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Adaptation and Preliminary Validation of the Advance Care Planning Engagement Survey for Surrogate Decision Makers

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Abstract

Context.—Although measures exist that assess patient engagement in the advance care planning (ACP) process, there are no validated tools to assess surrogate decision-makers' (SDM) role in ACP.

Objectives.—To adapt and begin to validate a patient-oriented questionnaire for use with SDMs of patients with chronic illness

Methods.—Questions from the 55-item patient-oriented ACP engagement survey were adapted for SDMs and assessed for face validity. The resultant 47-item questionnaire was administered to 65 SDMs of patient with chronic illness. Responses were assessed and items were flagged for removal based on item redundancy, nonresponses, and ceiling effects. A preliminary exploratory factor analysis was performed, internal consistency assessed, and domains constructed based on findings.

Results.—The 47-item questionnaire was administered to 65 participants (mean age 51.8; 81% female; 96% Caucasian). 17 items were removed due to redundancy (r>0.80), 13 items lacking face validity were removed. In preliminary exploratory factor analysis of the resultant 17-item questionnaire, a 3-factor solution was deemed most statistically and conceptually sound. Items were organized into domains: 1) serving as a SDM (7-items); 2) contemplation (4-items); 3) Readiness (6-items). Internal consistency for each domain was high (Cronbach alpha 0.90–0.91).

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DISCLOSURES
No authors have any conflicts of interest to disclose.

Conclusion.—The 17-item ACP Engagement Survey for SDMs (ACP-17-SDM) is a conceptually sound and reliable questionnaire adaptation of the original ACP Engagement Survey. This questionnaire may be used by researchers in parallel with the patient-oriented ACP Engagement survey to more fully understand the impact of ACP interventions on SDMs. Larger studies are needed to more closely examine construct validity.

Keywords

Advance care planning; Psychometrics; Surveys and questionnaires; Terminal care; Caregivers; Decision-making

INTRODUCTION

Advance care planning (ACP) was recently defined by an international consensus panel as a process intended to “help ensure people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness”.[1] The panel also noted that ACP should include selection of an surrogate decision-makers (SDM) capable of making medical decisions should the patient become incapacitated.[1] The role of the SDM may also vary based on legal and cultural factors. When ACP is performed in advance of major medical events, patients experience less distress, improved satisfaction with care and are more likely to receive care consistent with their wishes. [2–8] Similarly, SDMs of patients who have done ACP are less likely to experience distress from medical decision-making and have improved satisfaction with care. [9, 2, 10] Despite these known benefits, however, < 30% of Americans and Canadians have completed the ACP process. [11–14]

Finding new ways to engage patients and their families in these important conversations is critical if we hope to increase the number of individuals who have documented advance care plans so clinicians and families may carry out their wishes. It is equally important to consider the role of SDMs in the ACP process since studies have found that up to 70% of individuals will need some or all of their end of life decisions to be made by a surrogate.[4] As ACP interventions have been developed and tested, however, assessment has focused primarily on patient engagement with ACP, either by measuring advance directive completion rates, [15, 16] or more recently, engagement in the comprehensive ACP process as measured by the ACP Engagement Survey.[17, 18] Absent, however, is a measure of ***surrogate*** engagement in the ACP process.

To measure patient engagement in ACP, Sudore et. al developed and validated a questionnaire grounded in Social Cognitive Theory and the Trans-theoretical Model of Behavior Change that has been utilized as an important outcome measure in several studies and interventional trials.[17–22] Although the psychometrics of that questionnaire, called the *ACP Engagement Survey,* have been well studied, it has not been adapted for use with the patients’ SDMs. The purpose of this study was to adapt the existing 55-item patient-oriented *ACP Engagement Survey* for use with SDMs and begin to assess the validity of the adapted survey.

METHODS

The study was approved by the Penn State Hershey Institutional Review Board; all participants provided consent via implied consent via return of the questionnaire.

This prospective study was conducted in five phases (Figure 1).

Phase 1: Adapting the original ACP Engagement Survey for use with SDMs.

The patient version of the 55-item ACP Engagement Survey (ACP-55)[17] assesses four domains: 1) SDMs; 2) values and quality of life; 3) leeway in surrogate decision-making; and 4) asking doctors questions.[18] For each domain, items assess four behavior change constructs arising from the Trans-theoretical model of behavior change and Social Cognitive Theory: 1) knowledge; 2) contemplation; 3) self-efficacy; and 4) readiness.[18] The ACP-55 has been previously shown to have high reliability (Cronbach alpha 0.97) and construct validity based on both statistically significant associations between survey scores and completion of advance directives as well as correlations between change scores in response to an ACP intervention ($r=0.89$, $p<0.001$).[17] The survey has been used as an outcome in several studies examining the impact of ACP interventions.[23, 20, 21]

The ACP-55 question stems were reworded to apply to SDMs and then examined by an 8-person panel of ACP researchers, clinicians, and laypersons for face validity. Resultantly, 8 items were removed and 6 items flagged for re-evaluation after data collection. The result was a 47-item survey (ACP-SDM-47).

Phase 2: Administration of the ACP-SDM-47

After Institutional Review Board approval, the Penn State Survey Research Center recruited a convenience sample of participants identified from medical record databases using the following inclusion criterion: 1) >18 years old; 2) can read and write English; 3) had a family member who has a chronic illness (defined using Iezonni's ICD-9 Criterion of chronic illness)[24]; and 4) were willing to complete and return the survey. The Iezonni chronic illness codes are grouped into eight categories that include: cancer with poor prognosis; chronic pulmonary disease; cornonary artery disease; congestive heart failure; peripheral vascular disease; severe, chronic liver disease; diabetes with end organ damage; and renal failure. Participants were also recruited from the community around Penn State University Park via flyers, social media postings, and community email lists. Interested participants contacted the survey center and screened by phone to confirm a) their family member had a qualifying chronic illness (via self- report) and b) that they did not have mental impairment as measured by a score of >21 on the Montreal Cognitive Assessment (MoCA, phone version).[25] Eligible participants were sent a paper copy of the ACP-SDM-47, a pre-paid return envelope, and a $10.00 stipend. Since this study focused on the feasibility, usability and acceptability of the adapted questionnaire and because we used a convience sampling strategy, a power analysis was not conducted.

Phase 3, Initial Item Reduction

First, frequency counts for each of the 47 items were examined for those with >10% nonresponses or missing data with the intention of item removal. Second, responses were examined for ceiling effect, defined as any item where the selection of the item at the top of the scale occurred in >80% of instances. Third, an item correlation matrix was constructed to assess for item redundancy, defined as those items with an $r > 0.8$. Redundant items were flagged for removal. Finally, the study team re-evaluated the face validity of all 47 items, informed by the psychometric results.

Phase 4, Preliminary Exploratory Factor Analysis

After removing items identified through the above item reduction process, a preliminary exploratory factor analysis (EFA) of this small sample was conducted to see if the remaining items grouped into domains. To avoid losing participants with some missing items, prior to the implementing the factor analysis, we used the Expectation-maximization (EM) algorithm to impute the most likely values for missing items given the values of the participants' non-missing items and assuming the correlation structure observed between items among all participants.

We used the common factor model with PROMAX oblique factor rotation to allow for correlation between the underlying factors. The first step in the EFA was to decide how many factors should be retained. When making this decision we considered the amount of variance explained by the 2, 3, 4 and 5-factor solutions as well as the interpretability and parsimony of the resulting rotated factor solutions.[26]

Once the number of factors was decided upon and the rotated factor solution was obtained, we examined the factor loading matrix and identified the factors on which each item loaded most strongly. We grouped variables according to which item they loaded most heavily on (>0.5) and labelled the resultant grouping ('domain') to reflect the contents of its items. Face validity of the item groupings and the strength of the loadings and cross-loadings across domains were considered to determine whether any items should be placed in a domain other than the one that they loaded most heavily on. This was done through consensus among authors, only for situations where the factor loadings of an item were very similar between two domains, and if the item was felt to be more conceptually aligned to the domain with the slightly lower loading.

Phase 5, Evaluation of Internal Consistency

Internal reliability of the domains was assessed by Cronbach's alpha. We reassessed Cronbach's alpha after removing one item at a time from each domain to see if any item was reducing the internal consistency of the domain it was placed in.

All analyses were conducted in SAS Version 9.4 (SAS Institute Inc., Cary, NC, USA).

