these overall life goals/values to guide medical treatment recommendations. It was also discussed that based on the individual's stage of disease and readiness to engage, ACP conversations should start with overall personal life goals and values and then these values should be translated by clinicians into more specific discussions concerning medical treatments over time.

Should ACP Focus on Future or Current in-the-moment Medical Decision Making? This concept was very difficult for the panel to reach consensus. It was discussed that in an acute setting or as a patient's disease progresses, ACP for future (or hypothetical) decisions often flows into current goals of care and treatment discussions.[5,8] Several members commented that ACP should be defined as an ongoing process from discussions about values and life goals through to shared or in-the-moment decision making related to current medical care. Other members argued that ACP and shared medical decision making are distinct processes, based on different theoretical constructs, and thus, should be separate. The panel also observed that the concept of autonomy and laws concerning ACP and medical and surrogate decision making are held to different legal standards in different countries with country-specific legal tasks that must be considered (i.e., risks and benefits) as part of informed shared medical decision making.[24] The panel decided not only to emphasize preparation for "future" medical decisions in the ACP definition statement but also to include creating a current medical care plan as an important strategy in clinical practice. Important qualifiers, such as needing to include a health care provider and follow local health care laws, were also included.

How to Conduct ACP

Should ACP Include the Assessment of Readiness to Engage in ACP? Although some panel members discussed that all patients should be offered ACP regardless of their readiness, the majority felt that it was important to tailor ACP information to the individual's readiness stage.[25] Thus, another strategy for supporting adults in ACP is to include information about readiness to ensure patients are receiving information that they are ready and able to discuss.

Should ACP Include a Discussion of Prognosis? Some panelists felt that because we are broadening ACP to include healthy states and chronic illness, prognosis

Table 4
ACP Concepts Requiring a Delphi Process to Reach Consensus

Key Tension	Quote	Decision for the ACP Definition
Population to include in the ACP definition		
1. What populations should be included in this ACP definition?—children, parents, adults who lack decision making capacity?	"For parents and children, there are many issues to take into account. For example, there are different stages of development and making a decision for a 2-year old versus a 17-year old are very different for a parent. I do not think we can address those nuances in this definition." "People with dementia or limited cognitive capacity raise the same issues as children, and the legal issues regarding ACP and decision making are too nuanced for this overarching definition."	This ACP definition focuses on adults, given the specific considerations warranted for a pediatric population and adults who lack decision making capacity (Sentence 1).[a]
Scope of the ACP definition		
2. Should the scope of the ACP definition be prescriptive or broad?	"I still think tighter is better if you want people to use it. A tight definition fits on an aims page or in a newspaper article, a long one does not." "There is a conceptual difference between what ACP is and how to do it. Those 2 things should be separated. A definition with a goal statement should be separated from recommendations about how to do it optimally." "… care must match goals in order to say ACP was successful!"	Create a one-sentence definition of ACP Include a goal statement after the definition (sentences 1 and 2).
3. Should the ACP definition focus on patient or clinician behaviors?	"It is the patient's job to talk about life goals and it is the clinician's job to operationalize a medical care plan." "It is most important for clinicians to encourage and engage in creating, reviewing ACP documents and … bringing surrogates and patients together to discuss ACP."	Create a patient-centered definition Describe clinical strategies to support adults in ACP (sentences 1–3: for individuals; sentences 4–10 for clinicians)
4. Should the ACP definition include surrogates, family, and friends?	"Can you do ACP without designating a surrogate? I think you can, and if you can then it maybe should not be in the definition of ACP." "I believe that naming a surrogate has equal standing with values, goals and preferences. Thus, if the definition mentions values, goals, and preferences, it should also mention naming a surrogate. Someone can name a surrogate, but not address values, goals, and preferences and it's a perfectly legal document." "If using the language 'families', should we mention that 'family' should be interpreted broadly and inclusively?"	ACP may include choosing and preparing trusted person(s), based on the availability of trusted individuals (Sentence 3) Trusted individuals may include surrogate decision makers, family members, and others (sentences 4, 8, and 11)
5. Can the ACP definition be used for a health care audience and the general public?	From the patient advisory group: "These words are confusing. What do you mean by values and goals. I do not use those words … most people walking around do not use those words in life. I use quality of life." "I do not see how you are going to get this information up a billboard or health information sheet for the public."	This ACP definition is intended for a health care audience. It should be adapted for use by the general public (all sentences).
Purpose of the ACP definition—what constitutes ACP?		
6. Is ACP on a continuum over time or a one-time event, such as completion of an advance directive or medical order?	"ACP is not a one and done, and this is a process that needs to be revisited over time." "There is a continuum of medical decision making … some very upstream that does	Describe ACP as a process on a continuum over time. Recognize that ACP should be revisited, especially with changes in life circumstances or disease course

