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Other ways of knowing: considerations for information communication in decision aid design[1]

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Abstract

Background—Patients with advanced stage chronic obstructive pulmonary disease (COPD) may suffer severe respiratory exacerbations and need to decide between accepting life sustaining treatments versus foregoing these treatments (choosing comfort care only). We designed the InformedTogether decision aid to inform this decision, and describe results of a pilot study to assess usability focusing on participants' trust in the content of the decision aid, acceptability, recommendations for improvement; and emotional reactions to this emotionally-laden decision.

Methods—Study participants (N=26) comprised of clinicians, patients, and surrogates viewed the decision aid, completed usability tasks, and participated in interviews and focus groups assessing comprehension, trust, perception of bias, and perceived acceptability of InformedTogether implementation. Mixed methods were used to analyze results.

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Results—Almost all participants understood the gist (general meaning) of InformedTogether. However, many lower literacy participants had difficulty answering the more detailed questions related to comprehension, especially when interpreting icon arrays, and many were not aware that they had misunderstood the information. Qualitative analysis showed a range of emotional reactions to the information. Participants with low verbatim comprehension frequently referenced lived experiences when answering knowledge questions, which we termed "alternative knowledge".

Conclusion—We found a range of emotional reactions to the information, and frequent use of alternative knowledge frameworks for deriving meaning from the data. These observations led to insights into the impact of lived experiences on the uptake of biomedical information presented in decision aids. Communicating prognostic information could potentially be improved by eliciting alternative knowledge as a starting ground to build communication, in particular for low literacy patients. Decision aids designed to facilitate shared decision making should elicit this knowledge and help clinicians tailor information accordingly.

Introduction

Patients with severe chronic obstructive pulmonary disease (COPD) often face decisions about whether to accept life sustaining treatments for acute respiratory failure (COPD exacerbation), without the chance to consider the risks and benefits prior to hospitalization. There may be an initial survival benefit in choosing life sustaining treatments (also known as Full Code, or intubation), as compared to foregoing life supporting technologies and choosing to be treated with comfort measures only (also known as 'do not intubate'/(DNI)). However, there may be complications resulting from life sustaining treatments which lead to the inability to return home, frequent re-hospitalizations, and impaired quality-of-life. Conversations about treatment choices and patients' preferences in advance (advance-care-planning) could better prepare patients and surrogates for decision making. Clinicians are important partners in these conversations due to their knowledge about individual patients' illness trajectories. However, many clinicians do not initiate these conversations with their patients, mainly because these conversations are emotionally difficult, they lack the time and training, and they may not have prognostic information readily available.[1–5] Therefore, patients and their surrogates may be unprepared to make these decisions when they suffer acute respiratory failure.[6–8]

To facilitate clinician-patient shared decision making about choosing between life sustaining treatments vs. comfort measures only in the event of a severe COPD exacerbation, we designed the InformedTogether web-based decision aid. InformedTogether seeks to help patients answer the question: "If I need to be hospitalized tomorrow because I can't breathe, and all other treatments have failed, would I choose: life sustaining treatments or DNI?" Our design process followed International Patient Decision Aid Standards (IPDAS) standards and the Agency for Healthcare Research Quality (AHRQ) SHARE Approach. [9, 10] InformedTogether is intended to first be used in an outpatient setting by clinicians together with COPD patients. Patients can then access the decision aid at home and share with family members. It provides prognostic data using models derived from published clinical studies and a retrospective data analysis of Medicare beneficiaries treated.[11–16] Prognosis is communicated with icon arrays/pictographs,[17–20] using plain language text.[20, 21] We have outlined elsewhere the early design of the decision aid prototype and results from a smaller usability study where we focused specifically on icon array presentation, and the extent to which participants found using a web-based platform easy and acceptable during a clinic visit. [22] Based on the results of this initial round of usability testing, revisions were made to the decision aid. We then undertook additional usability testing in our computer-lab testing center, recruiting a new group of research participants comprised of COPD patients and clinicians, and we also included surrogate decision makers of COPD patients. This round of usability testing focused on participants' trust in the content of the decision aid, acceptability of content (e.g. message tone, and readability) and additional recommendations for improvement.

Information provided by decision aids improves patients' knowledge about options, reduces their decisional conflict, and stimulates patients to take a more active role in decision making without increasing their anxiety. [23–26] Studies suggest that the acceptance or rejection of a decision aid is in large part dependent on its usability.[27, 28] Studies also suggest that comprehension of the information in the decision aid, including risks vs. benefits, and terminology, varies based on education, health literacy, and numeracy levels[29]. Usability testing allows researchers to observe users as they interface with the tool and complete given tasks. This testing also allows researchers to observe reactions to the tool and to obtain feedback before implementation. We anticipated that InformedTogether would elicit strong emotional reactions because it describes tradeoffs between dying versus potentially impaired quality of life. We were cognizant of the effect of personal experiences on these reactions - either because participants had personal experience with respiratory failure, had seen family/friends with these experiences, and/or had pre-conceived ideas about life supporting treatments based on images seen in the media. We specifically wanted to elicit these reactions and recommendations for language and other design considerations to make InformedTogether as sensitive as possible to a range of lived experiences. We also sought feedback about acceptability and when, where, and how InformedTogether should be implemented. We therefore conducted iterative usability testing among key cohorts using small sample sizes to not only assess participants reactions to the decision aid and whether they could complete pre-specified tasks, but also to assess comprehension, trust, perception of bias, acceptability and recommendations for improvements, and implementation of InformedTogether, in light of potential emotional reactions. In what follows we present results of parts of usability testing measuring reactions to the decision aid and perceived acceptability of implementation. In particular, we highlight our discovery of the impact that lived experiences and other non-biomedical information play on patients' ability to derive meaning from the prognostic estimates communicated within InformedTogether specifically, and on the informed decision making process in general.

Methods

Study design and patients

We conducted 4 usability testing sessions, three in English and one in Spanish, using a three-phased data triangulation technique[30] among 3 separate cohorts: clinicians (n=8), COPD patients (n=13) and surrogate caregivers (n=5) between August 4, 2014 – March 19, 2015. The three English language sessions were stratified by cohort, so that clinicians, patients, and surrogates were in separate sessions. Due to the small number of Spanish speaking participants, this session contained a mixed group of Spanish speaking patients, surrogates, and 1 physician. Sessions lasted on average 180 minutes. We chose to work with a small sample size to ensure that each participant would have ample time to complete each phase of the study. At the start of the testing session, each participant sat at a computer terminal and a member of the research team further explained the study and how to use the decision aid. Each person was then instructed to view the entire contents of the decision aid (See Appendix 1 – PDF version of select screen shots from the decision aid). Following this, each person was asked to complete a series of usability tasks e.g. navigating among the pages on the website, and writing comments in the notes section. Usability tasks were chosen based on intended functionality of the decision aid (See Usability questions - Appendix 2). Participants were given up to 60 minutes to view the decision aid and complete the usability tasks. Next, during individual interviews, we tested participants' knowledge of decision aid content, and assessed reactions to the decision aid (See interview questionnaires- Appendix 2). Finally, all participants participated in a focus group. Focus groups were facilitated by experienced qualitative researchers using a script designed to elicit feedback about the decision aid content, design and implementation recommendations (See Focus Group Guide - Appendix 2). Detailed feedback on usability was obtained during both the individual interviews and the focus groups, allowing us to make improvements to the decision aid. Data was collected using audio-recordings and note-taking. Audio-recordings were professionally transcribed in order to enable a mixed-methods analytic approach. This method was chosen to not only quantitatively assess participant feedback of our decision aid, but to qualitatively gain deeper insights into reactions to the decision aid and variations in ability to understand the content of the decision aid (e.g., *why* someone might not understand the information), and perceptions of acceptability of use including emotional reactions to what they were seeing.

Recruitment—Clinician participants were recruited from the pulmonary and geriatric clinics within the Northwell Health System, and all were engaged in the care of COPD patients. Patient and surrogate participants were recruited from the health system's research volunteer recruitment registry, employee intranet, and pulmonary rehabilitation centers. Non-clinician inclusion criteria were: COPD patients or surrogate caregivers for patients with COPD, 18 years and older, who were either English or Spanish speakers.

Measures—Demographic questions asked during the interviews, were chosen based on factors commonly associated with comprehension and understanding[31–33] as outlined in our conceptual model (Figure 1). These included questions assessing: age, race/ethnicity, education levels, comfort using the internet, self-rating of their health, and basic numeracy. Numeracy was tested using five questions: three assessing understanding of probabilities and percentages [34, 35]; and two assessing an individual's ability to understand health information presented in graph format[36, 37](Table 1).

Outcomes measured were also guided by our conceptual model (Figure 1) and included questions assess comprehension, trust, perception of bias, acceptability of implementation, and recommendations for improvements. Comprehension of the decision aid was measured using: twelve closed-ended questions (six understanding of terminology questions, four understanding of icon array questions, and one question asking participants to apply the data to themselves); and several open-ended questions: asking if there was anything in the DA that the participant did not understand, gist-meaning questions (i.e., questions assessing comprehension of the general meaning of the decision aid), and asking participants to describe possible risks and benefits to someone associated with intubation and why someone might not want to get a breathing tube

Trust of the information contained in the decision aid was measured using five closed-ended questions.

Perception of biased presentation of information in the decision aid was measured using two closed-ended questions.

Acceptability of implementation of the decision aid in clinics was measured using two closed-ended questions).

Recommendations for improvements to the decision aid, and recommendations for when and where to implement the decision aid was measured using several open-ended questions.

The study was approved by the Northwell Health Institutional Review Board and we obtained written informed consent from all participants.

Data Analysis

Quantitative analyses—Data from closed-ended questions administered during one-on-one interviews with participants were summarized descriptively (frequency and percent for categorical variables; mean ± SD and median for continuous variables, Appendix 3). These descriptive analyses included comparisons of participant characteristics for those who had high comprehension of the decision aid content versus low comprehension of the content (Appendix 4: Table 4.1) and a comparison between participants who trusted the information in the decision aid versus those who did not (Appendix 4: Table 4.2). The Fisher's exact test was used to compare the groups for categorical variables and the Mann-Whitney test was used to compare the groups for continuous measures. All data were stored in RedCap™ [38] and analyzed using SAS version 9.4 (SAS Institute Inc., Cary, NC).