RESULTS

Phase 1; Adaptation of the ACP-55 and Review for Face Validity

During Phase 1, we adapted the original Patient Version of the 55-item ACP Engagement survey by altering the question stems to apply to SDMs and key informants (Appendix 1). For example, the patient-oriented ACP-55 item *"How confident are you that today you could ask someone to be your medical decision maker*?" was changed to *"As of today, how confident are you that you could serve as your loved one's medical decision maker*" for the ACP-47-SDM. We opted not to change the wording of the question stems from the original survey because these stems were generated from focus groups including both patients and surrogates and the original survey was vetted extensively by patients.[18, 23] Since our goal was to align the survey as closely as possible to the well-validated ACP-55, stems were kept as close to the original as possible.

After reviewing the stem adaptations, eight items were removed due to a lack of face validity. For example, one item for the patient-oriented survey asked "how much have you thought about whether or not certain health situations would make your life not worth living?" The adapted version of this question became "how much have you thought about whether or not your loved one has considered certain health situations that would make his/her life not worth living?" This was deemed to lack face validity because the item now examined whether the SDM thought about whether *the patient thought* about the issues, a somewhat abstract concept that is non-critical to serving in the role of an SDM.

Phase 2, Survey Administration

Next, the ACP-47-SDM was administered to 65 participants with mean age 51.8 years (SD 13.8) and 81% female. No participants were excluded due to cognitive dysfunction. Racial data was collected for 49 participants who were 96% Caucasian, 4% African American, and was missing for 21 participants due to administrative error.

Phase 3, Item Reduction

Table 1 shows the reasons for exclusion for each of the removed items. No items were deleted as a result of missing data, nonresponses, or ceiling effect. We removed 17 items due to redundancy (correlations with r>0.8; Appendix 2). Two items that were highly correlated (r=0.744) and therefore deleted due to their redundancy were: "how much have you thought about the possibility of being asked to make medical decisions for your loved one?" and "how much have you thought about your role as your loved one's medical decision-maker?" The remaining items were reviewed for face validity and 13 additional items were deleted. Reasons for deletion based on face validity included items involving two separate ideas within a single question (item #5), for example, thinking about playing the role of SDM and also thinking about being part of a discussion with others. Seven items were deleted because the group felt that the question inquired about thoughts/behaviors that were not the role of the SDM to initiate (for example, discussing one's role as a SDM with the patient's doctor; items # 6, 8, 9, 11,12, 23) and are also behaviors that the SDM cannot 'act' upon unless the patient themselves invited the action. Thus, including these items could negatively impact the SDM's engagement score with regards to behaviors outside their own control. Hence,

these items were deleted. Some items had multiple reasons for deletion as noted in Table 1. The resulting survey consisted of 17 remaining items.

Phase 4, Preliminary Exploratory Factor Analysis

Eight (12%) of the 65 participants had missing data for at least one of the 17 items. One participant, missed 7 items, and 7 respondents missed between 1 and 4 items. All missing item values were imputed priori to factor analysis so all 65 participants could be included (see methods).

A 1-factor solution explained 78% of the variance in the 17 items, 2 factors explained 86%, 3 factors explained 91%, 4 factors explained 95%, and 5 factors explained 99%. We reviewed the 2, 3, 4 and 5-factor solutions and selected the 3-factor solution for its simplicity and interpretability. The three factors were correlated with each other with the three pairwise Pearson's correlation coefficients ranging from 0.59 to 0.63.

We reviewed the items that loaded onto the 3-factor solution and grouped items according to their factor loadings (Table 2). The 7 items grouped in Factor 1 were reviewed for face validity by assessing the common features of these items with regards to their theoretical construct (e.g. self-perceived confidence). The identified similarities were that all items assessed either knowledge or self-efficacy about serving as a SDM, and thus the factor was labeled "serving as SDMs". No changes were made to Factor 1 based on face validity or clinical sensibility. The loadings of Factor 1 ranged from 0.48 to 0.89.

Factor 2 had 5 items which were reviewed using similar procedures. It was noted that 3 of the 5 items involved contemplation about various aspects of surrogate decision-making. One item (item #8; *how much have you thought about talking with your loved one about whether or not there are certain health situations that would make your loved one's life not worth living?)*) that was related to contemplation loaded weakly into the 3rd factor (0.38) with a loading of 0.24 in Factor 2. We decided to move this item into Factor 2 based on face validity since the other items in factor 2 all assessed contemplation. It was also noted that one item (item#17; *how ready are you to ask your loved one's doctor questions to help you make a good medical decision for your loved one if your loved one was unable to speak for themselves?)* loaded into Factor 2 with a value of 0.47 but had higher face validity in Factor 3 and was therefore moved to Factor 3. Factor 2 was named "Contemplation". The resulting Factor 2 had factor loadings ranging from 0.24 to 1.04.

After moving item#17 to Factor 3, that factor contained 6 items with a loading range of 0.28 to 0.93. All items in Factor 3 were related to readiness to serve in the role of SDM, and the factor was thus named "Readiness".

The resultant survey consists of 17-items with three factors ('domains') (see Appendix 3 for final survey): 1) Serving as SDM (7 items), 2) Contemplation (4 items), and 3) Readiness (6 items).

Phase 5, Evaluation of Internal Consistency

The Cronbach's alpha for factors 1, 2 and 3 were 0.91, 0.91 and 0.90 which is generally considered an indication of excellent internal consistency. In no cases did the Cronbach's alpha significantly increase when an item was removed.

DISCUSSION

It is increasingly recognized that ACP is a complex process involving multiple stakeholders in addition to patients themselves, such as family, friends, and clinicians. While much attention has been paid to the study of how ACP interventions engage *patients* in the ACP process, less work has focused on engaging the SDMs in ACP, despite their equally important role.[27] This may be due, in part, to a lack of validated measures that assess how interventions impact SDMs.

This study resulted in a questionnaire that measures the extent to which SDMs have engaged in the ACP process. To do so, we adapted a well-validated patient-centered survey that is grounded in behavior change theories and related constructs relevant to ACP (knowledge, contemplation, self-efficacy, and readiness). The result was a 47 item adapted questionnaire that was then shortened into a short, 17 item questionnaire. This questionnaire could be useful for researchers seeking to measures engagement in the ACP process by SDMs, but also may provide utility by allowing comparisons between engagement of the patients (using the original survey) with engagement of their SDMs. That said, relevant ACP behaviors for a patient may be slightly different than for a surrogate. For this reason, we did not anticipate that all items of the original 55-item survey would map onto the adapted SDM survey. Further, shortened versions of the original patient-oriented survey (4, 9, 15, and 34-items) have been published and are being validated.[17]

While our preliminary exploratory factor analysis is limited by small sample size, it provides useful information it resulted in identification of three domains within the final 17-item questionnaire (The ACP-17-SDM; Appendix 3). Domain 1, 'Serving as SDM', includes 7 items that assess knowledge (3-items), contemplation (1 item), self-efficacy (3-items). Domain 2, 'Contemplation', includes 4-items that assess contemplation (how much surrogates have thought about end-of-life issues).

The third domain, 'Readiness', includes 6 items that assess readiness and measure participants' stage of readiness to engage in various ACP behaviors. Responses to the readiness question are based on the trans-theoretical model's five stages of change, allowing the respondent's 'stage of change' for each of the 6 ACP behaviors to be assessed in addition to the total domain score. Given the limited precision of the factor loadings due to the small sample size, we recommend each factor be reported as a domain score computed as the unweighted average of the items in that domain. Larger studies are needed to verify the validity of these domains.

Still, the domain scores may be helpful for interventionalists examining mechanisms by which an intervention engages participants in ACP. For example, an intervention intended to start conversations would be expected to increase participants' contemplation scores with

lesser effect on ‘readiness’ scores (which assesses subsequent actions). Ideal ACP interventions will increase participants’ overall engagement in the ACP process and effect all of these domains equally, yet the complexity of the ACP process likely makes a single intervention insufficient, and consideration should be given to how ACP interventions effect each of these domains.

A limitation of this study is the small, homogenous, convenience sample which could limit the stability and generalizability of the results. Further, using convenience sampling may result in selection bias related to literacy or other factors. Second, we did not collect data on the patients’ medical conditions. Third, we have not yet assessed the tool’s responsiveness to intervention.[17] Fourth, some items had fairly low loadings on the factors they were assigned. Even so, this study introduces a brief, 17-item questionnaire that assesses SDM engagement in ACP and is derived from a well-validated patient-oriented survey. Additional studies with larger sample size and varied demographics, literacy and cultures are needed to further validate and possibly shorten the questionnaire to mirror work in the patient-oriented version of survey[17] and to assess its’ responsiveness to intervention.

