Technical Brief Disposition of Comments Report

Research Review Title: *Decision Aids for Advance Care Planning*

Draft review available for public comment from February 12, 2014 to March 11, 2014.

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Comments to Research Review

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The tables below include the responses by the authors of the review to each comment that was submitted for this draft review. The responses to comments in this disposition report are those of the authors, who are responsible for its contents, and do not necessarily represent the views of the Agency for Healthcare Research and Quality.

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Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #2	Abstract	Seems that another future direction concern is the finding of the high % that are proprietary - not going to help with dissemination. Seems needs to be a method for getting effective DA into use.	Adopted. Added “dissemination and access” as future need in abstract
Peer Reviewer #1	Background	Second paragraph (p.7) -- In the sentence that begins, “ACP generally has three parts…”,no mention is made of surrogacy, the discussion of which is an essential component of ACP. At a minimum, I suggest that four elements be listed here, beginning with … considering options for surrogate decision-makers in the event of incapacity.	Surrogacy is mentioned within the paragraph. We did not include it as a general component because there are instances where people do not have, or chose not to have, surrogates and instead rely on clinical staff to follow advance directives.
Peer Reviewer #1	Background	The first sentence of the third paragraph (p.7) is not only true, but it is also touches upon a framework for distinguishing and evaluating ACP tools that the authors give a nod to in several places, but never really make full use of in the later discussion in Implications and Next Steps. Framework: ACP (and thus tools for ACP) vary by the target group’s stage of life and health. The continuum in Figure 1 makes this point, although it is not clear where this particular figure came from. I suggest taking a look at the stages of ACP used by Respecting Choices and the Coalition to transform advance care. They are a bit more understandable than Figure 1, and essentially involve 3 stages: ACP for relatively healthy individuals; ACP for the individual with an established condition or conditions that are manageable; ACP for the individual with serious, advanced conditions. ACP for individuals that are hospice eligible is sometimes noted as another stage but can also be realistically considered part of advanced care. This is essentially a continuum of focus from broad value and goal identification along with establishing a surrogate to a focus increasingly on more specific decision options.	We have revised the background section to pull out the framework, revising Figure 1 to highlight the factors of the hypothetical and uncertainty aspects of ACP decisions. We also added a table to illustrate ACP characteristics across different health stages.
Peer Reviewer #2	Background	page 8 line 7: Opening sentence seems to imply that ACP only is relevant for life-sustaining interventions. In reality, ACP can apply to a range of issues and interventions, not only life-sustaining interventions. Recommend opening with the current last sentence in this paragraph, which is really the point.	Paragraph has been revised. Among other revisions, we added a different opening sentence: “Advance care planning (ACP) can be thought about as a way to inform care choices when the patient cannot express a preference, but it is also a planning tool.”
Peer Reviewer #2	Background	page 8 line 52: As written, this language perpetuates the either/or dichotomy which is the antithesis of efforts to integrate care that addresses comfort and quality of life with care that may prolong life. I strongly encourage a close read of this report and editing of language that perpetuates this false dichotomy.	The introduction section related to Figure 1 has been substantially revised. The sentence in line 52 is no longer present. We have worked to remove the dichotomy from the report.