Qualitative analyses—Initially, two qualitative researchers read all interview and focus group transcripts, and developed an outline of the themes using deductive and inductive coding techniques. This allowed us to include pre-identified themes from our conceptual model (which informed the development of the interview questions as described above), as well as new themes which emerged over time. Themes were iteratively refined and developed into a codebook in consultation with all investigators. Initial deductive codes that did not prove salient were eliminated, and numerous inductive codes were condensed. Nine primary themes based on topics that occurred with high frequency were included in the codebook. These were: 1) barriers to using the decision aid, 2) communication, 3) value congruence, 4) decision making process, 5) factors impacting understanding and information uptake, 6) important factors for decision making, 7) knowledge, 8) perceptions of the decision aid, and 9) recommendations for improvement. Using this codebook, all transcripts were coded by two coders using QSR NVivo 10 Software™. To test for inter-rater reliability, an NVivo coding comparison was conducted on 4 transcripts (1 interview transcript randomly selected from each usability session). Results showed 99.2% agreement and a Cohen's Kappa of .71 which indicates substantial agreement between the two coders (because the Kappa coefficient calculation takes into account the likelihood of the agreement between users occurring by chance, the value of Kappa can be low even though the percentage agreement is high).[39, 40]

Results

Participant characteristics

Participant characteristics for patients and surrogates, and for clinicians are detailed in Tables 1 and 2. While the small sample size makes it difficult to generalize, it is notable that 76.9% (n=10) of patients and 60% (n=3) of surrogate participants had lower numeracy, which we defined as answering incorrectly more than 1 out of the 5 basic numeracy questions.[34–36]

Questionnaire Reponses

The results from quantitative analyses of closed-ended questions are outlined in Appendix 3 and summarized below. We also describe the results from qualitative analyses of open-ended questions for comprehension, acceptability and recommendations for improvement.

Comprehension – Results of quantitative analysis—Questions measured comprehension of terminology used in the decision aid (e.g., COPD exacerbation, intubation, Full Code, advance directive) for which we provided clear definitions in the text, as well as a glossary at the end of the decision aid, and icon array comprehension – which was based on a person's ability to look at the icon arrays and interpret estimated survival outcomes based on what appeared in the icon arrays (See Appendix 1). We defined low comprehension as answering incorrectly more than 2 out of the 11 questions assessing terminology and icon array comprehension. Many of the patient participants had low comprehension (69.2%; n=9; median 5 out of 11 incorrect). Fewer surrogate participants had low comprehension (40%; n=2; median 4.5 out of 11 incorrect). Notably, half of these participants stated that there was nothing in the decision aid that they did not understand. All of the clinician participants had high comprehension.

We also assessed 'gist' understanding (i.e. the general meaning) [37] to determine if participants understood the central points of the decision aid. – i.e., that if a person chooses to forego intubation (after all other interventions have failed) they will very likely die in the hospital, and that many people who accept life sustaining treatments are discharged to a nursing home and may be re-hospitalized multiple times within the following year. In contrast to verbatim understanding, the majority of the patient and surrogate participants were able to correctly answer questions assessing gist understanding. For example, when asked what would likely happen if a person decided not to be treated with a breathing tube after all other treatments had failed, 76.9% (n=10) of patient participants, and 100% (n=5) of surrogate participants answered correctly that without the breathing tube, a person "will die", or "not live for very long". However, when asked questions requiring numerical responses, e.g. "Based on these pictures [showing icon arrays], if 100 people with severe COPD chose to be Full Code, how many people would likely be living after one year?", only 38.5% (n=5) of patient participants, and 60% (n=3) of surrogate participants answered this question correctly.

As expected, in the patient and surrogate groups, both low numeracy and low education levels were associated with lower verbatim understanding. All ten participants with lower numeracy had low understanding of the icon arrays; and 3 out of the 4 participants with no high school diploma had low understanding of the "technical terminology", e.g., intubation, mechanical ventilation, and COPD exacerbation, despite our efforts to use lay terms alongside technical terms, and testing overall language for 9th grade readability level.[41]

Comprehension – Results of qualitative analysis—As supported by our conceptual model, and other studies assessing numeracy and health comprehension [42, 43], for those with low numeracy levels, we noticed patterns of misunderstanding, e.g., when asked specific questions about probabilistic data, participants with low numeracy scores responded by referring to their experiences or beliefs rather than the data provided. Our initial code for these was "me-centric" responses (this became the basis for what we later began broadly referring to as *alternative knowledge* – see below). These me-centric responses stood in opposition to responses from participants with higher numeracy scores, which were derived from the data, i.e. "data-driven" responses. Text from our transcripts, seen below, highlights examples of both *me-centric* and *data-driven* responses.

> "Me-centric" response:
>
> Interviewer: OK. And so you may or may not agree with what the decision aid said about the risk of dying for those hospitalized with the COPD exacerbation. If you personally were to be hospitalized after a bad COPD exacerbation and chose to be full-code, what do you think is the chance of being alive after one year?
>
> Respondent: Well, I'm a fighter, so I know I'm going to last a few years.
>
> Interviewer: OK. So would you say after one year, there's 100% chance of being alive, or somewhere less than that?
>
> Respondent: No, I'm going to go with 100%. Like I said I'm a fighter. I'm not trying to go nowhere.
>
> (Patient participant- lower numeracy)
>
> "Data-driven" response:
>
> Interviewer: You may or may not agree with what the decision aid says about your risk of dying if you are hospitalized for a bad COPD exacerbation. If you personally were to be hospitalized after a bad COPD exacerbation and chose to be

> Full Code, what do you think is the chance that you will be living after one year? Please answer that on a scale from 0% to 100%.
>
> Respondent: Well, what did we say? 32… 32%.
>
> Interviewer: 32%?
>
> Respondent: Right? Is that, 17 and 15… right. Yeah, right – 32 over 100, right.
>
> Interviewer: Can you tell me how you arrived to your answer?
>
> Respondent: Yeah, from the chart.
>
> (Patient participant – higher numeracy)

Qualitative analysis showed other examples of participants drawing on *non-data-driven* sources to derive meaning or understanding of the information presented in the decision aid including e.g., personal experiences or cultural frameworks. We use the term "alternative knowledge" to describe ways of knowing, understanding or deriving meaning from data presented, not based on biomedical information. In our participant responses, we saw alternative knowledge in two settings. First, participants with low comprehension often drew on alternative knowledge in order to make sense of what they saw in the decision aid. In the example above, the participant was asked to interpret what the likelihood of survival with intubation would be, and in response she drew on her lived experience (i.e., focused on herself, hence "me-centric"), rather than the data. Second, participants' lived experiences sometimes impacted their ability to apply the information to themselves or loved-ones, despite high comprehension. For example, when asked how sure participants were that estimates given in the decision aid were correct, one participant stated, "you know, its interpreting how the results were established based on people in the study versus my own experience", and adjusted the probability of survival with intubation according to his own experience. In this way, alternative knowledge stood in opposition to the biomedical knowledge being conveyed in the decision aid. We have further identified three sub-types of alternative knowledge frameworks rooted in peoples' lived experiences, cultural backgrounds, and embodied knowledge[44], which we describe below:

We refer to a lived experience as knowledge derived from direct, first-hand experience - obtained through either living with, caring for, or directly witnessing the experiences of someone with an illness. For example, when asked by a researcher:

> "If you needed to decide whether to accept mechanical ventilation, what factors would you think about?"

The participant responded:

> "I don't wanna use it at all. I saw a friend of mine being intubated and I saw the look on her face, and she was on the breathing tube for six months until she passed away and I will never forget that look - oh my God. Well my mind is set already. I know what I want and my family knows what I want." (COPD Patient, Hispanic Female, age 74, High School graduate).

In this situation, information presented to the participant (including prognostic estimates, and a chart presenting a side-by-side comparison of the risks and benefits for each option), appears to not have been factored into her decision to decline intubation. The emotional experience she described of witnessing a close friend's intubation may have been the most important factor in her decision.

A cultural framework is another subtype of alternative knowledge which we define as social-group-centric knowledge (i.e., derived from religion, ethnicity, class, gender). For example, when asked by a researcher:

> "The decision aid gives a number for your chance of dying or living in a nursing home 12 months after you are hospitalized for a bad COPD exacerbation, how sure are you that the estimates given are correct?"

The participant responded:

> "I do not know how advanced is the medical science now, but for me 0%. Because machines can help, but God decides if a person should stay alive or die." (COPD Caregiver, Hispanic Female, age 63, High School)

In this example, the researcher's question referred directly to a series of prognostic estimates portrayed using icon arrays which showed a greater than 50% chance of living in a nursing home. The participant's response however indicated that prognosis was determined by God. Whether this was because the icon arrays were not understood or that they were understood and ignored/not believed is unclear. However, it raises the possibility that prognostic data may not factor into a person's decision if it is in conflict with a cultural framework.

Finally, we define embodied knowledge as subjective knowledge derived from an individual's perceptions of his/her body, how they feel, and the physical changes undergone by a person throughout the course of an illness. For example, when asked by the researcher,

> "How sure are you that the [prognostic] estimates given [in the decision aid] are correct? From 0 to 100%, how sure will you be that those estimates are correct?"

The participant responded:

> "As far as basing it on myself, I'm totally not sure. But based on the results of the study, I would say they're probably right, you know… I'll go with 50%…You know, it's interpreting how the results were established based on people in the study versus my own experience." (COPD Patient, White Male, age 67, College graduate)

In this example, the icon array indicated a 68% chance of survival. Although the participant believed that the estimate was correct for the population studied, when applying that estimate to himself, he felt that his chance was lower. This may have been because he felt his own health to be worse than those studied. In this way he adapted the estimate based on his subjective experience with COPD.

Trust- Results of Quantitative and Qualitative analyses—Based on our conceptual model, trust influences the uptake of health related messages. [45] We hypothesized that if a patient did not trust the information being presented, then they would not incorporate it into their decision – regardless of whether or not they had the skills to actually understand it.

Therefore, we asked a series of questions to assess trust in the decision aid. These included one direct question about whether participants trusted the decision aid, one concerning confidence in the accuracy of the estimates given, and one asking whether participants thought the numbers could be wrong. Most patient participants (N=11; 84.6%), and all surrogate participants trusted the contents of the decision aid, stating that: they trusted the source of the information (both the fact that the decision aid was linked to our health system, and because the decision aid itself contains a resources section where we provide information on how the estimates were generated, including the sources from which the estimates were generated)[13]; the information was consistent with what they had experienced; and the decision aid was not linked to any advertisements or corporate sponsors. However, on average, patient and surrogate participants stated that they were only about 60% sure (median: 50% and 70% for patient and surrogates) that the estimates given were correct, and almost all patient and surrogate participants stated that these numbers could be incorrect because: peoples' outcomes vary; the research could be based on people with unspecified co-morbidities; or the information was inconsistent with prior experiences. Of the clinician participants, most (n=7; 87.5%) stated that they trusted the contents of the decision aid. In contrast to the patient and surrogates, few clinicians (n=2; 25%) believed that the numbers given could be incorrect because: the numbers were consistent with what clinicians had seen in the patients that they treated; the data "made sense" based on what they already knew; and they were familiar with the statistics on which the numbers were based. However, during our clinician focus group, the participants discussed the extent to which existing co-morbidities among the cohorts sampled may result in different outcomes for their actual patients. Overall most participants understood that the outcomes provided in the decision aid were estimates based on a wider population, and that they might not apply to themselves/to their patients.