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Appendix

Appendix 1.

Adaptation of the 55-item Patient-Oriented ACP Engagement Survey

Item	Original Question (Patient Oriented)	Adapted Question (Surrogate Decision Maker oriented)	Group Decision After Phase 1 review
1	How well informed are you about who can be a medical decision maker?	Unchanged	Continued testing
2	How well informed are you about what makes someone a good medical decision maker?	Unchanged	Continued testing
3	How well informed are you about the types of decisions that a medical decision maker may have to make for you in the future?	How well informed are you about the types of decisions that you may have to make for your loved one in the future?	Continued testing
4	How much have you thought about who your medical decision maker should be?	How much have you thought about your role as your loved one’s medical decision-maker?	Continued testing
5	How much have you thought about asking someone to be your medical decision maker?	How much have you thought about the possibility of being asked to make medical decisions for your loved one?	Excluded due to a lack of face validity
6	How much have you thought about Talking with your doctors about who you want your medical decision maker to be?	How much have you thought about being part of a discussion with your loved one’s DOCTORS about your role as a medical decision-maker for your loved one?	Continued testing

Item	Original Question (Patient Oriented)	Adapted Question (Surrogate Decision Maker oriented)	Group Decision After Phase 1 review
7	How much have you thought about Talking with your OTHER family and friends about who you want your medical decision maker to be?	How much have you thought about being part of a discussion with your loved one's OTHER family and friends about your role as your loved one's medical decision-maker?	Continued testing
8	How confident are you that today you could Ask someone to be your medical decision maker?	As of today, how confident are you that you could serve as your loved one's medical decision maker?	Continued testing
9	How confident are you that today you could Talk with your doctors about who you want your medical decision maker to be?	As of today, how confident are you that you could be part of a discussion with your loved one's DOCTORS about your role as your loved one's medical decision maker?	Continued testing
10	How confident are you that today you could Talk with your OTHER family and friends about who you want your medical decision maker to be?	As of today, how confident are you that you could be part of a discussion with your loved one's OTHER FAMILY and FRIENDS about your role as your loved one's medical decision maker?	Continued testing
11	How ready are you to formally ask someone to be your medical decision maker	How ready are you to formally discuss with your loved one your role as their medical decision maker?	Continued testing
12	How ready are you to talk with your DOCTOR about who you want your medical decision maker to be?	How ready are you to be part of a discussion with your loved one's DOCTOR about your role as your loved one's medical decision-maker?	Continued testing
13	How ready are you to talk to your OTHER FAMILY and FRIENDS about who you want your medical decision maker to be?	How ready are you to be part of a discussion with your loved one's OTHER FAMILY and FRIENDS about your role as your loved one's medical decision maker?	Continued testing
14	How ready are you to SIGN OFFICIAL PAPERS naming a person or group of people to make medical decisions for you?	How ready are you to be named a medical decision maker in OFFICIAL PAPERS that are signed by your loved one?	Continued testing
15	How much have you thought about Whether or not certain health situations would make your life not worth living?	How much have you thought about whether or not your loved one has considered certain health situations that would make his/her life not worth living?	Excluded due to a lack of face validity
16	How much have you thought about Talking with your DECISION MAKER about whether or not certain health situations would make your life not worth living?	How much have you thought about talking with your loved one about whether or not there are certain health situations that would make your loved one's life not worth living?	Continued testing
17	How much have you thought about Talking with your DOCTORS about whether or not certain health situations would make your life not worth living?	How much have you thought about being part of a discussion with your loved one's DOCTORS about whether or not there are certain health situations that would make your loved one's life not worth living?	Continued testing
18	How much have you thought about Talking with your OTHER family and friends about whether or not certain health situations would make your loved one's life not worth living?	How much have you thought about being part of a discussion with your loved ones OTHER FAMILY and FRIENDS about whether or not there are certain health situations that would make your loved one's life not worth living?	Continued testing
19	How confident are you that today you could Talk with your decision maker about whether or not certain health situations would make your life not worth living?	As of today, how confident are you that you could talk with your loved one about whether or not certain health situations would their life not worth living?	Continued testing
20	How confident are you that today you could Talk with your doctors about whether or not certain health situations would make your life not worth living?	As of today, how confident are you that you could be part of a discussion with your loved one's DOCTORS about whether or not there are certain health situations that would make your loved one's life not worth living?	Continued testing

Item	Original Question (Patient Oriented)	Adapted Question (Surrogate Decision Maker oriented)	Group Decision After Phase 1 review
21	How confident are you that today you could Talk with your OTHER family and friends about whether or not certain health situations would make your life not worth living?	As of today, how confident are you that you could talk with your loved one's OTHER FAMILY and FRIENDS about whether or not there are certain health situations that would make your loved one's life not worth living?	Continued testing
22	How ready are you to decide whether or not certain health situations would make your life not worth living?	How ready are you to help your loved one decide whether or not certain health situations would make their life not worth living?	Excluded due to a lack of face validity
23	How ready are you to talk to your DECISION MAKER about whether or not certain health situations would make your life not worth living?	How ready are you to talk with your loved one about whether or not there are certain health situations that would make their life not worth living?	Continued testing
24	How ready are you to talk to your DOCTOR about whether or not certain health situations would make your life not worth living?	How ready are you to be part of a discussion with your loved one's DOCTOR about whether or not there are certain health situations that would make your loved one's life not worth living?	Continued testing
25	How ready are you to talk to your OTHER FAMILY and FRIENDS about whether or not certain health situations would make your life not worth living?	How ready are you to be part of a discussion with your loved one's OTHER FAMILY and FRIENDS about whether or not there are certain health situations that would make your loved one's life not worth living?	Continued testing
26	How ready are you to SIGN OFFICIAL PAPERS putting your wishes in writing about whether or not certain health situations would make your loved one's life not worth living?	How ready are you help your loved one SIGN OFFICIAL PAPERS putting his/her wishes in writing about whether or not there are certain health situations that would make your loved one's life not worth living?	Continued testing
27	How much have you thought about the care you would want if you were very sick or near the end of life?	How much have you thought about The care your loved one would want if he/she were very sick or near the end of life?	Excluded due to a lack of face validity
28	How much have you thought about talking with your decision maker about the care you would want if you were very sick or near the end of life?	How much have you thought about talking with your loved one about the care he/she would want if they were very sick or near the end of life?	Continued testing
29	How much have you thought about talking with your doctors about the care you would want if you were very sick or near the end of life?	How much have you thought about being part of a discussion with your loved one's DOCTORS about the care your loved one would want if he/she was very sick or near the end of life?	Continued testing
30	How much have you thought about talking with your OTHER family and friends about the care you would want if you were very sick or near the end of life?	How much have you thought about being part of a discussion with your loved one's OTHER FAMILY and FRIENDS about the care your loved one would want if he/she were very sick or near the end of life?	Continued testing
31	How confident are you that today you could Talk with your decision maker about the care you would want if you were very sick or near the end of life?	As of today, how confident are you that you could talk with your loved one about the care he/she would want if he/she were very sick or near the end of life?	Continued testing
32	How confident are you that today you could Talk with your doctors about the care you would want if you were very sick or near the end of life?	As of today, how confident are you that you could be part of a discussion with your loved one's doctors about the care your loved one would want if he/she were very sick or near the end of life?	Continued testing
33	How confident are you that today you could Talk with your OTHER family and friends about the care you would want if you were very sick or near the end of life?	As of today, how confident are you that you could be part of a discussion with your loved one's OTHER FAMILY and FRIENDS about the care your loved one would want if he/she were very sick or near the end of life?	Continued testing