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Peer Reviewer #2	Background	page 9, line 10+: not sure what the point is here -- this is a confusing sentence: "ACP decisions differ from end-of-life decisions because ACP requires people to imagine what life would be like under various conditions of disability, whereas within end-of-life decisions, the patient is directly experiencing the alternative to death."	The paragraph has been substantially revised and the sentence the reviewer refers to has been removed. We revised the paragraph to clarify the issue that people who are not directly experiencing a specific health state may have a difficult time imagining what experiencing that health state is like.
Peer Reviewer #2	Background	page 9, line 19: This seems to be an argument for revisiting ACP across the illness trajectory - that it isn't a "one and done" proposition. This should be emphasized	The concept of treating ACP as an on-going process is emphasized in the summary and implications section of the report.
Peer Reviewer #3	Background	Very nicely done. No concerns or recommended changes.	Thank you.
Peer Reviewer #4	Background	Refs 22 and 23 appear out of order.	References have been reformatted.
Peer Reviewer #4	Background	The background would benefit from a discussion of definitions of ACP. While people generally have an idea of what ACP is, I suspect there is less agreement on what it specifically entails. The authors should consider clearly defining what they consider ACP to be.	We agree that there are differences of opinion regarding definitions of ACP. We chose to use a common, broad definition and kept the discussion of ACP itself brief to support the Technical Brief's focus on the decision aids, not the ACP process itself.
Peer Reviewer #4	Background	Consider mentioning in the background the Cochrane review of Decision Aids – which specifically excluded decisions around the end-of-life.	Adopted. The review has been referenced.
Public Reviewer #1 Hajizadeh (Hofstra North Shore School of Medicine)	Background	On page 2 last line leading into page 3 the document describes physicians underestimating whether patients want life-prolonging treatment, even after reviewing the patients' advance directive. In the next line it states "Decision aids may be one way to improve... the effectiveness of ACP communication". In the aforementioned study, even though physicians saw the documentation they still under-estimated patients' preferences. A clarification might be : Decision aids could improve the effectiveness of ACP communication by facilitating clear documentation across platforms/providers and by providing insights into why the patient made decisions for or against life supporting technologies."	We added "by facilitating clear documentation across platforms/providers and by providing insights into why the patient made the decisions."
Peer Reviewer #1	Guiding Questions	Question 2d touches upon the explainesty of decision aids for ACP, but an additional question that may have helped shed light on the variability is whether there is any conceptual framework that explains the variability.	Thank you for the comment.

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Peer Reviewer #2	Guiding Questions	No concerns – very clearly stated.	Thank you for the comment.
Peer Reviewer #3	Guiding Questions	The guiding questions are very much on target. As per the above general comments, it is hard to understand how several of the key questions (1a, 1b, 2b, and 4b), as well as the topics addressed by the tool and the Decision Aid Criteria (see Table 2), can be answered without the authors having actually worked through the decision aids they discuss.	Thank you for the comment.
Peer Reviewer #4	Guiding Questions	No concerns	Thank you for the comment.
Public Commenter #1 Hajizadeh (Hofstra North Shore School of Medicine)	Guiding Questions	Did the guiding questions specify the source of data used in each decision aid? For example, the source of data for prognostic estimates? Also, whether there was personalization of the data presented? Trust in the decision aid's estimates influences whether physicians will use/continue to use the decision aid outside of trials. Our group has studied these attitudes specifically for ACP decision aids in the outpatient setting (manuscript recently submitted). Questions of feasibility of use of the decision aid in real life settings should also be included, including the length of the decision aid and considerations for effective patient centered communication including: educational level/literacy-numeracy levels/languages/cultural background etc.	In depth analysis of each identified decision aid was outside the scope of the Technical Brief. We have added a table with outcomes to assess an ACP decision aids effectiveness to the Next Steps section as a suggested starting place for the field to establish a core set of outcomes.
Peer Reviewer #1	Methods	Clear and concise.	Thank you for the comment.
Peer Reviewer #2	Methods	Methods are a definite strength – Clearly described, explicit, transparent.	Thank you for the comment.
Peer Reviewer #3	Methods	The general methodology for discovering publications and studies is reasonable, however, the authors should also search “backwards” from the decision aids they have identified to discover studies and grants that were awarded to investigate those decision aids. An example of this are three studies that were not identified for Making Your Wishes Known –two NIH awards (an ongoing 5-year R-01 RCT and a completed R-23) and an American Cancer Society grant (for a 4-year RCT). Given the potential for such oversights, it would be prudent for the authors to look “backwards” for other studies that might have been missed by their search methodology.	Technical Briefs are not systematic reviews and as such do not attempt to exhaustively search the literature. We did search on named decision aids, but the likelihood of finding references depends on how the articles are indexed, and if they are indexed by name. We added one additional study on Making Your Wishes Known to this report because of the outcomes represented in the study.