Additionally, we explored whether participants would apply the data to themselves for prediction of outcomes and how this differed from application of the data to others. We asked: "If you *personally* were to be hospitalized after a bad COPD exacerbation and chose to be Full Code, what do you think is the chance you would be living after one year?" Participants were again shown the icon array depicting 32% of 100 patients alive after one year. Despite this estimation, most people were more optimistic that they themselves would survive the scenario, with several stating there would be at least a 50% chance they *would* survive, and7 participants stating there would be a greater than 70% chance that they would be alive. Only one person stated that he believed that he personally had a 32% chance of being alive after 1 year. In contrast, when the question was asked, "If 100 people *just like you* (with severe COPD) chose to be Full Code, how many people would likely be dead after one year?", 44% (n=8) based their responses on the information provided. Taken together, these findings suggest both a difference between trust in the data being presented, versus confidence in the accuracy of the data, and a difference in trust/confidence in the data versus application of the data to self.

Perception of Bias- Results of Quantitative and Qualitative analyses—Most patient and surrogate participants stated that the information presented for intubation vs. DNI was completely balanced in the decision aid (61.5% and 80% of patient and surrogate participants respectively). However, 46% (n=6) of patient participants believed that there was bias toward Full Code (none believed there was bias towards DNI). Of the surrogate participants, none believed there was a bias towards Full Code, however one participant believed there was bias towards DNI. In contrast, of the clinician participants only 25% of the clinician participants believed the information was completely balanced, with most believing there was a bias towards DNI (n=5; 62.5%).

In seeking an explanation for these differences in perception of bias between patient and clinician participant perspectives, qualitative analysis revealed that several of the patient and surrogate participants simply equated DNI with being dead, (e.g., as stated by a COPD patient participant: “Either do this [choose Full Code] or you’re going to die.”), and so as a result, may have seen the decision aid as being biased toward Full Code which they equated with being alive. Many of the patient participants who felt there was bias towards Full Code had both low overall comprehension and had made statements equating DNI with “choosing” death and Full Code with “choosing” to stay alive, and stated that a person should do whatever it takes to stay alive. The one surrogate participant who stated there was a bias towards DNI had an above college education and scored highly on comprehension questions. This may suggest that if someone does not fully understand the risks of intubation, and only considers this as a choice between being alive or dead, then they may inherently view the decision aid as biased toward the more favorable option i.e., Full Code, because it would keep them alive longer. In contrast, clinicians, who understood that the risks of choosing Full Code were poor quality of life, poor functional status, and the high likelihood of dying anyway, may have seen the decision aid as being biased toward DNI because it had more favorable outcomes as perceived by the clinician. As stated by a clinician participant: “While they may live a little longer, they may not…that is like the gist of this, because if they are going to survive, they are going to be sicker, they are going to end up in a nursing home and the differences in survival are not that great, right?” This is an example of me-centric knowledge (in this case clinician-centric), i.e., knowledge that is directly rooted in a clinician’s lived experiences treating COPD patients, which may have influenced their perception of bias toward DNI.

Acceptability- Results of Quantitative and Qualitative analyses—Most participants stated they would be very likely to recommend that actual patients use the decision aid with their doctors (mean of 8.3, 7.4 and 7.3 for patients, surrogates and clinician participants respectively; 0–10 scale, not at all to extremely likely to recommend). For the patients and surrogates, we saw a wide range of responses regarding when participants thought it was appropriate to introduce an end-of-life discussion using the decision aid with a COPD patient. 44% (n=8) participants stated that the decision aid should be used early on, “so you’re not blindsiding the patient”, and 28% (n= 5) participants stated that it should be used at the point when a person was just beginning to experiencing more frequent exacerbations, For example, a COPD patient stated:

> “I think primarily the patient has to have the wherewithal to understand it. So I mean, if you’re in… What was that word you used about the hyper state of COPD? I don’t think you’re in a position to really start to answer these questions, right? I mean, you’re worried about breathing and stuff.”

Finally, 28% (n-5) stated that the decision aid should be used with a patient once their COPD become very severe, meaning that the need for decision making was imminent. We also saw variety in participants' emotional reactions to the information being presented. Some participants expressed that there were elements of the decision aid that made them uncomfortable, while others stated they liked that the information was realistic.

For example, one COPD caregiver participant stated that:

> "The picture of the gentleman with all the tubes in – the EKG, and all that hooked up to him, it kind of made me a little squirmy. And that was because I had seen my sister like that several times".

Some patients in the focus group stated that the information was "in your face", or "very frightening", with one focus group patient participant stating:

> "So you know, the initial emotions kicked in right away and it gets you to that defensive mode, 'OK, what else do you want to know?' So all of a sudden, I find myself just breezing through everything."

However another patient participant stated:

> "I think the pictures are good because people follow those more. And it makes them actually see reality. The pictures were like really, 'OK, this could really happen to me.' This is what's going to happen. I think that was good."

Table 3 shows the contrast in both preferences for what kind of information people wanted and their emotional reactions to the information contained in the decision aid.

Recommended use and recommendations for improvement- Results of qualitative analysis—Recommendations for improving the decision aid among physicians, patients and surrogates focused on: addressing barriers to accessing the tool; (e.g. offering a printout version for those who do not have access to a computer); making it easier to understand; (e.g. refining the icon arrays, and using even plainer/less technical language;) softening the language, e.g. using terms such as "will not survive" instead of "will be dead"; and making technical improvements related to the usability of the decision aid. Physician participants also recommended offering opportunities for 'adlibbing', e.g. offering an abbreviated version of the decision aid which only contained images and icon arrays; and offering training prior to using the tool. Additionally, in order to be better integrated into workflow, physicians recommended embedding the decision aid within the electronic health records (EHR); and that there should be a separate visit scheduled to use the decision aid.

Discussion

In general, most participants understood the content of the decision aid when tested for gist comprehension, even when verbatim knowledge was low. Almost all participants trusted the information, and were very likely to recommend the decision aid to others. Although we are limited in our ability to generalize due to the small sample size of a usability study, there were several findings that emerged which may benefit from further exploration. From this study, we gained insights into decision aid content revisions needed for improved usability, but realized that a ‘one-size-fits-all’ DA may not be possible, as evidenced by the range of emotional reactions to terms we initially used in the decision aid and suggestions for when to use the decision aid. It is clear in our study that alternative knowledge, including preconceived beliefs about what the treatment entails and its risks and benefit, impact both the comprehension and uptake of information. Therefore, a decision aid designed to facilitate shared decision making should assist clinicians in tailoring communication based on individuals’ preferences for information and style of presentation. Although important, broad demographic categories such as language, sex and race frequently used to tailor/target decision aids[46, 47] may not be sufficient because personal experiences and preferences may only be identified as patient-clinician communication is occurring. We realized that not only would we have to further simplify the presentation of data, but that we would need to include methods to enable clinicians to recognize each user’s alternative knowledge frameworks. Recognizing alternative knowledge may facilitate communication of information in a way that is both understood and accepted – which we have termed “uptake”. As such, we edited our conceptual model to include the influence of non-biomedical, alternative knowledge on the uptake of information communicated (Figure 2).

Our ideas around alternative knowledge emerged from the pattern of ‘me-centric’ responses from participants with low numeracy when asked to interpret the icon arrays. Here, participants drew from personal experiences in order to relate to the information. Additionally, one individual drew on alternative knowledge rather than the data because it did not reflect what he believed to be true based on his personal experience of living with COPD. Although a person may “understand” the data, as measured using knowledge questions, they may draw on a powerful lived experience which may prevent the uptake of the information when the data does not resonate with what they have seen/heard to be true (such as prognosis). Uptake of data may be necessary in order for patients to apply the data to their own decision making. In our adapted conceptual model, we make a distinction between ‘understanding’ and ‘uptake’, where understanding is associated with skills linked to education and literacy (health, statistical, computer, etc.) which are necessary for basic comprehension; and uptake is associated with both accepting the information and applying it to oneself. For uptake to occur, a person must trust the information being presented to him or her. However, alternative knowledge may still hinder uptake if it is at odds with biomedical knowledge and/or it leads to an emotional reaction to the information. This might be why more participants, across comprehension levels, had a difficult time providing a data-driven response when asked to apply the data to themselves (for predicted 1-year survival) vs. to a hypothetical group, despite stating that they trusted the data.

In our initial design, we tried to make the decision aid understandable to those with low literacy and numeracy levels, using plain language to define medical terminology, choosing to use icon arrays to present prognostic data and reduce problems associated with denominator neglect[48]. However, the findings from our usability testing showed that those with very limited numeracy and low education levels still had very low comprehension, specifically for the terminology and icon array questions. This reinforced our initial belief that the decision aid needs to first be introduced by a clinician who could explain the data presented, and include audio descriptions of the data within the decision aid.

We saw that while most of the patient and surrogate participants in our study trusted the information, they stated that the estimates given could be incorrect. This could mean that, while participants *trusted* the fact that they were not being misled deliberately, they also understood the uncertainty around the given estimates - which we intentionally tried to convey by using terms like ‘on average’ or ‘likely’ alongside the estimates. Clinicians’ responses indicating that very few thought these numbers could be wrong as opposed to the almost 100% of patients and surrogates, may indicate more confidence in the data, based on their clinician-centric knowledge of similar outcomes for their own COPD patients (their own lived experiences).

Finally, the fact that several people who had low comprehension also believed that they understood everything could have serious implications for informed decision making if some people mistakenly believe they understand the information they have received, and use it to make an “informed decision”. Although we have learned that the content of our decision aid needs to be revised to increase comprehension, this will not address the discordance between users’ perceptions of comprehension and actual comprehension. We suggest that decision aids should parallel communication strategies in clinical encounters – in particular those in which complex information is being introduced – using an ‘ask-tell-ask’ strategy. [49] This strategy not only starts with assessing patients’ baseline knowledge, and, allows for understanding of alternative knowledge which clinicians can use to tailor communication, but also asks the patient to describe in their own words what they have heard/understood from the medical information communicated by the clinician. This provides a rich opportunity for the clinician to not only learn a patients’ perspective, but also to immediately clarify any misunderstandings of medical information. We propose that decision aids should similarly start with questions about baseline knowledge and experiences, and incorporate measures of understanding, for example using embedded knowledge testing questions.