Item	Original Question (Patient Oriented)	Adapted Question (Surrogate Decision Maker oriented)	Group Decision After Phase 1 review
34	How ready are you to decide on the medical care you would want if you were very sick or near the end of life?	How ready are you to help your loved one decide on the medical care he/she would want if he/she were very sick or near the end of life?	Excluded due to a lack of face validity
35	How ready are you to talk to your DECISION MAKER about the kind of medical care you would want if you were very sick or near the end of life?	How ready are you to talk to your loved one about the kind of medical care he/she would want if they were very sick or near the end of life?	Continued testing
36	How ready are you to talk to your DOCTOR about the kind of medical care you would want if you were very sick or near the end of life?	How ready are you to be part of a discussion with your loved one's DOCTOR about the kind of medical care your loved one would want if he/she were very sick or near the end of life?	Continued testing
37	How ready are you to talk to your OTHER FAMILY and FRIENDS about the kind of medical care you would want if you were very sick or near the end of life?	How ready are you to be part of a discussion with your loved one's OTHER FAMILY and FRIENDS about the kind of medical care he/she would want if he/she were very sick or near the end of life?	Continued testing
38	How ready are you to SIGN OFFICIAL PAPERS putting your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life?	How ready are you to help your loved one SIGN OFFICIAL PAPERS putting his/her wishes in writing about the kind of medical care he/she would want if he/she very sick or near the end of life?	Continued testing
39	How well informed are you about what it means to give a medical decision maker flexibility to make future decisions?	Unchanged	Excluded due to a lack of face validity
40	How well informed are you about the different amounts of flexibility a person can give their medical decision maker?	Unchanged	Continued testing
41	How much have you thought about The amount of flexibility you would want to give your medical decision maker?	How much have you thought about the amount of flexibility you would have as your loved one's medical decision maker	Continued testing
42	How much have you thought about Talking with your decision maker about how much flexibility you want to give a medical decision maker?	How much have you thought about talking with your loved one about the amount of flexibility he/she would want to give you as a medical decision maker?	Continued testing
43	How much have you thought about Talking with your DOCTOR about how much flexibility you want to give your decision maker?	How much have you thought about being part of a discussion with your loved one's DOCTOR about the amount of flexibility you would have as the medical decision maker?	Continued testing
44	How much have you thought about Talking with OTHER friends and family about how much flexibility you want to give your decision maker?	How much have you thought about being part of a discussion with your loved one's OTHER family and friends about the amount of flexibility you would have as the medical decision maker?	Continued testing
45	How confident are you that today you could Talk with your DECISION MAKER about how much flexibility you want to give them as a medical decision maker?	As of today, how confident are you that you could talk with your loved one about how much flexibility he/she would want to give you as a medical decision maker?	Continued testing
46	How confident are you that today you could Talk with your DOCTOR about how much flexibility you want to give your medical decision maker?	As of today, how confident are you that you could be part of a discussion with your loved one's DOCTOR about how much flexibility your loved one would want to give you as a medical decision maker?	Continued testing
47	How confident are you that today you could Talk with your OTHER family and friends about how much flexibility you want to give your medical decision maker?	As of today, how confident are you that you could be part of a discussion with your loved one's OTHER family and friends about how much flexibility your loved one would want to give you as a medical decision maker?	Continued testing

Item	Original Question (Patient Oriented)	Adapted Question (Surrogate Decision Maker oriented)	Group Decision After Phase 1 review
48	How ready are you to talk to your DECISION MAKER about how much flexibility you want to give a medical decision maker?	How ready are you to talk to your loved one about how much flexibility he/she would want to give you as a medical decision maker?	Continued testing
49	How ready are you to talk to your DOCTOR about how much flexibility you want to give your decision maker?	How ready are you to be part of a discussion with your loved one's DOCTOR about how much flexibility your loved one would want to give you as a medical decision maker?	Continued testing
50	How ready are you to talk to your OTHER FAMILY and FRIENDS about how much flexibility you want to give your medical decision maker?	How ready are you to be part of a discussion with your loved one's OTHER FAMILY and FRIENDS about how much flexibility your loved one would want to give you as a medical decision maker?	Continued testing
51	How ready are you to SIGN OFFICIAL PAPERS putting your wishes in writing about how much flexibility to give your decision maker?	How ready are you to help your loved one SIGN OFFICIAL PAPERS about how much flexibility he/she would want to give you as a medical decision maker?	Continued testing
52	How well informed are you about The types of questions you can ask your doctor that will help you make a good medical decision?	How well informed are you about the types of questions you and your loved one can ask his/her doctor that will help them make a good medical decision for your loved one?	Excluded due to a lack of face validity
53	How much have you thought about Questions you will ask your doctor to help make good medical decisions?	How much have you thought about questions you will ask your loved one's doctor to help make good medical decisions for your loved one?	Excluded due to a lack of face validity
54	How confident are you that today you could Ask the right questions of your doctor to help make good medical decisions?	How confident are you that today you could ask the right questions of your loved one's doctors to help make good medical decisions for your loved one if your loved one was unable to speak for themselves?	Continued testing (underline words were accidentally deleted from survey)
55	How ready are you to ask your doctor questions to help you make a good medical decision?	How ready are you to ask your loved one's doctor questions to help you make a good medical decision for your loved one if your loved one was unable to speak for themselves?	Continued testing

Appendix 2.

Item by item correlation analysis

	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10
Item 1	1.000	.734	.672	.514	.448	.516	.516	.379	.476	.500
Item 2	.734	1.000	.715	.563	.576	.495	.549	.526	.582	.454
Item 3	.672	.715	1.000	.450	.441	.517	.559	.516	.532	.464
Item 4	.514	.563	.450	1.000	.744	.589	.431	.367	.454	.539
Item 5	.448	.576	.441	.744	1.000	.735	.429	.440	.508	.459
Item 6	.516	.495	.517	.589	.735	1.000	.494	.469	.544	.519
Item 7	.516	.549	.559	.431	.429	.494	1.000	.892	.738	.516
Item 8	.379	.526	.516	.367	.440	.469	.892	1.000	.792	.454
Item 9	.476	.582	.532	.454	.508	.544	.738	.792	1.000	.472

Item 10	.500	.454	.464	.539	.459	.519	.516	.454	.472	1.000
Item 11	.386	.423	.462	.590	.608	.602	.504	.494	.537	.742
Item 12	.395	.368	.423	.493	.537	.767	.543	.531	.636	.667
Item 13	.570	.487	.523	.568	.573	.597	.467	.394	.519	.713
Item 14	.475	.478	.445	.487	.513	.611	.611	.544	.566	.581
Item 15	.420	.433	.318	.525	.677	.669	.499	.481	.473	.436
Item 16	.398	.460	.421	.469	.615	.768	.509	.499	.558	.445
Item 17	.408	.477	.214	.306	.453	.362	.442	.401	.446	.292
Item 18	.451	.466	.374	.481	.640	.621	.610	.527	.540	.401
Item 19	.390	.469	.322	.386	.565	.562	.539	.508	.628	.327
Item 20	.504	.536	.493	.420	.446	.644	.543	.492	.516	.559
Item 21	.535	.626	.562	.468	.562	.654	.514	.429	.499	.487
Item 22	.473	.541	.434	.432	.562	.733	.492	.461	.518	.475
Item 23	.552	.478	.445	.512	.553	.610	.450	.406	.512	.612
Item 24	.539	.600	.580	.510	.630	.714	.550	.472	.463	.567
Item 25	.453	.481	.481	.500	.669	.697	.537	.462	.502	.353
Item 26	.507	.525	.404	.468	.642	.797	.477	.467	.565	.415
Item 27	.502	.583	.434	.421	.531	.507	.497	.492	.526	.414
Item 28	.558	.578	.590	.595	.770	.794	.665	.638	.727	.554
Item 29	.421	.525	.473	.461	.687	.719	.593	.627	.803	.481
Item 30	.462	.560	.505	.507	.507	.695	.510	.494	.531	.671
Item 31	.505	.523	.519	.556	.595	.772	.493	.422	.471	.591
Item 32	.487	.557	.489	.472	.598	.756	.441	.448	.516	.530
Item 33	.518	.473	.515	.425	.520	.582	.390	.348	.465	.566
Item 34	.540	.491	.539	.451	.548	.584	.520	.436	.388	.351
Item 35	.364	.432	.411	.512	.660	.688	.517	.400	.505	.336