(*Continued*)

Table 4
Continued

Key Tension	Quote	Decision for the ACP Definition
	not include the medical team and further down the stream where medical orders are made and then there is care at the bedside. I think we need to agree that there is a continuum of a process that occurs over time."	Recognize that ACP can focus on specific medical plans (sentences 6–9)
7. Is ACP appropriate when healthy or only in serious illness and at the end of life?	"I am a little concerned that having ACP include both pre-illness work AND illness-facing work … [this] risks trying to be everything for everyone and consequently very vague." "I agree that ACP is a lot broader than medical decision making in late serious illness. In (X country) ACP is essentially viewed as the patient's perspective, and will inform but not control medical decision making." "ACP can be done far upstream from serious illness, or very proximal to or during serious illness. However, it does not typically address routine health decisions … ACP was developed because serious illness comes to nearly all of us, and reflecting on values in advance is useful."	ACP includes both "serious" and "chronic" illness ACP is relevant across the life continuum (sentences 1, 2, and 7)
8. Should ACP focus on preparing a surrogate or the individual for their own decision making?	"Many people worry that ACP means they immediately lose the right to make their own medical decisions. Would add: 'if the individual becomes too sick or is otherwise unable to make those decisions'." "Suggest adding language, 'Since serious illnesses may limit a person's ability to advocate for themselves, advance care planning may also focus on surrogates'."	ACP includes preparing the individual for their own decision making *or* the potential for incapacity (sentences 3, 4, 8, and 9)
9. Should ACP focus on discussions or documentation, such as an advance directive?	"Documentation of an advance directive [is] not necessarily good or appropriate for all patients." "Conversations are more important than documentation. I do not conflate ACP with advance directives." "Many people from disenfranchised populations will not complete legal advance directive forms, but it does not mean that we cannot foster meaningful discussions. Then these discussions can be documented." "Documentation of directives in the medical record is essential for linking outcomes in the future and ensuring that the information is there when needed." "Documentation of decisions is essential but discussions are required for ACP to be fully meaningful and effective."	ACP focuses on both conversations and documentation to ensure that medical care provided is aligned with an individual's preferences (sentences 1, 5, and 10–12)
10. Should ACP address personal life goals and values or medical treatments?	"ACP is about eliciting patient's life goals and then it is the clinician's job to come up with a specific treatment plan that best aligns with these goals." "It is important to link preferences, values and goals to a specific care plan that anticipates problems or concerns that the patient will face while dying. You can have the most beautiful [values-based] ACP, but if you do not have a care plan in place, those preferences will not be honoured."	ACP links discussion of personal values and life goals to specific medical care plans. "Goals" are person-centered, such as wanting to remain independent, or participating in a life event (sentences 7–9)

(*Continued*)