Limitations

An important limitation of our study is that it was not tested within an actual clinical encounter. As such, the results may not accurately reflect the comprehension and acceptability of implementation, for the setting in which it is intended to be used. In addition, it is clear that decision making in hypothetical scenarios differs from real-life situations. A second limitation is that we used a 9th grade readability level for the language of the decision aid. We believe this may have contributed to the inability of some participants to fully understand the contents of the decision aid. Nevertheless, this early stage and iterative usability testing allowed for early modifications to be made which aimed to increase the likelihood that real-life application would be feasible and acceptable.

Future directions

Our next steps will be to embed questions which can elicit patients’ alternative knowledge within InformedTogether, and questions to measure patients’ understanding of the biomedical knowledge presented. We hope these modifications will enrich shared decision making conversations and truly inform decision making about accepting life sustaining treatments versus comfort measures alone. Additionally, we are undertaking feasibility testing where we are observing clinicians using the decision aid with patients in an outpatient setting. We believe that due to the sensitive topic being covered, and supported by our interview and focus group responses, an in-person interaction between a clinician and a patient is important for a patient's first encounter with the decision aid. Following the initial use of the decision aid in the clinic, we provide all patients with the ability to access the decision aid online, as well as with a printed out version of the decision aid to take home. To address physicians' concerns regarding the lack of time to use the decision aid, we have included alternative strategies such as allowing nurse practitioners and respiratory therapists to use the decision aid with patients. This strategy has thus-far been successful in ongoing testing – allowing for the decision aid to be used within the context of shared decision making for which it was designed. Given changes in insurance reimbursements which now compensate clinicians for dedicated advance care planning discussions, we have also suggested scheduling patients for a designated advance-care-planning visit.

CONCLUSION

Decision aids which are intended to be used within the context of shared decision making should include assessments of patients' understanding of the biomedical data presented, and their alternative knowledge frameworks in order to allow tailoring of communication and increased comprehension and uptake of the information. Knowledge assessments paralleling the ask-tell-ask model of communication, which first asks what patients' baseline knowledge and experiences are and then asks patients to explain in their own words what they have learned from the medical communication/decision aid, can assess overall comprehension/gist (particularly for those with lower level education) and provide opportunity for clarification. Further, attempts to elicit patients' knowledge frameworks and reactions to the data should be part of clinician training for using the decision aid.

Because alternative knowledge is rooted in the experiences of each individual, designing a tailored decision aid to address different alternative knowledge frameworks will be difficult. Instead, decision aids could help clinicians tailor conversations while using the decision aid, based on the alternative knowledge elicited during shared decision making conversations. Communicating within the context of a patient's alternative knowledge framework may be critical to patient uptake of information. Therefore, tools of knowledge clarification and information exchange can present fruitful opportunities for clinicians to address misunderstandings and opportunities for clinicians to understand the patients' perspective and that of his/her social network. One example is when patients apply anecdotal information that does not necessarily pertain to their own disease state. This exchange of information is at the core of the shared decision making process, leading to a clearer understanding of goals and preferences, and a collaborative approach to decision making. Shared decision making helps to achieve 'shared mind'[50] wherein clinician and patient/patients' families understand each other's perspectives and goals, and decision aids should support the exchange of both biomedical and alternative knowledge necessary for achieving shared mind and for preparing patients to make more informed, values-based medical decisions.

Finally, our research findings raise questions about whether decision aid effectiveness needs to be assessed with measures beyond those commonly used (e.g., change in knowledge and decisional conflict), to include measurement of uptake of the data about prognosis and risks and benefits of treatment choices presented within the decision aid.

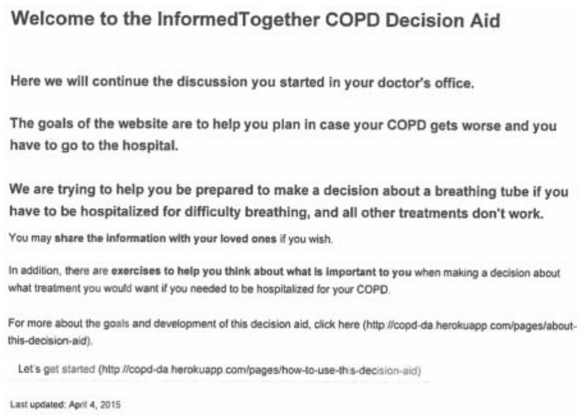
References

1. Christakis NA, Iwashyna TJ. Attitude and self-reported practice regarding prognostication in a national sample of internists. Arch Intern Med. 1998; 158:2389–2395. [PubMed: 9827791]
2. Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. BMJ. 2000; 320:469–472. [PubMed: 10678857]
3. Knauft E, Nielsen EL, Engelberg RA, Patrick DL, Curtis JR. Barriers and facilitators to end-of-life care communication for patients with COPD. Chest. 2005; 127:2188–2196. [PubMed: 15947336]
4. Curtis JR, Patrick DL, Caldwell ES, Collier AC. Why don't patients and physicians talk about end-of-life care? Barriers to communication for patients with acquired immunodeficiency syndrome and their primary care clinicians. Arch Intern Med. 2000; 160:1690–1696. [PubMed: 10847263]
5. Curtis JR. Palliative and end-of-life care for patients with severe COPD. Eur Respir J. 2008; 32:796–803. [PubMed: 17989116]
6. Barnato AE, Albert SM, Angus DC, Lave JR, Degenholtz HB. Disability among elderly survivors of mechanical ventilation. Am J Respir Crit Care Med. 2011; 183:1037–1042. [PubMed: 21057004]
7. Hopkins RO, Jackson JC. Short- and long-term cognitive outcomes in intensive care unit survivors. Clin Chest Med. 2009; 30:143–153. ix. [PubMed: 19186286]
8. Connors AF, Dawson NV, Thomas C, et al. Outcomes following acute exacerbation of severe chronic obstructive lung disease. The SUPPORT investigators (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments). Am J Respir Crit Care Med. 1996; 154:959–967. [PubMed: 8887592]
9. Criteriafor Judging the Quality of Patient Decision Aids. http://ipdas.ohri.ca/IPDAS_checklist.pdf2005
10. The SHARE Approach. Agency for Healthcare Research and Quality; Sep. 2015 http://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/index.html2015
11. Hajizadeh N, Crothers K, Braithwaite RS. Using modeling to inform patient-centered care choices at the end of life. J Comp Eff Res. 2013; 2:497–508. [PubMed: 24236746]
12. Hajizadeh N, Goldfeld K. Burden of Transitions After Invasive Mechanical Ventilation for U.S. Individuals with Severe Chronic Obstructive Pulmonary Disease: Opportunity to Prepare for Preference-Congruent End-of-Life Care? J Am Geriatr Soc. 2016; 64:434–435. [PubMed: 26889846]
13. Hajizadeh N, Goldfeld K, Crothers K. What happens to patients with COPD with long-term oxygen treatment who receive mechanical ventilation for COPD exacerbation? A 1-year retrospective follow-up study. Thorax. 2015; 70:294–296. [PubMed: 24826845]
14. Taksler GB, Keshner M, Fagerlin A, Hajizadeh N, Braithwaite RS. Personalized estimates of benefit from preventive care guidelines: a proof of concept. Ann Intern Med. 2013; 159:161–168. [PubMed: 23922061]
15. Hajizadeh N, Crothers K, Braithwaite RS. Informing shared decisions about advance directives for patients with severe chronic obstructive pulmonary disease: a modeling approach. Value Health. 2012; 15:357–366. [PubMed: 22433768]
16. Hajizadeh N, Crothers K, Braithwaite RS. A theoretical decision model to help inform advance directive discussions for patients with COPD. BMC Med Inform Decis Mak. 2010; 10:75. [PubMed: 21172022]
17. iconarray.com. University of Michigan: Risk Science Center and Center for Bioethics and Social Sciences in Medicine.
18. Garcia-Retamero R, Cokely E. Communicating health risks with visual aids. Psychological Science Sage. 2013; 22:5392–5399.
19. Galesic M, Garcia-Retamero R, Gigerenzer G. Using icon arrays to communicate medical risks: overcoming low numeracy. Health Psychol. 2009; 28:210–216. [PubMed: 19290713]

20. Fagerlin A, Zikmund-Fisher BJ, Ubel PA. Helping patients decide: ten steps to better risk communication. J Natl Cancer Inst. 2011; 103:1436–1443. [PubMed: 21931068]
21. Plain and clear writing communications. U.S. Department of Health and Human Services; http://www.plainlanguage.gov/
22. Uhler LM, Pérez Figueroa RE, Dickson M, et al. InformedTogether: Usability Evaluation of a Web-Based Decision Aid to Facilitate Shared Advance Care Planning for Severe Chronic Obstructive Pulmonary Disease. JMIR Hum Factors. 2015; 2:e2. [PubMed: 27025896]
23. Sepucha, Karen, Borkhoff C, et al. Establishing the effectiveness of patient decision aids: key constructs and measurement instruments. BMC Medical Informatics and Decision Making. 2013; 13:1–11. BioMed Central. [PubMed: 23289362]
24. O'Connor, A., Bennett, C., et al. Medical Decision Making. Vol. 27. Sage; 2007. Do patient decision aids meet effectiveness criteria of the International Patient Decision Aid Standards Collaboration? A systematic review and meta-analysis; p. 554-574.
25. Bennett, S., Barry, C., Col, M., et al. Cochrane Collaboration. Wiley; 2012. Decision aids for people facing health treatment or screening decisions (Review); p. 1-215.
26. O'Connor A, Llewellyn-Thomas H, Flood A. Modifying unwarranted variations in health care: shared decision making using patient decision aids. Health Affairs: Project HOPE. 2004; VAR 65:4–11.
27. Usability Testing. U.S. Dept. of Health and Human Services; 2006. www.usability.gov
28. Kushniruk AW, Patel VL, Cimino JJ. Usability testing in medical informatics: cognitive approaches to evaluation of information systems and user interfaces. Proc AMIA Annu Fall Symp. 1997:218–222. [PubMed: 9357620]
29. Reyna VF, Nelson WL, Han PK, Dieckmann NF. How numeracy influences risk comprehension and medical decision making. Psychol Bull. 2009; 135:943–973. [PubMed: 19883143]
30. Quinn, Patton, M. Qualitative Research and Evaluation Methods. London: Sage Publications; 2002.
31. Williams MV, Parker RM, Baker DW, et al. Inadequate functional health literacy among patients at two public hospitals. JAMA. 1995; 274:1677–1682. [PubMed: 7474271]
32. David RA, Rhee M. The impact of language as a barrier to effective health care in an underserved urban Hispanic community. Mt Sinai J Med. 1998; 65:393–397. [PubMed: 9844369]
33. Lukoschek P, Fazzari M, Marantz P. Patient and physician factors predict patients' comprehension of health information. Patient Educ Couns. 2003; 50:201–210. [PubMed: 12781935]
34. Schapira MM, Davids SL, McAuliffe TL, Nattinger AB. Agreement between scales in the measurement of breast cancer risk perceptions. Risk Anal. 2004; 24:665–673. [PubMed: 15209937]
35. Schwartz LM, Woloshin S, Black WC, Welch HG. The role of numeracy in understanding the benefit of screening mammography. Ann Intern Med. 1997; 127:966–972. [PubMed: 9412301]
36. Galesic M, Garcia-Retamero R. Graph literacy: a cross-cultural comparison. Med Decis Making. 2011; 31:444–457. [PubMed: 20671213]
37. Hawley ST, Zikmund-Fisher B, Ubel P, Jancovic A, Lucas T, Fagerlin A. The impact of the format of graphical presentation on health-related knowledge and treatment choices. Patient Educ Couns. 2008; 73:448–455. [PubMed: 18755566]
38. REDcap. https://projectredcap.org/
39. Viera A, Garrett J. Understanding interobserver agreement: the kappa statistic. Family Medicine. 2005; 37:360–363. [PubMed: 15883903]
40. Run a Coding Comparison query. QSR International; http://help-nv10.qsrinternational.com/desktop/procedures/run_a_coding_comparison_query.htm
41. Readability Score. https://readability-score.com/
42. Nutbeam D. The evolving concept of health literacy. Soc Sci Med. 2008; 67:2072–2078. [PubMed: 18952344]
43. Gazmararian JA, Baker DW, Williams MV, et al. Health literacy among Medicare enrollees in a managed care organization. JAMA. 1999; 281:545–551. [PubMed: 10022111]
44. Browner, C., Press, N. Med Anth Quarterly. Vol. 10. Amer Anth Assoc; 1996. The production of authoritative knowledge in American prenatal care.