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Peer Reviewer #4	Methods	No concerns	Thank you for the comment.
Public Reviewer #2 Fine (Baylor Health Care System)	Methods	A nice literature search was performed but this report failed to look at a new ACP tool, MyDirectives.com, that Baylor Health Care System is utilizing as an online decision aid for patients as well as a digital storage and retrieval mechanism for advance directives. Although we don't have data to share, our anecdotal experience has been very positive and we routinely encourage patients across our health care system to utilize MyDirectives. We believe the interactive and iterative nature of this tool is significantly superior to the tools listed in tables 2a and 2b.	Thank you for the comment. MyDirectives was mentioned in the report for its digital storage function. We have also added it to tables 2a and 2b.
Peer Reviewer #1	Findings	I think the findings are laid out well	Thank you for the comment.
Peer Reviewer #1	Findings	The tools described were divided into those for relatively healthy older adults (Table 2a) and those for individuals with life limiting illness (Table 2b). Think of this as a distinction in stages of ACP.	Thank you for the comment.
Peer Reviewer #1	Findings	Under “Evidence Map,” p. 14, it is noted that, “The patient populations included in studies of decision aids for advanced care planning or end-of-life care include both patients with serious or advanced illness, and community-dwelling older adults…” and… “This is an important distinction because the valuation of health state change with increasing age and experience of illness.” This is an extremely important acknowledgement.	Thank you for the comment.
Peer Reviewer #1	Findings	Evaluating ACP Decision Aids, p. 13, second paragraph says that five of the tools identified in Table 1 “do not focus on decision(s) and are, therefore, not evaluated.” I think this statement may reflect a bias towards wanting every index decision to be specifically medically related. Tools such as the Conversation Project’s starter kit do aid in making decisions about broad guiding values and priorities (e.g., about whether one wants to know a lot about their EOL choices or a little; whether one places a priority on length of life or quality of life; how involved one wants their loved ones involved in decisions; and more). These are real decisions for person in stage 1 of ACP (healthy) and they are appropriately not focused on discrete medical decisions, yet the answers would be quite relevant to specific medical decisions if such person were suddenly faced with a medical crisis and could not speak for him/herself.	We agree that broader discussions are part of ACP and appropriate focus for ACP conversations. Since we chose the IPDAS criteria to structure our evaluations, the concept of the medical nature of index questions is a structural artifact. Our primary audience for this TB is clinicians.

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Peer Reviewer #1	Findings	The acknowledgement on p. 13 that "decision aids for ACP should be consistent with state's laws and regulations" somewhat blurs the distinction between two different aspects of potential decision aids: the decision aid itself and the means of communicating the decision. It's the latter that has to be sure to comply with state law, as the example illustrates re how proxy authority may need to be explicit about tube feeding decisions. Another example: a tool can be very helpful in educating the individual about the need for and function of a proxy and help the individual think about who would be the best proxy and make a choice. A tool that goes only that far can work just fine in any state. But if the tool also intends to assist in effectively operationalizing that decision, then it needs to comply with state-specific legal requirements for executing a power of attorney for health care, including complying with any limitations on who may be selected as proxy, how the proxy's authority is defined, and how the instrument is signed and witnessed.	We agree there is a distinction between a decision aid and the tool for communicating the decisions. The sentence referred to the "content of decision aids for ACP" being consistent so that the information given to the person using the decision aid does not mislead the person with regard to what the documentation can or should provide.
Peer Reviewer #2	Findings	page 13, line 33: States that the difference of ACP from other decisions is that ACP can occur without a health care provider. It seems that this misses one of the other key differences about ACP – that it is not usually about a discrete decision (such as whether or not to have knee replacement), but is more of a process and about documenting goals and values (and selecting a surrogate decision maker).	We agree with the comment, and the technical brief does take up this issue in greater detail in the discussion. As this particular paragraph pertained to shared decision making specifically, we did not amend this paragraph. However, the introduction has been revised to also highlight the process nature of ACP.
Peer Reviewer #2	Findings	Tables 2a and 2B are quite useful.	Thank you for the comment.
Peer Reviewer #2	Findings	Provides a comprehensive review of the (sparse) published literature.	Thank you for the comment.
Peer Reviewer #2	Findings	Use of the IPDAS standards to evaluate existing DA is a definite strength as this is the international standard.	Thank you for the comment.
Peer Reviewer #3	Findings	The authors' findings are nicely organized and described. The construct of the tables is logical and easy to follow, and their evaluative categories are helpful for readers wishing to understand the advantages and limitations of ACP decision aids. The one major drawback is the absence of findings related to the actual functioning of the decision aids, which would have informed both the authors and readers of key properties of the tools being described.	Thank you for the comment. This level of detailed analysis is beyond the scope of the technical brief.