Table 4
Continued

Key Tension	Quote	Decision for the ACP Definition
	"DNR/DNI is only important in that it is an order—by itself it may say less about a patient's overall values than we want it to and thus is less informative overall than documented ACP discussions covering a range of values, preferences, and goals."	
11. Should ACP focus on future or current in-the-moment medical decision making?	"ACP and shared medical decision making are not the same and should remain separate." "I see ACP as a vin diagram that encompasses values and goals and also goals of care decisions and in-the-moment decision making. If we do ACP correctly, this is a seamless transition from discussions about overall life goals to future medical decisions to real-time medical decision making." "Anything related to the 'future', whether this is related to identification of values and goals for overall care, future levels of care, aggressiveness of an overall future treatment plan, or goals of care for CPR and mechanical ventilation to me is ACP." "When we move to medical decision making, we can still call it ACP, but we need to make sure that we follow a process that is consistent with that state or country's local regulations or healthcare laws." "Medical decision making usually follows some legal process to obtain informed consent in the context of a clinical problem There needs to be a rich discussion about risks/benefits, outcomes, etc., and this then gets reduced to a medical order."	While the continuum of ACP ranges from values clarification to "in-the-moment" decision making, the definition emphasizes "future" decisions. Any current medical decision making, as part of a broad definition of ACP, must meet local health care laws (sentences 1, 9, and 10)
Important considerations for how to conduct ACP		
12. Should ACP include assessing readiness to engage in ACP?	"While I think that it's important to recognize that people will vary in the extent to which they want to engage in ACP, I am not sure it needs to be included in the broader definition." "Would it make better sense to frame this not by the lifespan but by the stage of readiness? So language such as 'Ideally, this process is matched to the person's readiness to make such decisions, consistent with their health status and psychological preparedness'."	ACP should recognize the person's level of readiness and tailor information and discussion to the person's willingness to engage (sentences 5 and 10)
13. Should ACP include a discussion of prognosis?	"Including 'prognosis' assumes the individual is ill, when they may not be, so I removed it." "My addition outlines the responsibilities of the clinicians to provide the desired education about a person's prognosis and likely future treatment decisions, then develop a coherent care plan." "Patients and families should have the information they want about the patient's medical condition and treatment options."	ACP discussions should include prognosis, based on how much information the person wants to know about their health and prognosis (sentences 5 and 10)
Semantics and word choices	"Use people instead of patients because 'patients are people'." Defining surrogates, families, and friends as "loved ones" may "discriminate against socially isolated individuals," or	"People" (sentences 2 and 3) "trusted person or persons" (Sentence 3) and "individuals whom the person trusts to be included in decision making" (Sentence 11)

(*Continued*)

Table 4
Continued

Key Tension	Quote	Decision for the ACP Definition
	those who "may not want individuals close to them to be involved." Changed to "individuals whom the person trusts to be included in decision making." Using "clinician" or "medical provider" changed to "healthcare providers" because "chaplains or social workers may not see themselves as 'medical' providers." "Interdisciplinary providers/teams" was not used because the panel did not want to imply that "more than one provider was required for an ACP conversation." Using "medical wishes" was felt to be "too closely associated with a wish for a miracle." The panel decided to use "medical preferences."	"health care providers" (sentences 4, 10, and 11) "preferences regarding medical care" (sentences 1, 2, 4, and 12)

[a]Sentence numbers correspond to the sentences listed in the final consensus ACP definition in the Table 1.

may not apply to all individuals and, therefore, should not be included. Others felt that, especially as conversations about ACP become more specific when discussing future medical care options, it is important to ensure that patients understand their clinical context and treatment options within the context of that prognosis. Other panelists highlighted the need to tailor prognostic information to the patients' readiness. Therefore, recommended strategies to support adults in ACP include a discussion of prognosis, when appropriate, based on how much information the individual is willing and ready to hear.

Finally, the panel deliberated on semantics that resulted in significant decisions about specific word choices for the final consensus definition (Table 4).

Discussion

A 52-member multidisciplinary, panel of international ACP experts created a consensus ACP definition for adults to be used by clinicians, researchers, and policy makers. Based on the panel's recommendations, this definition also includes a statement of the goal of ACP and clinical and policy strategies that panelists deemed necessary to optimally support adults in ACP. This work represents the first ACP definition developed using Delphi methodology and offers a uniform framework in which to define patient-centered ACP outcomes, ACP clinical programs, and ACP policy.