45. Clayman ML, Manganello JA, Viswanath K, Hesse BW, Arora NK. Providing health messages to Hispanics/Latinos: understanding the importance of language, trust in health information sources, and media use. J Health Commun. 2010; 15(Suppl 3):252–263. [PubMed: 21154097]
46. Alden DL, Friend J, Schapira M, Stiggelbout A. Cultural targeting and tailoring of shared decision making technology: a theoretical framework for improving the effectiveness of patient decision aids in culturally diverse groups. Soc Sci Med. 2014; 105:1–8. [PubMed: 24606791]
47. Myers RE, Sifri R, Hyslop T, et al. A randomized controlled trial of the impact of targeted and tailored interventions on colorectal cancer screening. Cancer. 2007; 110:2083–2091. [PubMed: 17893869]
48. Garcia-Retamero R, Galesic M. Communicating treatment risk reduction to people with low numeracy skills: a cross-cultural comparison. Am J Public Health. 2009; 99:2196–2202. [PubMed: 19833983]
49. French JC, Colbert CY, Pien LC, Dannefer EF, Taylor CA. Targeted Feedback in the Milestones Era: Utilization of the Ask-Tell-Ask Feedback Model to Promote Reflection and Self-Assessment. J Surg Educ. 2015; 72:e274–279. [PubMed: 26123726]
50. Epstein RM, Street RL. Shared mind: communication, decision making, and autonomy in serious illness. Ann Fam Med. 2011; 9:454–461. [PubMed: 21911765]

Appendix 1



Welcome to the InformedTogether COPD Decision Aid

Here we will continue the discussion you started in your doctor's office.

The goals of the website are to help you plan in case your COPD gets worse and you have to go to the hospital.

We are trying to help you be prepared to make a decision about a breathing tube if you have to be hospitalized for difficulty breathing, and all other treatments don't work.

You may **share the information with your loved ones** if you wish.

In addition, there are **exercises to help you think about what is important to you** when making a decision about what treatment you would want if you needed to be hospitalized for your COPD.

For more about the goals and development of this decision aid, click here (http //copd-da herokuapp com/pages/about-this-decision-aid).

Let's get started (http //copd-da herokuapp com/pages/how-to-use-th s-decision-aid)

Last updated: April 4, 2015

How to use this decision aid

What does it mean to be on a breathing tube for life support?

In the hospital, patients may need to have a breathing tube which goes into their mouth and into their "windpipe". This tube is attached to a breathing machine. This is called intubation. The breathing machine is also called a mechanical ventilator.

Benefits and Risks of a breathing tube

Patients can choose **NOT to be treated with a breathing tube. This is called DNI (Do Not Intubate).**

If patients choose not to get a breathing tube they may **not survive.**

So why would some people choose to have a DNI advance directive? This is because treatment with a breathing tube (intubation) has **risks.**

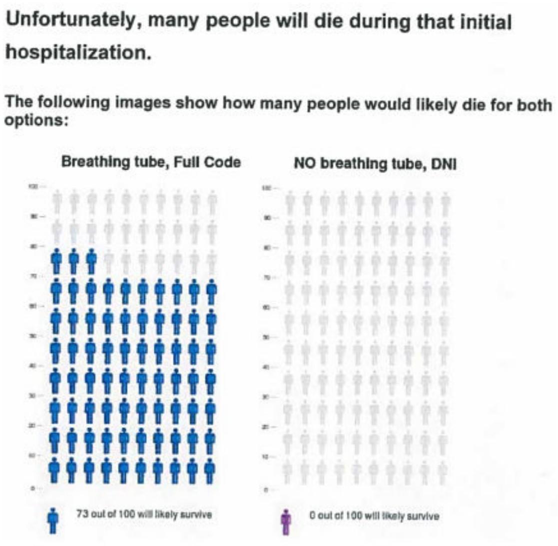
Benefits of a breathing tube (intubation)	**Risks** of a breathing tube (intubation)
• The most important benefit is that **a patient may live longer**. The chance of this depends on the patient and we will talk about this in the next few pages.	• They may not be able to come off of the breathing machine. Therefore, they may need to be placed in a (nursing home) [long-term care home]. The risk for this is around **20-30%** although studies on patients with severe COPD have not been performed and its possible that this risk is higher for patients with severe COPD)
• Breathing is usually easier because a machine is doing the breathing for the patient.	• Not being able to talk **100%** of patients who are on a breathing machine cannot speak, but may be able to communicate by pointing to words and writing
	• Not being able to eat food **100%** of patients who are on a breathing machine cannot eat food by mouth but can get nutrition through a feeding tube or through their veins.
	• Usually not being able to walk **Almost 100%** cannot walk because they are attached to a breathing machine.
	• **Discomfort** with breathing tube Although patients receive pain medications, many patients describe discomfort with having a "tube" in their mouth.

References: Robriquet Journal of Critical Care (2006) 21, 185– 192

Advance Directives

An **advance directive** lets your doctor and loved ones know what treatments you would like in case you cannot speak for yourself.
Two options for advance directives are:

- **Full Code**. This advance directive means you would allow treatment with a breathing tube.
- **DNI**. This advance directive means you do NOT wish to receive a breathing tube.



Unfortunately, many people will die during that initial hospitalization.

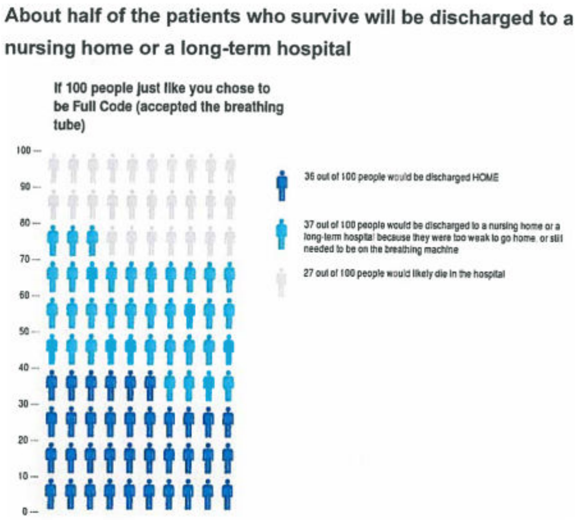
The following images show how many people would likely die for both options:

Breathing tube, Full Code

NO breathing tube, DNI

73 out of 100 will likely survive

0 out of 100 will likely survive



About half of the patients who survive will be discharged to a nursing home or a long-term hospital

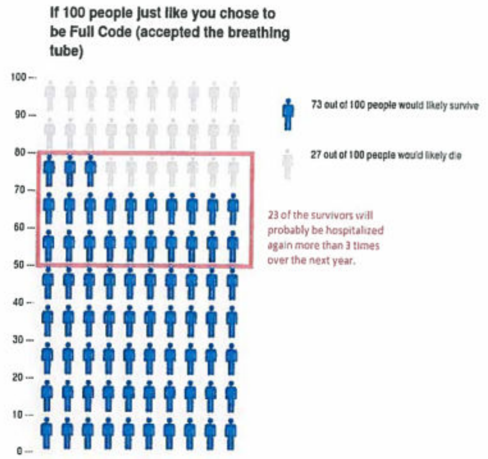
If 100 people just like you chose to be Full Code (accepted the breathing tube)

36 out of 100 people would be discharged HOME

37 out of 100 people would be discharged to a nursing home or a long-term hospital because they were too weak to go home or still needed to be on the breathing machine

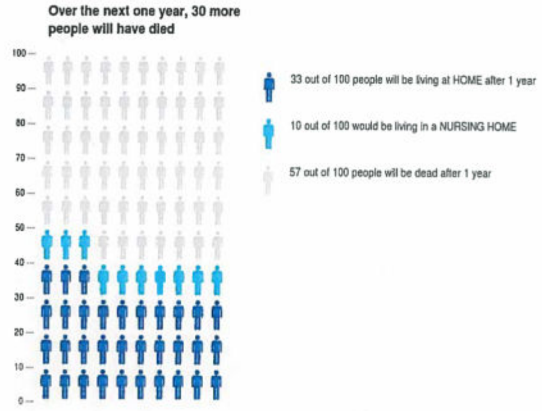
27 out of 100 people would likely die in the hospital

Many survivors are rehospitalized at least 3 times over the next year of life


If 100 people just like you chose to be Full Code (accepted the breathing tube)

23 of the survivors will probably be hospitalized again more than 3 times over the next year.

And unfortunately 30 more patients will have died one year after that first hospital stay - for a total of 57 patients who died after being treated with a breathing tube


Over the next one year, 30 more people will have died

Glossary

Advance directive – An advance directive is a decision someone makes about future medical care they want to receive. An advance directive is made before the patient becomes very sick and is unable to speak for themselves. An advance directive tells the patient's doctors and family members what type of care they would like.

Breathing machine – Also known as a mechanical ventilator, this machine is used when someone can no longer breathe on their own. It moves air into the lungs, making it easier for the person to breathe. Using a breathing machine is one form of life support.