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Peer Reviewer #3	Findings	So, for example, working through the Making Your Wishes Known decision aid would have informed the authors (cf. table 5) that Making Your Wishes Known provides in-depth information about common life-threatening conditions and life-saving treatments (including probabilities of success/recovery); values clarification exercises; assistance choosing a proxy decision maker; opportunities to express one's preferences regarding place of care, pain control, organ donation, and the relative priority of one's advance directive document; the ability to revisit one's choices over time; as well as an output advance directive document that includes both a general wishes statement and preferences specific to particular conditions and treatments.	Thank you for the comment. This level of detailed analysis is beyond the scope of the technical brief.
Peer Reviewer #3	Findings	It is not clear to what extent the properties of other decision aids were accurately described. But without the ACP decision aids themselves being tested/experienced, there must be concern that key findings were likewise missed for other ACP tools.	Thank you for the comment. This level of detailed analysis is beyond the scope of the technical brief.
Peer Reviewer #4	Findings	I've never seen decisionmaking written as one word.	That is a style preferred by AHRQ
Peer Reviewer #4	Findings	Page 7: "Advance" not "Advanced" (a mistake this reviewer frequently makes)	The typo has been corrected through-out the document.

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Peer Reviewer #4	Findings	Tables 2a and 2b: I know the list wasn't Some Decision Aids seemed missing – a. Peace of Mind: Personal Stories about Advance Directives – Informed Medical Decisions Foundations. Arguable more ACP than the Making Choices, Medical Care for Serious Illness. b. Several tools from the University of Ottawa (separate from the A-Z guide for decision aids): (http://decisionaid.ohri.ca/decaids.html) including one on mechanical ventilation in COPD and one on feeding tubes in dementia.	A. The Informed Medical Decisions Foundations related program, Looking Ahead: Choices for Medical Care When You're Seriously Ill, was included in the tables. However, since preparing the report draft, the Peace of Mind and the Look Ahead tools became proprietary. See: http://www.healthdialog.com/Utility/News/PressRelease/14-01-17/Health_Dialogue_and_the_Informed_Medical-Decisions_Foundation_Restructure_Longstanding_Relationship.aspx#. B. Certainly, as we state in the report, Tables 2a. and 2b. represent a sample of what is currently available in the grey literature. The tools we chose from the Ottawa Hospital Research Institute (OHRI) were identified as end-of-life care decision aids. The tools mentioned here may apply to patients at the end of life, or may be used more broadly. The OHRI is a very rich source for patient decision aids.
Peer Reviewer #4	Findings	Study Designs: When discussing potential harms of decision aids, the authors briefly mention stress, anxiety, and hope. The authors should seriously consider if someone feeling stress while thinking about the end of their life is truly a "harm" vs. a "side effect." I imagine that when I have an advanced illness and start thinking about death, I may feel stress, anxiety, and even depression – but is this a harm of the DA or a hazard of being alive and becoming aware of one's own mortality. Anyway, the authors should seriously consider what a meaningful harm is – perhaps this section needs more discussion.	The comment is important. The three studies mentioned in this section looked for increased distress in the person using the decision aid in terms of stress, anxiety, or loss of hope. We have changed the language in that section and added the need to consider how harms should be conceptualized in the Next Steps section.
Peer Reviewer #4	Findings	Table 3 would benefit if the authors include the sample size in the study.	We have added study sample size information to the table.
Peer Reviewer #4	Findings	Table 4: NE = Not evaluated. What is a blank cell? Perhaps NE = no effect and a blank cell = not evaluated.	That is correct. We have corrected the table notation.