Item 36	.410	.464	.410	.469	.646	.658	.582	.468	.542	.503
Item 37	.384	.364	.376	.415	.597	.611	.530	.432	.462	.470
Item 38	.356	.450	.336	.406	.626	.700	.518	.475	.517	.467
Item 39	.451	.522	.357	.239	.393	.399	.443	.403	.393	.431
Item 40	.451	.508	.495	.427	.613	.601	.636	.522	.575	.411
Item 41	.419	.488	.446	.320	.548	.565	.595	.484	.647	.347
Item 42	.549	.542	.599	.554	.617	.668	.518	.443	.487	.733
Item 43	.450	.478	.475	.438	.567	.610	.410	.372	.449	.462
Item 44	.495	.555	.528	.484	.619	.702	.447	.421	.506	.457
Item 45	.526	.478	.530	.446	.552	.631	.431	.414	.462	.628
Item 46	.350	.501	.416	.375	.472	.557	.658	.632	.665	.439
Item 47	.395	.470	.493	.417	.539	.621	.429	.461	.497	.447
	Item 11	Item 12	Item 13	Item 14	Item 15	Item 16	Item 17	Item 18	Item 19	Item 20
Item 1	.386	.395	.570	.475	.420	.398	.408	.451	.390	.504
Item 2	.423	.368	.487	.478	.433	.460	.477	.466	.469	.536
Item 3	.462	.423	.523	.445	.318	.421	.214	.374	.322	.493
Item 4	.590	.493	.568	.487	.525	.469	.306	.481	.386	.420
Item 5	.608	.537	.573	.513	.677	.615	.453	.640	.565	.446
Item 6	.602	.767	.597	.611	.669	.768	.362	.621	.562	.644
Item 7	.504	.543	.467	.611	.499	.509	.442	.610	.539	.543
Item 8	.494	.531	.394	.544	.481	.499	.401	.527	.508	.492
Item 9	.537	.636	.519	.566	.473	.558	.446	.540	.628	.516
Item 10	.742	.667	.713	.581	.436	.445	.292	.401	.327	.559
Item 11	1.000	.770	.666	.575	.531	.462	.132	.358	.299	.486
Item 12	.770	1.000	.617	.595	.572	.671	.149	.414	.450	.516
Item 13	.666	.617	1.000	.539	.521	.518	.309	.520	.430	.612
Item 14	.575	.595	.539	1.000	.746	.702	.530	.719	.636	.744
Item 15	.531	.572	.521	.746	1.000	.806	.467	.788	.634	.671
Item 16	.462	.671	.518	.702	.806	1.000	.488	.688	.693	.689

Item 17	.132	.149	.309	.530	.467	.488	1.000	.683	.669	.579
Item 18	.358	.414	.520	.719	.788	.688	.683	1.000	.874	.727
Item 19	.299	.450	.430	.636	.634	.693	.669	.874	1.000	.664
Item 20	.486	.516	.612	.744	.671	.689	.579	.727	.664	1.000
Item 21	.591	.517	.577	.665	.643	.623	.433	.669	.637	.792
Item 22	.551	.699	.464	.688	.740	.813	.415	.668	.695	.781
Item 23	.549	.521	.896	.526	.643	.598	.428	.661	.578	.722
Item 24	.489	.489	.499	.678	.654	.705	.622	.635	.515	.743
Item 25	.482	.507	.467	.574	.722	.767	.508	.608	.544	.591
Item 26	.434	.668	.484	.563	.753	.865	.388	.640	.654	.578
Item 27	.289	.326	.370	.523	.420	.517	.848	.559	.522	.551
Item 28	.607	.699	.638	.691	.724	.730	.472	.776	.712	.609
Item 29	.543	.724	.570	.618	.559	.738	.487	.643	.779	.569
Item 30	.590	.620	.616	.669	.565	.668	.498	.554	.494	.884
Item 31	.688	.726	.531	.508	.662	.682	.250	.500	.442	.638
Item 32	.621	.764	.506	.558	.625	.781	.318	.519	.571	.659
Item 33	.524	.484	.798	.356	.524	.494	.301	.477	.401	.646
Item 34	.387	.389	.405	.235	.364	.458	.409	.445	.386	.460
Item 35	.422	.486	.427	.435	.593	.686	.391	.590	.510	.526
Item 36	.528	.576	.444	.535	.557	.651	.516	.535	.482	.596
Item 37	.543	.618	.422	.411	.548	.593	.279	.431	.420	.483
Item 38	.508	.644	.423	.519	.664	.744	.316	.542	.524	.523
Item 39	.257	.234	.305	.375	.316	.350	.746	.478	.383	.522
Item 40	.412	.440	.487	.420	.537	.555	.549	.748	.663	.601
Item 41	.360	.487	.462	.420	.493	.595	.530	.665	.692	.526
Item 42	.747	.674	.747	.579	.550	.499	.321	.453	.311	.636

Item 43	.547	.559	.534	.330	.548	.502	.271	.403	.303	.458
Item 44	.513	.597	.526	.398	.551	.632	.315	.443	.416	.531
Item 45	.585	.528	.760	.494	.617	.552	.298	.572	.443	.697
Item 46	.455	.455	.424	.532	.587	.617	.410	.670	.575	.579
Item 47	.605	.588	.438	.353	.536	.491	.231	.361	.299	.508
	Item 20	Item 21	Item 22	Item 23	Item 24	Item 25	Item 26	Item 27	Item 28	Item 29
Item 1	.504	.535	.473	.552	.539	.453	.507	.502	.558	.421
Item 2	.536	.626	.541	.478	.600	.481	.525	.583	.578	.525
Item 3	.493	.562	.434	.445	.580	.481	.404	.434	.590	.473
Item 4	.420	.468	.432	.512	.510	.500	.468	.421	.595	.461
Item 5	.446	.562	.562	.553	.630	.669	.642	.531	.770	.687
Item 6	.644	.654	.733	.610	.714	.697	.797	.507	.794	.719
Item 7	.543	.514	.492	.450	.550	.537	.477	.497	.665	.593
Item 8	.492	.429	.461	.406	.472	.462	.467	.492	.638	.627
Item 9	.516	.499	.518	.512	.463	.502	.565	.526	.727	.803
Item 10	.559	.487	.475	.612	.567	.353	.415	.414	.554	.481
Item 11	.486	.591	.551	.549	.489	.482	.434	.289	.607	.543
Item 12	.516	.517	.699	.521	.489	.507	.668	.326	.699	.724
Item 13	.612	.577	.464	.896	.499	.467	.484	.370	.638	.570
Item 14	.744	.665	.688	.526	.678	.574	.563	.523	.691	.618
Item 15	.671	.643	.740	.643	.654	.722	.753	.420	.724	.559
Item 16	.689	.623	.813	.598	.705	.767	.865	.517	.730	.738
Item 17	.579	.433	.415	.428	.622	.508	.388	.848	.472	.487
Item 18	.727	.669	.668	.661	.635	.608	.640	.559	.776	.643
Item 19	.664	.637	.695	.578	.515	.544	.654	.522	.712	.779
Item 20	1.000	.792	.781	.722	.743	.591	.578	.551	.609	.569
Item 21	.792	1.000	.818	.614	.672	.587	.602	.441	.625	.596
Item 22	.781	.818	1.000	.522	.633	.591	.783	.428	.635	.669
Item 23	.722	.614	.522	1.000	.572	.572	.571	.424	.662	.567

Item 24	.743	.672	.633	.572	1.000	.842	.659	.721	.658	.546
Item 25	.591	.587	.591	.572	.842	1.000	.751	.578	.669	.587
Item 26	.578	.602	.783	.571	.659	.751	1.000	.448	.706	.716
Item 27	.551	.441	.428	.424	.721	.578	.448	1.000	.620	.596
Item 28	.609	.625	.635	.662	.658	.669	.706	.620	1.000	.850
Item 29	.569	.596	.669	.567	.546	.587	.716	.596	.850	1.000
Item 30	.884	.734	.736	.650	.795	.565	.544	.615	.614	.606
Item 31	.638	.741	.785	.561	.732	.706	.713	.366	.634	.549
Item 32	.659	.760	.922	.501	.614	.561	.790	.415	.636	.696
Item 33	.646	.620	.472	.840	.563	.557	.484	.385	.585	.503
Item 34	.460	.458	.443	.429	.605	.648	.486	.552	.531	.452
Item 35	.526	.515	.567	.491	.679	.784	.655	.419	.624	.564
Item 36	.596	.535	.590	.441	.745	.733	.579	.544	.615	.572
Item 37	.483	.444	.565	.416	.603	.675	.563	.314	.549	.532
Item 38	.523	.463	.687	.477	.582	.635	.710	.346	.643	.606
Item 39	.522	.383	.347	.352	.699	.464	.311	.771	.445	.398
Item 40	.601	.597	.520	.569	.658	.627	.563	.560	.729	.651
Item 41	.526	.532	.519	.512	.612	.638	.632	.511	.689	.720
Item 42	.636	.624	.536	.657	.691	.573	.429	.447	.647	.518
Item 43	.458	.570	.549	.528	.620	.623	.566	.390	.509	.460
Item 44	.531	.631	.664	.511	.655	.642	.659	.416	.570	.576
Item 45	.697	.595	.541	.832	.634	.518	.512	.345	.624	.495
Item 46	.579	.564	.591	.544	.615	.593	.589	.431	.643	.571
Item 47	.508	.506	.543	.492	.638	.674	.551	.393	.532	.479