COPD exacerbation – A COPD exacerbation happens when someone's COPD symptoms suddenly get much worse. If someone is having a severe (very bad) COPD exacerbation, they need to go to the hospital to get treatment, and may need to choose whether to accept a breathing tube.

Do Not Intubate (DNI) – DNI is an advance directive that tells people you would NOT allow a breathing machine. However, someone who has a DNI directive would allow oxygen through a mask and other medications.

Full Code – Full Code is an advance directive that tells people you would allow treatment with a breathing machine.

Hospice care – Hospice care is end of life care. It always involves palliative care.

Intubation – Putting a breathing tube into a patient's mouth and lungs is called intubation.

Mechanical ventilator – Also known as a breathing machine or ventilator, this machine is used when someone can no longer breathe on their own. It moves air into the lungs, making it easier for the person to breathe. Using a breathing machine is one form of life support.

Nursing Home – A nursing home is a place where you may need to live if you become sick and are unable to take care of yourself at home.

Palliative care – Palliative care relieves symptoms without curing your disease. You may receive palliative care at any stage of disease. The goal is to make you comfortable and improve your quality of life.

Appendix 2 Usability Tasks, Interview and Focus Group Questions

Usability Tasks

Task #1

You want to get a better look at the breathing tube. Go back to the page in the decision aid with the two pictures of the breathing tube.

Task #2

You want to explain the two types of advance directives to your family member. Find the definition of “Full Code”.

Task #3

Find the page that compares how many people would be living at home vs. living in a nursing home, for those who chose the breathing tube.

Task #4

Part 1: Add a note to the current page you are viewing, writing your thoughts about the page. Save the note.

Part 2: Go to the page where you can view all your notes and print them.

Patient Questionnaire

Patient Questionnaire

QUESTIONNAIRE INTRO SCRIPT

"Thanks again for your participation in the study. In this portion of the study, we will ask you to respond to several questions providing feedback about the decision aid, or website, that you just viewed. The last part asks questions about you and your health. The conversation will be audio recorded so that my research team and I can listen to it and analyze it later. The recording will be kept safely in a locked cabinet until it is analyzed and then it will be destroyed. We will not keep any information that would allow individual participants to be linked to specific statements. Remember, your participation is voluntary and you are free to stop participating at any time.

Do you have any questions at this point?

Let's begin."

Start recording
"Today is (date and time), my name is (investigator), and I'm with participant (ID number)."

Part 1: Questions about the decision aid.
1) What does intubation mean?

2) What is a breathing machine?

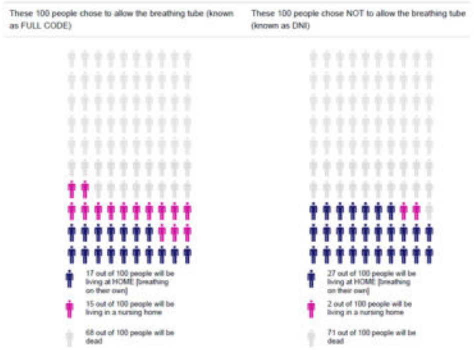
3) What is a COPD exacerbation?

4) If a person decides not to be treated with a breathing machine, what will happen to them?

    4a) Are there other options for treatment?

5) Who do you think this decision aid was meant for?

6) In the decision aid, you saw these pictures. Please interpret the pictures in your own words.



I'll now ask you some questions based on these pictures.

7) Which advance directive (Full Code or DNI) results in the highest survival (that is, the greatest number of people still living after one year)?

8) Which advance directive (Full Code or DNI) results in fewer people living in a nursing home?

9) Based on these pictures, if 100 people just like you (with severe COPD) chose to be Full Code, how many people would likely be living after one year?

10) Based on these pictures, if 100 people just like you (with severe COPD) chose to be Full Code, how many people would likely be dead after one year?

"You may or may not agree with what the decision aid said about your risk of dying if you are hospitalized for a bad COPD exacerbation."

11) If you **personally** were to be hospitalized after a bad COPD exacerbation and chose to be Full Code, what do you think is the chance you would be living after one year? Please answer on a scale of 0% to 100%.

For example,

0%=no chance of being living after one year
100%=completely certain to be living after one year

0% |————————————————————|100%
Low chance of being alive High chance of being alive

You can pick any number between 0 and 100.
_____%

11a) Can you tell me about how you arrived at your answer?

12) What were the areas of the decision aid that you did not understand?

13) Did anything make you uncomfortable while you were looking at the decision aid?
__Yes __No
If yes, please explain.

14) Did you **trust** what you were seeing in the decision aid?
__Yes __No
Please explain. For example, if yes, what do you trust about it? If no, what do you not trust about it?

"The decision aid gives a number for your chance of dying or living in a nursing home 12 months after you are hospitalized for a bad COPD exacerbation."

15) How sure are you that the estimates given are correct? You can show me on the line below:
For example,
0%=no chance of being correct
100%=completely certain to be correct

0% |————————————————————|100%
No chance of estimates being correct (in other words, estimates are definitely wrong) Completely certain estimates are correct

You can pick any number between 0 and 100.
_____%

15a) Please explain your answer.

16) Could these numbers be wrong?

__Yes __No
Please explain.

"I am now going to ask you some questions about how fair you think the information was presented in the decision aid."

17) Did you think the decision was giving you more information about the risks and benefits of one treatment compared to the other?
__Much more information about Full Code
__A little more information about Full Code
__The same amount of information about each option
__A little more information about Do Not Intubate (DNI)
__Much more information about Do Not Intubate (DNI)

18) Did you feel it was trying to persuade you to one choice over the other? If so, which choice?
__Clearly persuading me to choose DNI
__Persuading me a little to choose DNI
__Completely balanced and not persuading me one way or the other
__Persuading me a little to choose Full Code
__Clearly persuading me to choose Full Code

"I am now going to ask you for your recommendations on how to improve the decision aid."

19) On a scale of 0-10 with 0 being not at all likely and 10 being extremely likely, how likely are you to recommend that actual patients use this decision aid with their doctors? (Please choose a number on the scale below).

0	1	2	3	4	5	6	7	8	9	10
Not at all likely										Extremely likely

20) Are there any other recommendations you have for how we can improve the decision aid?

Prompt 1: Should anything be taken out of the decision aid?
Prompt 2: Should anything be added to the decision aid?

21) When do you think the best time would be to use this decision aid? I mean at what point in the patient's illness should this be used?

Prompt: For example, before they are sick or only after they are sick?

22) What do you think are the most important things for a patient with severe COPD to think about when deciding whether to be treated with a breathing machine?

23) What risks and benefits do you think a person with severe COPD should think about when deciding whether to be treated with a breathing machine?

24) Why do you think some patients may decide NOT to be treated with a breathing machine?

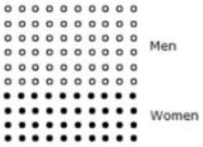
"I am now going to ask some general questions about numbers and graphs."

26) Imagine that you flip a coin 100 times. About how many times will the coin come up heads in 100 flips?
____ times of 100

27) 100 people have entered the Spring City Run. 70% of the runners will finish the race. Of the 100 people who enter the race, how many will finish?
____ persons out of 100

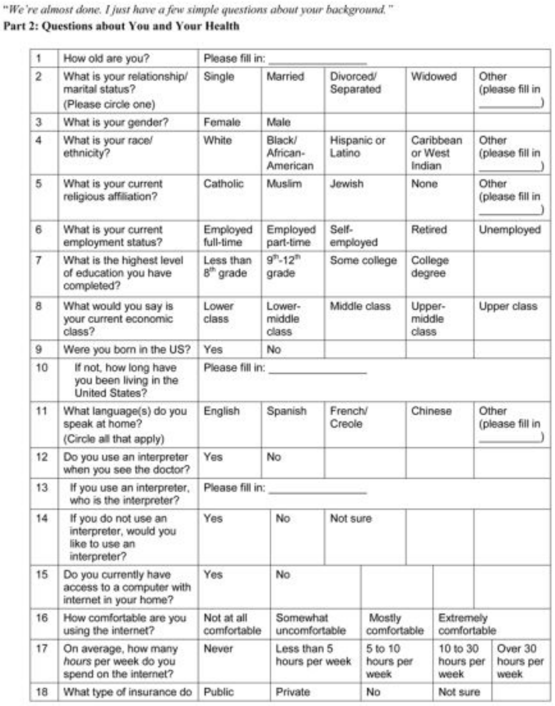
28) In the Washington School raffle 5 people out of 100 who enter will win a prize. What percentage (%) of the people who enter the raffle will win a prize?
____%

The following figure shows the number of men and women among patients with disease X. The total number of circles is 100.



29) Of 100 patients with disease X, how many are women?
________ women

30) How many more men than women are there among 100 patients with disease X?
________ men

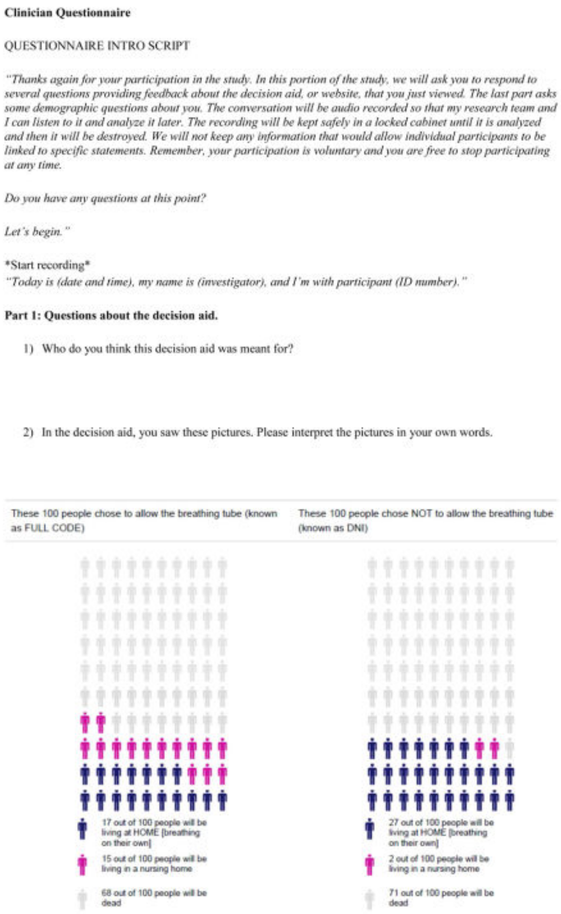


"We're almost done. I just have a few simple questions about your background."