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Peer Reviewer #4	Findings	Table 5: What is meant by "guide decision deliberation" – some in this area talk about explicit vs. implicit guides of the values clarification. Given that, some of the video may be using patient testimonials as implicit values clarification exercises.	We approached the "guide decision deliberation" from the explicit perspective. If a decision aid guided a person through the decision process in a structured manner, the item was identified as present or met. We have clarified this in the Evaluating ACP Decision Aids section.
Public Reviewer #1 Hajizadeh (Hofstra North Shore School of Medicine)	Findings	On page 20 the document describes an effective aid as being one which leads to decisions that are informed and consistent with the decision maker's values. An important clarification is that the patient him/herself does not actually have to arrive at a decision for the ACP decision aid to be effective if it leads to communication with surrogate decision makers (and physicians) about which outcomes are most important to patients and what they value most in considering the tradeoffs. This will support the surrogate decision maker who often makes the ultimate decision at the time of dying. In fact, advance directives have been criticized for not being able to be applied to different clinical settings by surrogate decision makers.	We have clarified the statement, adding "whether those decisions are ultimately made by the patient or by the surrogate."
Public Reviewer #3 Pauker (Tufts Medical Center)	Findings	Briefly, these aids provide information but do not really help the patient in making this complex stressful decision, ie, integrating the facts and their preferences and values. Much additional research is needed there.	Thank you for the comment.
Public Reviewer #6	Findings	With a search strategy involving PubMed, EMBASE, Cochrane, SCOPUS, Web of Science, CINAHL, PsycINFO, and Sociological Abstracts, the PCORI group captured 4962 unique articles which, after title/abstract search and inclusion of hand search articles, was refined to 196 articles for full review and 37 articles for inclusion. Of note, the PCORI group specifically targeted instrument-based ACP studies and excluded conversation-based studies. However, while the PCORI group found 31 articles that are not listed in the AHRQ review, the AHRQ review has 2 articles that were not captured in the PCORI review – thus perhaps bespeaking the relative immaturity of ACP-related MeSH terms and article categorizations in the various databases.	Thank you for the comment. This level of systematic review literature search is beyond the scope of the technical brief.
Public Reviewer #6	Findings	For Figure 2 (though it is described in the text as "Figure 3" on page 13), the authors could use a more archetypical PRISMA diagram and there are apparent inconsistencies between the diagram and text that describes the diagram.	We have corrected the typos. We used an abbreviated form of the PRISMA diagram because a full systematic review literature search is beyond the scope of the technical brief.

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Public Reviewer #6	Findings	Please also consider how tables and appendices are listed in the text for there currently are misdirected citations (the text on page 14 which directs the reader to "Appendix C" is actually referring to data in Appendix D, etc.). In some places, the references also do not match the number of studies being cited – in "Study Designs" on page 14, the text notes there are "eight…RCT's" but only 7 citations follow, in "Patient Population" on page 14, the text notes that "five studies evaluated decision aids on patients with serious or advanced illness" but only 4 citations follow.	Thank you for the comment. We have put the report through a careful edit in preparation for publication.
Public Reviewer #6	Findings	In table 4 on pgs 18-19 in comparison to the text describing it on page 15, the table doesn't correspond with the text in multiple instances (i.e. – text notes that the outcome of "patient knowledge of advance directives or disease process" was in "(11/15)" trials but in the table, it is only marked for 9 of the 15 studies; text notes that the outcome of "clarity regarding patient preference for comfort care" was in "(7/15)" trials but in the table, it is only marked for 5 of the studies, etc.)	Thank you for the comment. We have put the report through a careful edit in preparation for publication.
Peer Reviewer #1	Summary and Implications	The discussion on p. 23 starts with noting that many key informants and ACP web sites promote a "population-specific approach." I don't think that characterization best captures the themes that seem apparent throughout the technical brief. Wouldn't it be more accurate and descriptive to say that they promote a staged approach to ACP with the goals and outcomes of ACP varying by the individual's stage of life and health, as described in the Background section comments above. This frames ACP as an evolving process for the individual. This characterization is actually consistent with the examples and discussion in paragraphs 3 through 7 of this section, which indeed talk about how the needs and options are different at different stages of health and that the process is ongoing.	We agree, and adopted the language change suggestion of "staged approach … varying by the individual's particular circumstances" rather than "population-specific".