	Item 29	Item 30	Item 31	Item 32	Item 33	Item 34	Item 35	Item 36	Item 37	Item 38	Item 39
Item 1	.421	.462	.505	.487	.518	.540	.364	.410	.384	.356	.451

Item 2	.525	.560	.523	.557	.473	.491	.432	.464	.364	.450	.522
Item 3	.473	.505	.519	.489	.515	.539	.411	.410	.376	.336	.357
Item 4	.461	.507	.556	.472	.425	.451	.512	.469	.415	.406	.239
Item 5	.687	.507	.595	.598	.520	.548	.660	.646	.597	.626	.393
Item 6	.719	.695	.772	.756	.582	.584	.688	.658	.611	.700	.399
Item 7	.593	.510	.493	.441	.390	.520	.517	.582	.530	.518	.443
Item 8	.627	.494	.422	.448	.348	.436	.400	.468	.432	.475	.403
Item 9	.803	.531	.471	.516	.465	.388	.505	.542	.462	.517	.393
Item 10	.481	.671	.591	.530	.566	.351	.336	.503	.470	.467	.431
Item 11	.543	.590	.688	.621	.524	.387	.422	.528	.543	.508	.257
Item 12	.724	.620	.726	.764	.484	.389	.486	.576	.618	.644	.234
Item 13	.570	.616	.531	.506	.798	.405	.427	.444	.422	.423	.305
Item 14	.618	.669	.508	.558	.356	.235	.435	.535	.411	.519	.375
Item 15	.559	.565	.662	.625	.524	.364	.593	.557	.548	.664	.316
Item 16	.738	.668	.682	.781	.494	.458	.686	.651	.593	.744	.350
Item 17	.487	.498	.250	.318	.301	.409	.391	.516	.279	.316	.746
Item 18	.643	.554	.500	.519	.477	.445	.590	.535	.431	.542	.478
Item 19	.779	.494	.442	.571	.401	.386	.510	.482	.420	.524	.383
Item 20	.569	.884	.638	.659	.646	.460	.526	.596	.483	.523	.522
Item 21	.596	.734	.741	.760	.620	.458	.515	.535	.444	.463	.383
Item 22	.669	.736	.785	.922	.472	.443	.567	.590	.565	.687	.347
Item 23	.567	.650	.561	.501	.840	.429	.491	.441	.416	.477	.352
Item 24	.546	.795	.732	.614	.563	.605	.679	.745	.603	.582	.699
Item 25	.587	.565	.706	.561	.557	.648	.784	.733	.675	.635	.464
Item 26	.716	.544	.713	.790	.484	.486	.655	.579	.563	.710	.311
Item 27	.596	.615	.366	.415	.385	.552	.419	.544	.314	.346	.771
Item 28	.850	.614	.634	.636	.585	.531	.624	.615	.549	.643	.445

Item 29	1.000	.606	.549	.696	.503	.452	.564	.572	.532	.606	.398
Item 30	.606	1.000	.740	.731	.645	.486	.552	.652	.548	.555	.590
Item 31	.549	.740	1.000	.838	.642	.563	.672	.668	.689	.653	.415
Item 32	.696	.731	.838	1.000	.505	.460	.537	.584	.589	.676	.332
Item 33	.503	.645	.642	.505	1.000	.499	.531	.473	.484	.415	.376
Item 34	.452	.486	.563	.460	.499	1.000	.639	.682	.647	.512	.621
Item 35	.564	.552	.672	.537	.531	.639	1.000	.843	.792	.735	.418
Item 36	.572	.652	.668	.584	.473	.682	.843	1.000	.859	.798	.613
Item 37	.532	.548	.689	.589	.484	.647	.792	.859	1.000	.787	.415
Item 38	.606	.555	.653	.676	.415	.512	.735	.798	.787	1.000	.350
Item 39	.398	.590	.415	.332	.376	.621	.418	.613	.415	.350	1.000
Item 40	.651	.574	.584	.499	.583	.686	.701	.685	.635	.552	.675
Item 41	.720	.488	.566	.510	.529	.560	.681	.671	.617	.556	.635
Item 42	.518	.749	.758	.600	.782	.506	.557	.656	.649	.526	.504
Item 43	.460	.563	.736	.622	.635	.586	.577	.602	.706	.551	.475
Item 44	.576	.642	.800	.735	.648	.594	.688	.673	.689	.641	.471
Item 45	.495	.705	.645	.566	.811	.483	.504	.535	.555	.577	.442
Item 46	.571	.602	.575	.534	.474	.473	.648	.530	.492	.581	.454
Item 47	.479	.604	.761	.614	.618	.573	.593	.598	.708	.553	.466

	Item 40	Item 41	Item 42	Item 43	Item 44	Item 45	Item 46	Item 47
Item 1	.451	.419	.549	.450	.495	.526	.350	.395
Item 2	.508	.488	.542	.478	.555	.478	.501	.470
Item 3	.495	.446	.599	.475	.528	.530	.416	.493
Item 4	.427	.320	.554	.438	.484	.446	.375	.417
Item 5	.613	.548	.617	.567	.619	.552	.472	.539
Item 6	.601	.565	.668	.610	.702	.631	.557	.621
Item 7	.636	.595	.518	.410	.447	.431	.658	.429
Item 8	.522	.484	.443	.372	.421	.414	.632	.461
Item 9	.575	.647	.487	.449	.506	.462	.665	.497
Item 10	.411	.347	.733	.462	.457	.628	.439	.447

Item 11	.412	.360	.747	.547	.513	.585	.455	.605
Item 12	.440	.487	.674	.559	.597	.528	.455	.588
Item 13	.487	.462	.747	.534	.526	.760	.424	.438
Item 14	.420	.420	.579	.330	.398	.494	.532	.353
Item 15	.537	.493	.550	.548	.551	.617	.587	.536
Item 16	.555	.595	.499	.502	.632	.552	.617	.491
Item 17	.549	.530	.321	.271	.315	.298	.410	.231
Item 18	.748	.665	.453	.403	.443	.572	.670	.361
Item 19	.663	.692	.311	.303	.416	.443	.575	.299
Item 20	.601	.526	.636	.458	.531	.697	.579	.508
Item 21	.597	.532	.624	.570	.631	.595	.564	.506
Item 22	.520	.519	.536	.549	.664	.541	.591	.543
Item 23	.569	.512	.657	.528	.511	.832	.544	.492
Item 24	.658	.612	.691	.620	.655	.634	.615	.638
Item 25	.627	.638	.573	.623	.642	.518	.593	.674
Item 26	.563	.632	.429	.566	.659	.512	.589	.551
Item 27	.560	.511	.447	.390	.416	.345	.431	.393
Item 28	.729	.689	.647	.509	.570	.624	.643	.532
Item 29	.651	.720	.518	.460	.576	.495	.571	.479
Item 30	.574	.488	.749	.563	.642	.705	.602	.604
Item 31	.584	.566	.758	.736	.800	.645	.575	.761
Item 32	.499	.510	.600	.622	.735	.566	.534	.614
Item 33	.583	.529	.782	.635	.648	.811	.474	.618
Item 34	.686	.560	.506	.586	.594	.483	.473	.573
Item 35	.701	.681	.557	.577	.688	.504	.648	.593
Item 36	.685	.671	.656	.602	.673	.535	.530	.598
Item 37	.635	.617	.649	.706	.689	.555	.492	.708
Item 38	.552	.556	.526	.551	.641	.577	.581	.553
Item 39	.675	.635	.504	.475	.471	.442	.454	.466
Item 40	1.000	.910	.571	.604	.622	.589	.647	.582
Item 41	.910	1.000	.494	.586	.644	.520	.565	.558
Item 42	.571	.494	1.000	.695	.676	.756	.448	.719
Item 43	.604	.586	.695	1.000	.867	.712	.471	.875
Item 44	.622	.644	.676	.867	1.000	.682	.496	.759
Item 45	.589	.520	.756	.712	.682	1.000	.548	.679
Item 46	.647	.565	.448	.471	.496	.548	1.000	.519
Item 47	.582	.558	.719	.875	.759	.679	.519	1.000

Appendix 3.