Part 2: Questions about You and Your Health

1	How old are you?	Please fill in: ________________				
2	What is your relationship/ marital status? (Please circle one)	Single	Married	Divorced/ Separated	Widowed	Other (please fill in ____________)
3	What is your gender?	Female	Male			
4	What is your race/ ethnicity?	White	Black/ African-American	Hispanic or Latino	Caribbean or West Indian	Other (please fill in ____________)
5	What is your current religious affiliation?	Catholic	Muslim	Jewish	None	Other (please fill in ____________)
6	What is your current employment status?	Employed full-time	Employed part-time	Self-employed	Retired	Unemployed
7	What is the highest level of education you have completed?	Less than 8th grade	9th-12th grade	Some college	College degree	
8	What would you say is your current economic class?	Lower class	Lower-middle class	Middle class	Upper-middle class	Upper class
9	Were you born in the US?	Yes	No			
10	If not, how long have you been living in the United States?	Please fill in: ________________				
11	What language(s) do you speak at home? (Circle all that apply)	English	Spanish	French/ Creole	Chinese	Other (please fill in ____________)
12	Do you use an interpreter when you see the doctor?	Yes	No			
13	If you use an interpreter, who is the interpreter?	Please fill in: ________________				
14	If you do not use an interpreter, would you like to use an interpreter?	Yes	No	Not sure		
15	Do you currently have access to a computer with internet in your home?	Yes	No			
16	How comfortable are you using the internet?	Not at all comfortable	Somewhat uncomfortable	Mostly comfortable	Extremely comfortable	
17	On average, how many *hours* per week do you spend on the internet?	Never	Less than 5 hours per week	5 to 10 hours per week	10 to 30 hours per week	Over 30 hours per week
18	What type of insurance do you have?	Public insurance (Medicaid, Medicare, VA, etc)	Private insurance (United, BlueCross, etc)	No insurance	Not sure	
19	What is your current living arrangement?	Live alone	Live with a spouse or partner	Live with another family member	Other (please fill in ________________)	
20	How would you rate your health in general?	Excellent	Very Good	Good	Fair	Poor
21	Considering all parts of my life – physical, emotional, social, spiritual, and financial – over the past two (2) days, how would you rate the quality of your life?	(circle a number on the scale): 0 1 2 3 4 5 6 7 8 9 10 Very bad … Excellent				
22	Do you have COPD?	Yes	No			
23	If you have COPD, how severe do you believe your COPD is?	Very mild	Mild	Moderate	Severe	Very severe
24	Do you have an advance directive?	Yes	No			
25	Has your doctor ever talked to you about planning in case you need to make decisions about mechanical ventilation (like the decisions shown in the decision aid)?	Yes	No			
26	Would you describe yourself as a person who likes to take risks?				Yes	No

Clinician Questionnaire



Clinician Questionnaire

QUESTIONNAIRE INTRO SCRIPT

"Thanks again for your participation in the study. In this portion of the study, we will ask you to respond to several questions providing feedback about the decision aid, or website, that you just viewed. The last part asks some demographic questions about you. The conversation will be audio recorded so that my research team and I can listen to it and analyze it later. The recording will be kept safely in a locked cabinet until it is analyzed and then it will be destroyed. We will not keep any information that would allow individual participants to be linked to specific statements. Remember, your participation is voluntary and you are free to stop participating at any time.

Do you have any questions at this point?

Let's begin."

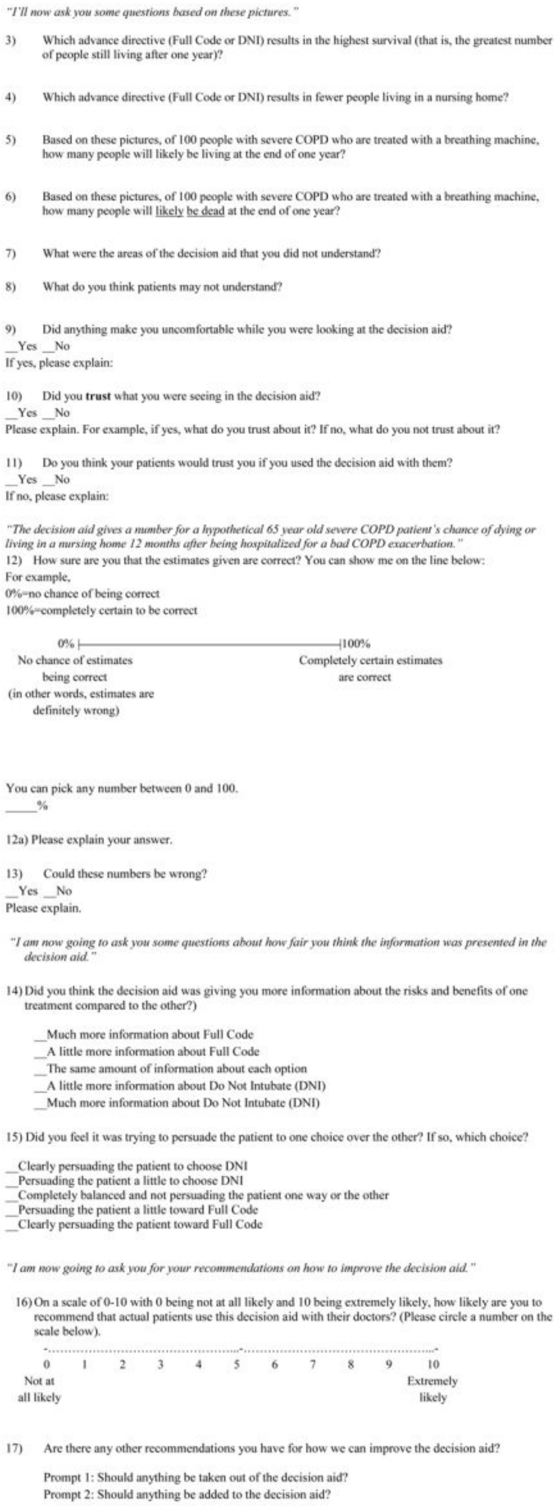
Start recording
"Today is (date and time), my name is (investigator), and I'm with participant (ID number)."

Part 1: Questions about the decision aid.

1) Who do you think this decision aid was meant for?

2) In the decision aid, you saw these pictures. Please interpret the pictures in your own words.

These 100 people chose to allow the breathing tube (known as FULL CODE)	These 100 people chose NOT to allow the breathing tube (known as DNI)
17 out of 100 people will be living at HOME [breathing on their own]	27 out of 100 people will be living at HOME [breathing on their own]
15 out of 100 people will be living in a nursing home	2 out of 100 people will be living in a nursing home
68 out of 100 people will be dead	71 out of 100 people will be dead



"I'll now ask you some questions based on these pictures."

3) Which advance directive (Full Code or DNI) results in the highest survival (that is, the greatest number of people still living after one year)?

4) Which advance directive (Full Code or DNI) results in fewer people living in a nursing home?

5) Based on these pictures, of 100 people with severe COPD who are treated with a breathing machine, how many people will likely be living at the end of one year?

6) Based on these pictures, of 100 people with severe COPD who are treated with a breathing machine, how many people will likely be dead at the end of one year?

7) What were the areas of the decision aid that you did not understand?

8) What do you think patients may not understand?

9) Did anything make you uncomfortable while you were looking at the decision aid?
__Yes __No
If yes, please explain:

10) Did you **trust** what you were seeing in the decision aid?
__Yes __No
Please explain. For example, if yes, what do you trust about it? If no, what do you not trust about it?

11) Do you think your patients would trust you if you used the decision aid with them?
__Yes __No
If no, please explain:

"The decision aid gives a number for a hypothetical 65 year old severe COPD patient's chance of dying or living in a nursing home 12 months after being hospitalized for a bad COPD exacerbation."
12) How sure are you that the estimates given are correct? You can show me on the line below:
For example,
0%=no chance of being correct
100%=completely certain to be correct

0% |——————————————————|100%
No chance of estimates being correct (in other words, estimates are definitely wrong)
Completely certain estimates are correct

You can pick any number between 0 and 100.
_____%

12a) Please explain your answer.

13) Could these numbers be wrong?
__Yes __No
Please explain.

"I am now going to ask you some questions about how fair you think the information was presented in the decision aid."

14) Did you think the decision aid was giving you more information about the risks and benefits of one treatment compared to the other?)

__Much more information about Full Code
__A little more information about Full Code
__The same amount of information about each option
__A little more information about Do Not Intubate (DNI)
__Much more information about Do Not Intubate (DNI)

15) Did you feel it was trying to persuade the patient to one choice over the other? If so, which choice?

__Clearly persuading the patient to choose DNI
__Persuading the patient a little to choose DNI
__Completely balanced and not persuading the patient one way or the other
__Persuading the patient a little toward Full Code
__Clearly persuading the patient toward Full Code

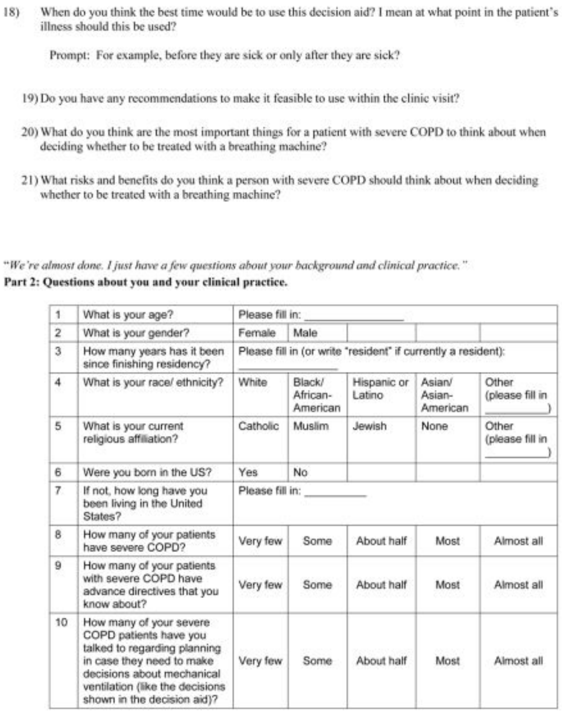
"I am now going to ask you for your recommendations on how to improve the decision aid."

16) On a scale of 0-10 with 0 being not at all likely and 10 being extremely likely, how likely are you to recommend that actual patients use this decision aid with their doctors? (Please circle a number on the scale below).

0 1 2 3 4 5 6 7 8 9 10
Not at all likely
Extremely likely

17) Are there any other recommendations you have for how we can improve the decision aid?

Prompt 1: Should anything be taken out of the decision aid?
Prompt 2: Should anything be added to the decision aid?



18) When do you think the best time would be to use this decision aid? I mean at what point in the patient's illness should this be used?

Prompt: For example, before they are sick or only after they are sick?

19) Do you have any recommendations to make it feasible to use within the clinic visit?