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Peer Reviewer #1	Summary and Implications	why not offer a tentative paradigm to organize future thinking and research about ACP decision aids. If one uses a paradigm of staged ACP, then the index decisions and evaluation criteria vary by stage. In stage one (healthy), a key index decision is "Who will be my surrogate if one should be needed?" and "What cross-cutting values and priorities of life do I want to articulate as guidance for any surrogate?" The educational component of a tool would focus on those decisions. For someone in stage two (established, manageable condition), deciding on a proxy will still be a component, but the decision about the values and priorities should now include more detail about one's goals of care specific to the person's chronic condition. Educational components can be tailored to differing chronic conditions or combinations of conditions. For someone in stage three (advanced stage of serious illness), a proxy decision is still critical if it has not already been made, but the decisions now begin to focus life trade-offs related to the trajectory of illness and specific medical interventions. The communication and implantation tools here also change, as this is where POLST and DNR orders become relevant. The educational component may be very specific about the intervention and decisions will be much more imminent. ACP begins to converge with care planning. The tools at each of the three stages are not intended to lead to the same outcomes, so any evaluation strategy has to distinguish the purpose of the tools in this broader paradigm. This paradigm is not carved in stone, but putting it forward as a possible dynamic unifying framework helps make sense out of all the variation in tools described in the brief and could help to add greater rigor in tool development and evaluation.	We carried the "staged" approach through to provide a such a tentative paradigm. "A staged approach to ACP, based on how hypothetical the decision aid index question and the level of uncertainty regarding the possible care choices to consider, would help guide the important education components, appropriate evaluation, and convergence with care planning."
Peer Reviewer #1	Summary and Implications	Very helpful points are made in the discussion about the diversity of the population and the possible option for trained facilitators.	Thank you for the comment.
Peer Reviewer #2	Summary and Implications	No concerns- very clearly stated and follow logically from the findings.	Thank you for the comment.
Peer Reviewer #3	Summary and Implications	In general, the summary and implications section is well thought out.	Thank you for the comment.

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Peer Reviewer #3	Summary and Implications	The authors' assertion (p.23, 3rd full paragraph) that "[a]n important role of decision aids is to provide methods to inform patients about their prognosis…" may be inspirational, but seems a bit off the mark. Linking an ACP decision aid with a clinical database that could provide estimates of treatment success, survival, etc. may be a worthy long-term goal, but it is at least premature, given the enormous challenges inherent to providing accurate prognoses. A more realistic goal is to develop enhanced functionality that will enable decision aids to address how people psychologically process information –particularly in situations involving significant uncertainty. In short there is important foundational work yet to be done just to help people (i) systematically think through decisions so that their choices express their deepest values, and (ii) engage in effective conversations with others about ACP.	We agree that this issue is still aspirational. We have amended the sentence to "important role of decision aids could be to provide methods to inform patients about their prognosis…"
Peer Reviewer #3	Summary and Implications	The authors' observation that "physicians often are the most challenged to facilitate conversations" is accurate as far as it goes. Also worth acknowledging are barriers that hinder physicians from engaging in ACP conversations –notably time constraints, financial disincentives, and the absence of system-based strategies for promoting effective ACP conversations.	We agree with the comment and have added the barriers to the paragraph.
Peer Reviewer #3 Matlock	Summary and Implications	Type in second paragraph: "…approach in in contrast…"	The typo has been addressed.
Public Reviewer #2 Fine (Baylor Health Care System)	Summary and Implications	The summary is fine as far as the literature review went, but as mentioned above, the reviewers did not report on a service we believe is very useful both for creating advance care plans at any stage of illness as well as for storing and retrieving those plans.	Thank you for the comment. MyDirectives was mentioned in the Findings section of the report for its digital storage function. We have also added it to tables 2a and 2b.
Public Reviewer #3 Pauker (Tufts Medical Center)	Summary and Implications	Nicely done.	Thank you for the comment.
Peer Reviewer #1	Next Steps	A unifying framework, even tentative, would be helpful in guiding next steps.	We have substantially revised the introduction and Figure 1 to highlight the framework.
Peer Reviewer #2 Kutner	Next Steps	No concerns. Very clear and follow logically from the data presented.	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #3	Next Steps	The authors' recommendations for "Next Steps" are nicely thought out. The one issue they miss is the need to develop a broad array of decision aids that can be used to augment and/or facilitate effective ACP with various professionals, in different settings, and at variable stages along the continuum of medical decision-making.	Thank you for the comment. We have added text, "and appropriate to patients in various settings working with various facilitators" to highlight this concern. We did not include the suggestion of "broad array" as the range of tools needed is itself an empirical question.
Peer Reviewer #4 Matlock	Next Steps	The authors call for more predictive models of life expectancy in the next steps. Why do we need more cognitive information in ACP. Perhaps we need a better acknowledgement of uncertainty.	Coping with or adapting to uncertainty is an important issue. We have added this to the next step on prognostics as an alternative view to consider.
Public Reviewer #1 Hajizadeh (Hofstra North Shore School of Medicine)	Next Steps	Next steps should also include: - Whether and in what settings patients find ACP acceptable – should this be inpatient/outpatient? At what stage of disease? Should the doctor be allowed to initiate this discussion? Must a surrogate be present? Does a patient need to be prepared that this discussion will happen? Can it be a part of a routine visit? –	Thank you for the comment. We have added text, "and appropriate to patients in various settings working with various facilitators" to address the concerns listed here from a more generalized level.
Public Reviewer #1 Hajizadeh (Hofstra North Shore School of Medicine)	Next Steps	Comparisons needs to be made of Shared decision making as the model of decision making versus prompting doctors to educate their patients about their prognosis and offer educational support tools rather than engaging in formal shared decision making. How does this vary across cultures (including age, ethnicity etc.) – Support for models to estimate prognosis and personalize these estimates such as decision analytic models. For example, we have designed a decision analytic model comparing alternative advance directives for patients with severe COPD (Hajizadeh N, Crothers K, Braithwaite RS Using modeling to inform patient centered care choices at the end of life. Comparative Effectiveness Research. 2013;2(5):497-508.)	Thank you for the comment. Shared decision making itself is outside the scope of this technical brief.
Public Reviewer #5 Lynn (Altarum Institute)	Next Steps	We agree with the suggested future directions for research, training and use of social media	Thank you for the comment.
Public Reviewer #5 Lynn (Altarum Institute)	Next Steps	Note that the fourth category appears to be missing	This typo has been corrected.