Final 17-item ACP Engagement Survey- Surrogate Decision-Maker

Item	Theoretical Construct	Domain (Factor)
1. How well informed are you about who can be a medical decision maker?	Knowledge	Serving as surrogate decision-maker
2. How well informed are you about what makes someone a good medical decision maker?	Knowledge	Serving as surrogate decision-maker
3. How well informed are you about the types of decisions that you may have to make for your loved one in the future?	Knowledge	Serving as surrogate decision-maker
4. How much have you thought about your role as your loved one's medical decision-maker?	Contemplation	Serving as surrogate decision-maker
5. As of today, how confident are you that you could serve as your loved one's medical decision maker?	Self-efficacy	Serving as surrogate decision-maker
6. As of today, how confident are you that you could talk with your loved one about the care he/she would want if he/she were very sick or near the end of life?	Self-efficacy	Serving as surrogate decision-maker
7. As of today, how confident are you that you could be part of a discussion with your loved one's DOCTOR about the care your loved one would want if he/she were very sick or near the end of life?	Self-efficacy	Serving as surrogate decision-maker
8. How much have you thought about talking with your loved one about whether or not there are certain health situations that would make your loved one's life not worth living?	Contemplation	Contemplation
9. How much have you thought about being part of a discussion with your loved one's DOCTORS about whether or not there are certain health situations that would make your loved one's life not worth living?	Contemplation	Contemplation
10. How much have you thought about talking with your loved one about the care he/she would want if they were very sick or near the end of life?	Contemplation	Contemplation
11. How much have you thought about being part of a discussion with your loved one's DOCTORS about the care he/she would want if they were very sick or near the end of life?	Contemplation	Contemplation
12. How ready are you to formally discuss with your loved one your role as their medical decision maker?	Readiness	Readiness
13. How ready are you to talk to your loved one about the kind of medical care he/she would want if they were very sick or near the end of life?	Readiness	Readiness
14. How ready are you to talk to your loved one about whether or not there are certain health situations that would make your loved one's life not worth living?	Readiness	Readiness
15. How ready are you to be part of a discussion with your loved one's DOCTOR about whether or not there are certain health situations that would make your loved one's life not worth living?	Readiness	Readiness
16. How ready are you to be part of a discussion with your loved one's DOCTOR about the kind of medical care your loved one would want if he/she were very sick or near the end of life?	Readiness	Readiness
17. How ready are you to ask your loved one's DOCTOR questions to help you make a good medical decision for your loved one if your loved one was unable to speak for themselves?	Readiness	Readiness

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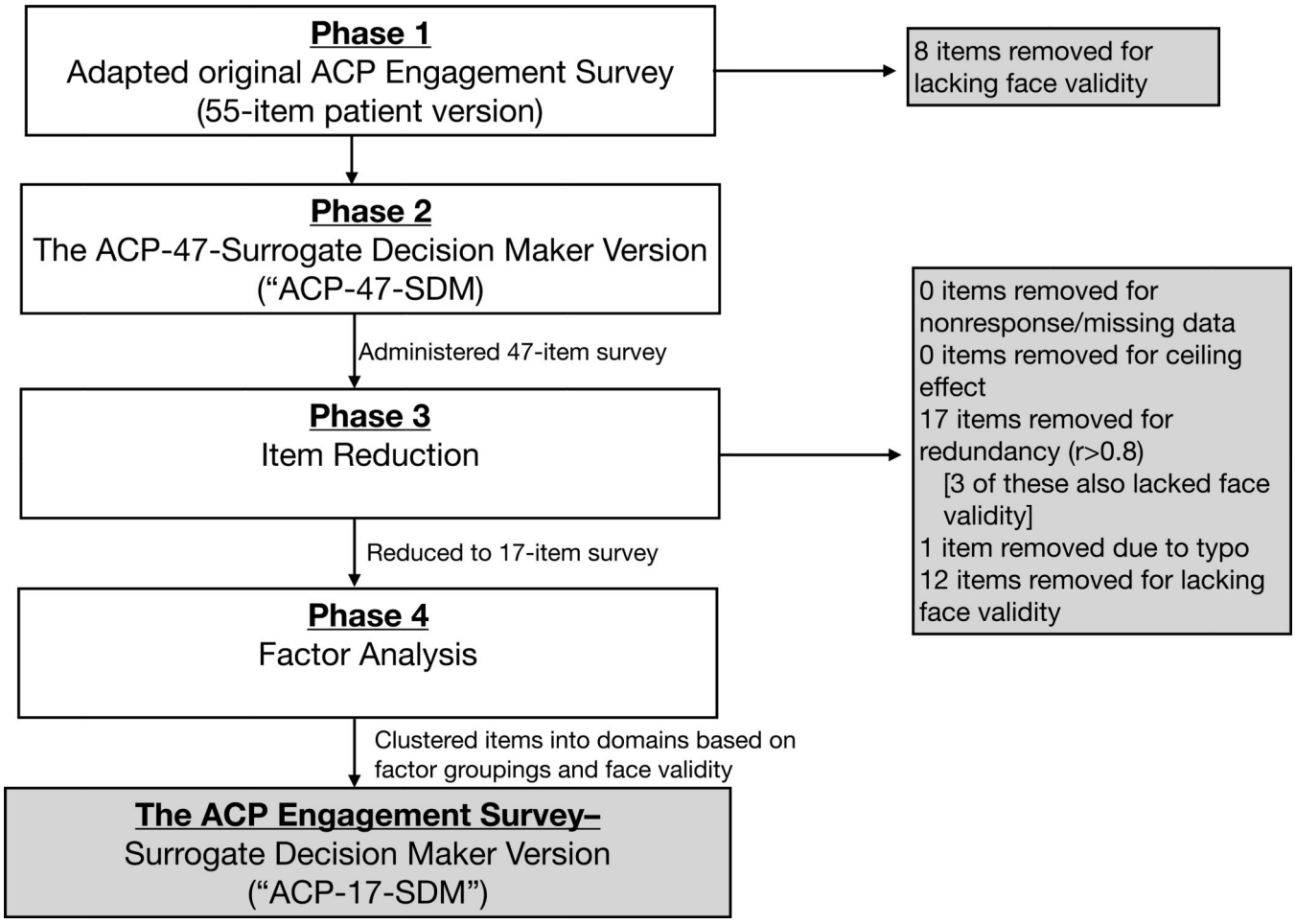

Figure 1.
Methods for creating and validating the ACP Engagement Survey Surrogate Decision Maker Version (17 items)

Table 1.

Reasons for item exclusions from the 47-item ACP Engagement Survey- Surrogate Decision Maker version (post-survey administration)

Item	Question	Reason For Exclusion
1	How well informed are you about who can be a medical decision maker?	Not Excluded
2	How well informed are you about what makes someone a good medical decision maker?	Not Excluded
3	How well informed are you about the types of decisions that you may have to make for your loved one in the future?	Not Excluded
4	How much have you thought about your role as your loved one's medical decision-maker?	Not Excluded
5	How much have you thought about being part of a discussion with your loved one's DOCTORS about your role as a medical decision-maker for your loved one?	Lacked Face Validity; doublebarreled question
6	How much have you thought about being part of a discussion with your loved one's OTHER family and friends about your role as your loved one's medical decision-maker?	Lacked Face Validity
7	As of today, how confident are you that you could serve as your loved one's medical decision maker?	Not Excluded
8	As of today, how confident are you that you could be part of a discussion with your loved one's DOCTORS about your role as your loved one's medical decision maker?	Redundant with other items, lacked face validity
9	As of today, how confident are you that you could be part of a discussion with your loved one's OTHER FAMILY and FRIENDS about your role as your loved one's medical decision maker?	Redundant with other items, lacked face validity
10	How ready are you to formally discuss with your loved one your role as their medical decision maker?	Not Excluded
11	How ready are you to be part of a discussion with your loved one's DOCTOR about your role as your loved one's medical decision-maker?	Lacked Face Validity
12	How ready are you to be part of a discussion with your loved one's OTHER FAMILY and FRIENDS about your role as your loved one's medical decision maker?	Redundant with other items, lacked face validity
13	How ready are you to be named a medical decision maker in OFFICIAL PAPERS that are signed by your loved one?	Lacked Face Validity
14	How much have you thought about talking with your loved one about whether or not there are certain health situations that would make your loved one's life not worth living?	Not Excluded
15	How much have you thought about being part of a discussion with your loved one's DOCTORS about whether or not there are certain health situations that would make your loved one's life not worth living?	Not Excluded
16	How much have you thought about being part of a discussion with your loved ones OTHER FAMILY and FRIENDS about whether or not there are certain health situations that would make your loved one's life not worth living?	Redundant with other items
17	As of today, how confident are you that you could talk with your loved one about whether or not certain health situations would their life not worth living?	Redundant with other items
18	As of today, how confident are you that you could be part of a discussion with your loved one's DOCTORS about whether or not there are certain health situations that would make your loved one's life not worth living?	Redundant with other items
19	As of today, how confident are you that you could talk with your loved one's OTHER FAMILY and FRIENDS about whether or not there are certain health situations that would make your loved one's life not worth living?	Redundant with other items items
20	How ready are you to talk with your loved one about whether or not there are certain health situations that would make their life not worth living?	Not Excluded
21	How ready are you to be part of a discussion with your loved one's DOCTOR about whether or not there are certain health situations that would make your loved one's life not worth living?	Not Excluded