This definition complements several previous ACP descriptions,[4–8] a recent IOM report,[12] a Canadian conceptual framework for end-of-life communication,[5] and recent CMS billing instructions.[3,13] Concepts similar to previous descriptions include conceptualizing ACP as a process that occurs over time, that ACP can begin at any age or stage of life, that ACP should be revisited and become more specific with changing health states, and that discussions, as well as documentation, are important.

The current definition differs in several ways from previous ACP descriptions, including the IOM report description. First, it is a consensus definition resulting from 10 rounds of input from a large Delphi panel of multidisciplinary, international ACP experts. Second, in addition to the one-sentence definition statement, an explicit "goals statement" and a strategies section for how to optimally support adults in ACP are included. Third, this definition is only for adults and does not address the specific nuances of ACP for children, parents, or guardians.[26–28] Fourth, the purpose of this ACP definition is not solely to prepare surrogates for making decisions in the event of a patient's incapacity but also to prepare the person for their own medical decision making. Fifth, attention was given to addressing issues for individuals who may lack an appropriate surrogate. Sixth, the concepts of readiness to engage in ACP[25] and prognosis discussions[11,29] were addressed under strategies to support adults in ACP. Seventh, to address the needs of different international legal jurisdictions, we added that these decisions must "… follow local healthcare laws." Eighth, this ACP definition and strategies section includes preferences regarding "future care" and current shared medical decision making, which may help inform clinical quality metrics and policy standards. And finally, similar to the IOM report description, but different from other ACP descriptions, the strategies section of this consensus definition addresses the great importance of documenting ACP discussions in addition to legal forms and medical orders.

This definition has several limitations. First, this definition does not include children, parents, guardians, or adults who lack decision making capacity. In addition, it does not yet meet the standards for use

with the lay public. Furthermore, all Delphi panels are, by nature, self-selecting, which may result in selection and information bias. In particular, five Delphi rounds included a subgroup of panelists. However, the full panel initially defined the issues that needed clarity for the subgroup in the first three rounds, and the full panel was able to re-review and provide input after the subgroup review and agreed with the final definition. In addition, the panel members were only from four countries (U.S. predominant) and four disciplines; therefore, this definition may lack generalizability. In addition, we used a modified Delphi method and, therefore, are unable to report ranking data. We acknowledge that initial disagreement about an ACP definition is likely due, in part, to a lack of evidence about what constitutes clinically meaningful ACP. With ongoing research, we recognize that this definition will evolve over time. For example, medical-legal partnerships may help expand ACP beyond medical planning.[30,31] Furthermore, although the panelists felt that the definition and goals statements could not be disentangled from strategies to support adults in ACP, these suggestions do not represent a rigorous systematic review of the literature. Research concerning these strategies is needed.

In conclusion, a multidisciplinary panel of international ACP experts created a consensus-based, ACP definition, goals statement, and described strategies to optimally support adults in ACP. This definition can provide critical guidance for ACP clinical interventions, research studies, and policy initiatives. Future studies are needed to modify this definition for use by the lay public, to ensure generalizability to a larger international audience, and to determine whether this definition can be used to define ACP quality metrics and result in improved clinical ACP practice.

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Supplemental Table 1

IOM Description of Advance Care Planning for Adults

Institute of Medicine Report Dying in America Description
Advance care planning is a process for setting goals and plans with respect to medical treatments and other clinical considerations. It brings together patients, families, and clinicians to develop a coherent care plan that meets the patients' goals, values, and preferences. It can begin at any point in a person's life, regardless of his or her current health state; is revisited periodically; and becomes more specific as changing health status warrants.[a]
Ideally, these discussions would start early in adulthood, addressing global values and the identification of potential surrogate decision makers, and focusing on more specific treatment preferences for older persons and those facing serious illness. With changes in health status, they would take on increasing specificity. "Putting it in writing" remains important but does not substitute for the discussion.[b]

[a]Chapter 3 of the IOM report, page 120 and page 122, Box 3–1.[12]
[b]Chapter 3 of the IOM report, page 118.[12]