Commentator & Affiliation	Section	Comment	Response
Public Reviewer #5 Lynn (Altarum Institute)	Next Steps	There are critical components missing that are imperative in any current discussion of advance care planning and the types of decision aids envisioned for the future: 1) the need to embed ACP into an overall comprehensive care plan; People with complex care needs must have a negotiated, comprehensive, appropriate plan of care at every point in time that is realistic, understood, implemented, and documented and portable to all point of care. In that regard, advance care planning becomes an essential component of the over-all care plan. We must conduct a much more comprehensive assessment than is normally done; construct a longitudinal care plan that all service providers adhere to and which reflects a person's treatment preferences and forward-looking goals; and design novel person-centered and experience of care measures that monitor the effectiveness of this plan in achieving the elderly person's goals. In addition we must develop methods for evaluating care plan quality, which because requires measuring outcomes against initial priorities and preferences of individual beneficiaries (and their families). Care plans must reflect the person's situation and goals, and thus their quality in the individual case requires measuring against personal preferences and goals, and their quality as a metric for the system requires a method of summing up the overall performance	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Public Reviewer #5 Lynn (Altarum Institute)	Next Steps	2) the critical need to include ACP & care plans in the electronic health record (EHR). Although health care providers have a central role in promoting advance directive completion and advance care planning, clinicians do not typically discuss advance care planning during routine visits or even during acute health crises, hence the need for embedding ACP into the overall care plan. Over the past two decades, the practice of placing reminders in patient charts to prompt health care providers to perform particular procedures has demonstrated success in improving performance of a number of underperformed care processes (particularly at the VA). Electronic Health Records (EHRs) incorporate many features, including documentation of all of a patient's care, regardless of the provider. EHRs have the potential to enable physician reminders to be added automatically to charts, as appropriate, and also enable a patient's medical chart to be shared among all providers with access to the system. Thus, health information technology (HIT) has the potential both to stimulate overall care planning, advance care planning and advance directive completion and to increase the accessibility of a patient's advance directive across care sites. Yet, current "meaningful use" virtually ignores care plans and the proposals for Meaningful Use Stage 3 do not clearly take it on. AHRQ should investigate and recommend that electronic record systems at least have a place for some key elements (e.g., surrogate decision-maker, decisions to forgo certain life-sustaining treatments, identification of the caregiver(s), important goals and priorities, living situation, services planned and important gaps or risks remaining, treatments and "red flags," care team members) within a few years.	Thank you for the comment. We agree that care plans and directives are of little value if they are not available to the appropriate provider at the time of care need. This is however beyond the scope of the technical brief. We did not examine the literature on this aspect and thus are not in a position to comment about it in the technical brief.
Public Reviewer #5 Lynn (Altarum Institute)	Next Steps	In addition, among the "Next Steps" for decision aids and ACP AHRQ should invest in research and demonstrations to guide optimizing the care planning process, learning to evaluate care plans over time and settings, and using care plans in system monitoring and design as well as determining how to best use decision aids in the process.	Thank you for the comment. This is however, beyond the scope of the technical brief.