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Item	Question	Reason For Exclusion
22	How ready are you to be part of a discussion with your loved one's OTHER FAMILY and FRIENDS about whether or not there are certain health situations that would make your loved one's life not worth living?	Redundant with other items
23	How ready are you help your loved one SIGN OFFICIAL PAPERS putting his/her wishes in writing about whether or not there are certain health situations that would make your loved one's life not worth living?	Lacked Face Validity
24	How much have you thought about talking with your loved one about the care he/she would want if they were very sick or near the end of life?	Not Excluded
25	How much have you thought about being part of a discussion with your loved one's DOCTORS about the care your loved one would want if he/she was very sick or near the end of life?	Not Excluded
26	How much have you thought about being part of a discussion with your loved one's OTHER FAMILY and FRIENDS about the care your loved one would want if he/she were very sick or near the end of life?	Redundant with other items
27	As of today, how confident are you that you could talk with your loved one about the care he/she would want if he/she were very sick or near the end of life?	Not Excluded
28	As of today, how confident are you that you could be part of a discussion with your loved one's doctors about the care your loved one would want if he/she were very sick or near the end of life?	Not Excluded
29	As of today, how confident are you that you could be part of a discussion with your loved one's OTHER FAMILY and FRIENDS about the care your loved one would want if he/she were very sick or near the end of life?	Redundant with other items
30	How ready are you to talk to your loved one about the kind of medical care he/she would want if they were very sick or near the end of life?	Not Excluded
31	How ready are you to be part of a discussion with your loved one's DOCTOR about the kind of medical care your loved one would want if he/she were very sick or near the end of life?	Not Excluded
32	How ready are you to be part of a discussion with your loved one's OTHER FAMILY and FRIENDS about the kind of medical care he/she would want if he/she were very sick or near the end of life?	Redundant with other items
33	How ready are you to help your loved one SIGN OFFICIAL PAPERS putting his/her wishes in writing about the kind of medical care he/she would want if he/she very sick or near the end of life?	Redundant with other items; lacked Face Validity
34	How well informed are you about the different amounts of flexibility a person can give their medical decision maker?	Lacked Face Validity
35	How much have you thought about the amount of flexibility you would have as your loved one's medical decision maker?	Redundant with other items; lacked Face Validity
36	How much have you thought about talking with your loved one about the amount of flexibility he/she would want to give you as a medical decision maker?	Lacked Face Validity
37	How much have you thought about being part of a discussion with your loved one's DOCTOR about the amount of flexibility you would have as the medical decision maker?	Redundant with other items; lacked Face Validity
38	How much have you thought about being part of a discussion with your loved one's OTHER family and friends about the amount of flexibility you would have as the medical decision maker?	Lacked Face Validity
39	As of today, how confident are you that you could talk with your loved one about how much flexibility he/she would want to give you as a medical decision maker?	Lacked Face Validity
40	As of today, how confident are you that you could be part of a discussion with your loved one's DOCTOR about how much flexibility your loved one would want to give you as a medical decision maker?	Lacked Face Validity
41	As of today, how confident are you that you could be part of a discussion with your loved one's OTHER family and friends about how much flexibility your loved one would want to give you as a medical decision maker?	Lacked Face Validity
42	How ready are you to talk to your loved one about how much flexibility he/she would want to give you as a medical decision maker?	Lacked Face Validity

Item	Question	Reason For Exclusion
43	How ready are you to be part of a discussion with your loved one's DOCTOR about how much flexibility your loved one would want to give you as a medical decision maker?	Redundant with other items; lacked Face Validity
44	How ready are you to be part of a discussion with your loved one's OTHER FAMILY and FRIENDS about how much flexibility your loved one would want to give you as a medical decision maker?	Redundant with other items; lacked Face Validity
45	How ready are you to help your loved one SIGN OFFICIAL PAPERS about how much flexibility he/she would want to give you as a medical decision maker?	Redundant with other items; lacked Face Validity
46	How confident are you that today you could ask the right questions of your loved one's doctors to help make good medical decisions for your loved one if your loved one was unable to speak for themselves?	Deleted due to typo in question stem
47	How ready are you to ask your loved one's doctor questions to help you make a good medical decision for your loved one if your loved one was unable to speak for themselves?	Not Excluded

Table 2.

Exploratory Analysis of the 17-item questionnaire

Items	Theoretical construct	Factor 1 Serving as SDM Domain	Factor 2 Contemplation Domain	Factor 3 Readiness Domain	Communality[1]
1. How well informed are you about who can be a medical decision maker?	Knowledge	0.89	−0.03	−0.02	0.74
2. How well informed are you about what makes someone a good medical decision maker?	Knowledge	0.89	−0.12	0.06	0.75
3. How well informed are you about the types of decisions that you may have to make for your loved one in the future?	Knowledge	0.70	0.09	0.03	0.62
4. How much have you thought about your role as your loved one's medical decisionmaker?	Contemplation	0.52	0.19	0.12	0.53
5. As of today, how confident are you that you could serve as your loved one's medical decision maker?	Self-efficacy	0.70	0.06	0.03	0.57
6. As of today, how confident are you that you could talk with your loved one about the care he/she would want if he/she were very sick or near the end of life?	Self-efficacy	0.48	0.23	0.14	0.55
7. As of today, how confident are you that you could be part of a discussion with your loved one's DOCTOR about the care your loved one would want if he/she were very sick or near the end of life?	Self-efficacy	0.51	0.31	0.11	0.67
8. How much have you thought about talking with your loved one about whether or not there are certain health situations that would make your loved one's life not worth living?	Contemplation	0.29	0.24	0.38	0.62
9. How much have you thought about being part of a discussion with your loved one's DOCTORS about whether or not there are certain health situations that would make your loved one's life not worth living?	Contemplation	0.06	0.49	0.30	0.57
10. How much have you thought about talking with your loved one about the care he/she would want if they were very sick or near the end of life?	Contemplation	0.14	0.62	0.28	0.86
11. How much have you thought about being part of a discussion with your loved one's DOCTORS about the care he/she would want if they were very sick or near the end of life?	Contemplation	0.05	1.04	−0.12	1.00
12. How ready are you to formally discuss with your loved one your role as their medical decision maker?	Readiness	0.38	−0.06	0.50	0.56
13. How ready are you to talk to your loved one about the kind of medical care he/she would want if they were very sick or near the end of life?	Readiness	−0.04	0.09	0.93	0.92
14. How ready are you to talk to your loved one about whether or not there are certain health situations that would make your loved one's life not worth living?	Readiness	0.16	0.07	0.72	0.76
15. How ready are you to be part of a discussion with your loved one's DOCTOR about whether or not there are certain health situations that would make your loved one's life not worth living?	Readiness	0.20	0.22	0.49	0.63
16. How ready are you to be part of a discussion with your loved one's DOCTOR about the kind of medical care your loved one would want if he/she were very sick or near the end of life?	Readiness	0.00	0.42	0.46	0.63
17. How ready are you to ask your loved one's DOCTOR questions to help you make a good medical decision for your loved one if your loved one was unable to speak for themselves?	Readiness	−0.11	0.47	0.28	0.37

[1]The communality is the proportion of the variance of the item accounted for by the 3 factors solution. Ideally, the communality would be near 1 and would be caused by a near 1 loading on single factor, but communalities greater than 0.4 or 0.5 are typically considered acceptable.

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