Public Reviewer #4 Williams-Murphy	References	Should consider MyDirectives.com template also in evaluation of online ACPs. Broad, accessible and thorough. Also www.oktodie.com has downloadable end of life preparation checklists which move far beyond standard medical decision-making to include social legacy formation as well as estate and funeral preparations	MyDirectives has been added to Tables 2a and 2b.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #1	Appendix	Appendix C: Three organizations whose tools are listed in Table 2a are not listed in App. C (, specifically, American Bar Assn., Center for Practical Bioethics, and Georgia Health Decisions). How did they escape being in App. C since their materials all rely on the web for distribution?	The tools were accessed from different search engines rather than through the sites listed. However, we have added the three to the list, since the list may serve as a resource for readers interested in delving more deeply into the topic.
Peer Reviewer #1	General	Excellent and thorough overview of key issues and tools.	Thank you for the comment.
Peer Reviewer #1	General	The principal weakness is a failure to offer, even as a hypotheses for future research and development, a unifying ACP framework for explaining the variation in ACP decision-aids. It's actually there in the text in buts and pieces but never brought together clearly.	Thank you for the comment. See above responses regarding highlighting the framework.
Peer Reviewer #1	General	The report is very well done and easy to follow, but to repeat myself, a unifying framework is within reach.	Thank you for the comment. See above responses regarding highlighting the framework.
Peer Reviewer #2	General	Overall, this is a well-written and comprehensive report that presents a balanced and in-depth evaluation of the current state of evidence of advance care planning decision aids. It will be a significant contribution to the literature in this area.	Thank you for the comment.
Peer Reviewer #2	General	The report demonstrates excellent clarity and will be highly usable. It is well structured and organized. The main points are clearly presented. The conclusions will readily be used to inform future research.	Thank you for the comment.
Peer Reviewer #3	General	In most respects, this is a very nicely constructed technical brief that provides readers with an accurate description of decision aids for advance care planning (ACP) and a good, broad overview of what is to be found in the published literature regarding ACP decision aids.	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #3	General	The manuscript's greatest weakness is that the authors do not appear to have actually examined the decision aids they discuss. The very first of the technical brief's guiding questions is "What are the characteristics of the decision aid?" But to accurately describe the properties and functionality of a decision aid, due diligence requires working through it to see how it actually functions. Many of the decision aids described by the authors are readily available at no charge, and those that are proprietary are not prohibitively expensive. Relative to the work they have already done, it would be but a small investment for the authors to work through the various decision aids. Doing so would greatly enhance their technical brief by infusing a deeper sense of each decision aid's actual properties and functionality.	Thank you for the comment. This level of detailed analysis is beyond the scope of the technical brief.
Peer Reviewer #3	General	The technical brief is well-written, will be very accessible to a wide variety of readers, and will assist researchers in the field.	Thank you for the comment.
Peer Reviewer #4	General	This is an interesting technical brief reviewing the evidence on Decision Aids specifically for Advance Care planning. I thought the article was well-organized and, based on my knowledge of the area, provided a comprehensive review of the material.	Thank you for the comment.
Peer Reviewer #4	General	Yes, overall it is extremely well organized and easy to read.	Thank you for the comment.
Public Reviewer #5 Lynn (Altarum Institute)	General	The brief does an excellent job of reviewing the key issues with regard to the current use of decision aids in advance care planning (ACP).	Thank you for the comment.
Public Reviewer #6	General	The PCORI group grappled with how to organize interventions in this wide topic and noted that a key difference was whether the advance care planning (ACP) tool was based on a conversation with a trained individual (i.e. – Respecting Choices, etc.) or on the participant interacting with a specific instrument (i.e. – FiveWishes, PREPARE, etc.). As the first inherently involves training a cadre of interviewers who may or may not have standardization to what they do, conversation-based aids, as opposed to instrument-based aids, may be more difficult to disseminate. What are your thoughts on this?	Thank you for the comment.