20) What do you think are the most important things for a patient with severe COPD to think about when deciding whether to be treated with a breathing machine?

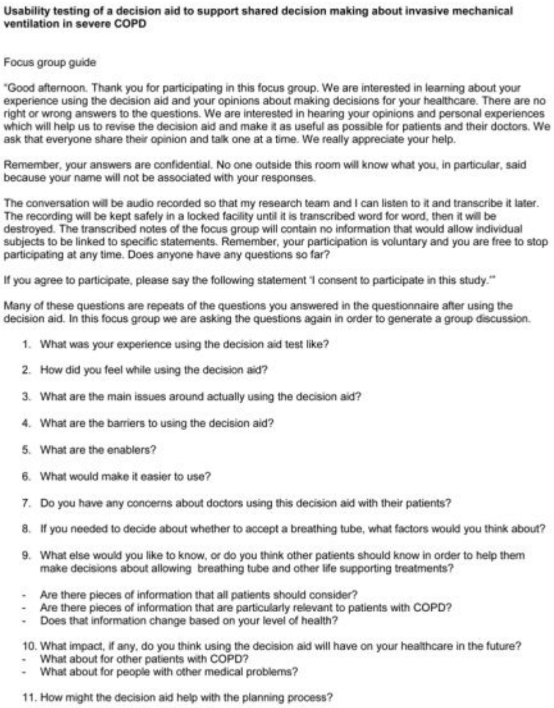
21) What risks and benefits do you think a person with severe COPD should think about when deciding whether to be treated with a breathing machine?

"We're almost done. I just have a few questions about your background and clinical practice."

Part 2: Questions about you and your clinical practice.

1	What is your age?	Please fill in: ________________				
2	What is your gender?	Female	Male			
3	How many years has it been since finishing residency?	Please fill in (or write "resident" if currently a resident): ________________				
4	What is your race/ ethnicity?	White	Black/ African-American	Hispanic or Latino	Asian/ Asian-American	Other (please fill in ___________)
5	What is your current religious affiliation?	Catholic	Muslim	Jewish	None	Other (please fill in ___________)
6	Were you born in the US?	Yes	No			
7	If not, how long have you been living in the United States?	Please fill in: __________				
8	How many of your patients have severe COPD?	Very few	Some	About half	Most	Almost all
9	How many of your patients with severe COPD have advance directives that you know about?	Very few	Some	About half	Most	Almost all
10	How many of your severe COPD patients have you talked to regarding planning in case they need to make decisions about mechanical ventilation (like the decisions shown in the decision aid)?	Very few	Some	About half	Most	Almost all

Usability testing of a decision aid to support shared decision making about invasive mechanical ventilation in severe COPD



Usability testing of a decision aid to support shared decision making about invasive mechanical ventilation in severe COPD

Focus group guide

"Good afternoon. Thank you for participating in this focus group. We are interested in learning about your experience using the decision aid and your opinions about making decisions for your healthcare. There are no right or wrong answers to the questions. We are interested in hearing your opinions and personal experiences which will help us to revise the decision aid and make it as useful as possible for patients and their doctors. We ask that everyone share their opinion and talk one at a time. We really appreciate your help.

Remember, your answers are confidential. No one outside this room will know what you, in particular, said because your name will not be associated with your responses.

The conversation will be audio recorded so that my research team and I can listen to it and transcribe it later. The recording will be kept safely in a locked facility until it is transcribed word for word, then it will be destroyed. The transcribed notes of the focus group will contain no information that would allow individual subjects to be linked to specific statements. Remember, your participation is voluntary and you are free to stop participating at any time. Does anyone have any questions so far?

If you agree to participate, please say the following statement 'I consent to participate in this study.'"

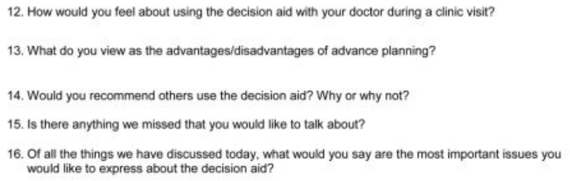
Many of these questions are repeats of the questions you answered in the questionnaire after using the decision aid. In this focus group we are asking the questions again in order to generate a group discussion.

1. What was your experience using the decision aid test like?
2. How did you feel while using the decision aid?
3. What are the main issues around actually using the decision aid?
4. What are the barriers to using the decision aid?
5. What are the enablers?
6. What would make it easier to use?
7. Do you have any concerns about doctors using this decision aid with their patients?
8. If you needed to decide about whether to accept a breathing tube, what factors would you think about?
9. What else would you like to know, or do you think other patients should know in order to help them make decisions about allowing breathing tube and other life supporting treatments?

- Are there pieces of information that all patients should consider?
- Are there pieces of information that are particularly relevant to patients with COPD?
- Does that information change based on your level of health?

10. What impact, if any, do you think using the decision aid will have on your healthcare in the future?
- What about for other patients with COPD?
- What about for people with other medical problems?

11. How might the decision aid help with the planning process?



12. How would you feel about using the decision aid with your doctor during a clinic visit?

13. What do you view as the advantages/disadvantages of advance planning?

14. Would you recommend others use the decision aid? Why or why not?

15. Is there anything we missed that you would like to talk about?

16. Of all the things we have discussed today, what would you say are the most important issues you would like to express about the decision aid?

Appendix 3

Table 1

Questionnaire Results – Patients' and Surrogates' and Clinicians' Comprehension of Decision Aid, Trust, and Acceptability*

COMPREHENSION	**Frequency (%) Correct or mean ± std (median)**		
General	**Patients (n=13)**	**Surrogates (n=5)**	**Clinicians (n=8)**
What does intubation mean?	8 (61.5%)	4 (80.0%)	N/A
What is a breathing machine?	11 (84.6%)	5 (100.0%)	N/A
What is a COPD exacerbation?	7 (53.9%)	4 (80.0%)	N/A
If a person decides not to be treated with a breathing machine, what will happen to them?	10 (76.9%)	5 (100.0%)	N/A
Are there other options for treatment?	7 (53.9%)	4 (80.0%)	N/A
Who do you think this decision aid was meant for?	8 (61.5%)	5 (100.0%)	N/A
Icon Array Specific			
Interpret icon arrays in your own words.	10 (76.9%)	3 (60.0%)	N/A
Which advance directive (Full Code or DNI) results in the highest survival (that is, the greatest number of people still living after one year)?	8 (61.5%)	5 (100.0%)	8 (100.0%)
Which advance directive (Full Code or DNI) results in fewer people living in a nursing home?	11 (84.6%)	4 (80.0%)	7 (87.5%)
Based on these pictures, if 100 people just like you (with severe COPD) chose to be Full Code, how many people would likely be living after one year?	5 (38.5%)	3 (60.0%)	N/A
Based on these pictures, of 100 people with severe COPD who are treated with a breathing machine, how many people will likely be living at the end of one year?	N/A	N/A	7 (87.5%)
Based on these pictures, of 100 people with severe COPD who are treated with a breathing machine, how many people will likely be dead at the end of one year?	N/A	N/A	8 (100.0%)
Low Comprehension	9 (69.2%)	2 (40.0%)	N/A
High Comprehension (No questions wrong)	3 (23.1%)	2 (40.0%)	N/A
TRUST	**(% Responded Yes)**	**(% Responded Yes)**	**(% Responded Yes)**

COMPREHENSION	**Frequency (%) Correct or mean ± std (median)**		
General	**Patients (n=13)**	**Surrogates (n=5)**	**Clinicians (n=8)**
Did you **trust** what you were seeing in the decision aid?	11 (84.6%)	5 (100.0%)	7 (87.5%)
How sure are you that the estimates given are correct? You can show me on the line below:	60.4 ± 28.5 (median = 50.0)	63.8 ± 41.4 (median = 70.0)	71.9 ± 18.7 (median = 72.5)
Could these numbers be wrong?	12 (92.3%)	5 (100.0%)	2 (25.0%)
Do you think your patients would trust you if you used the decision aid with them?			5 (62.5%)
If you **personally** were to be hospitalized after a bad COPD exacerbation and chose to be Full Code, what do you think is the chance you would be living after one year? Please answer on a scale of 0% to 100%.	51.9 ± 35.2 (median = 50.0)	39.0 ± 29.2 (median = 50.0)	N/A
PERCEPTION OF BIAS IN THE DATA PRESENTED			
Did you think the decision was giving you more information about the risks and benefits of one treatment compared to the other?			
Much more information about Full Code	3 (23.1%)	0 (0.0%)	0 (0.0%)
A little more information about Full Code	1 (7.7%)	0 (0.0%)	3 (37.5%)
The same amount of information about each option	8 (61.5%)	4 (80.0%)	3 (37.5%)
A little more information about Do Not Intubate (DNI)	1 (7.7%)	0 (0.0%)	2 (25.0%)
Much more information about Do Not Intubate (DNI)	0 (0.0%)	1 (20.0%)	0 (0.0%)
Did you feel it was trying to persuade you/your patient to one choice over the other? If so, which choice?			
Clearly persuading the patient to choose DNI	0 (0.0%)	1 (20.0%)	0 (0.0%)
Persuading the patient a little to choose DNI	0 (0.0%)	0 (0.0%)	5 (62.5%)
Completely balanced and not persuading the patient one way or the other	9 (69.2%)	4 (80.0%)	2 (25.0%)
Persuading the patient a little toward Full Code	3 (23.1%)	0 (0.0%)	1 (12.5%)
Clearly persuading the patient toward Full Code	1 (7.7%)	0 (0.0%)	0 (0.0%)
ACCEPTABILITY	**(% Responded Yes)**	**(% Responded Yes)**	**(% Responded Yes)**
Did anything make you uncomfortable while you were looking at the decision aid?	4 (30.8%)	4 (80.0%)	3 (37.5%)
Likelihood to recommend use			
On a scale of 0-10 with 0 being not at all likely and 10 being extremely likely, how likely are you to	8.3 ± 1.8 (median = 8.0) ** No subjects responded with <5*	7.4 ± 1.1 (median = 7.0) ** No subjects responded with <5*	7.3 ± 2.1 (median = 8.0) ** No subjects responded with <5*

COMPREHENSION	**Frequency (%) Correct or mean ± std (median)**		
General	**Patients (n=13)**	**Surrogates (n=5)**	**Clinicians (n=8)**
recommend that actual patients use this decision aid with their doctors? (Please choose a number on the scale below).			

Appendix 4

Table 4.2

Associations between patient responses to DA and participant characteristics BY TRUST

Question: Did you trust what you were seeing in the decision aid?		**Yes (n=11)**	**No (n=2)**	**p-value**
Age		58.7 ± 10.9 (median = 62.0)	56.0 ± 15.6 (median = 56.0)	0.9214
Marital Status	Single	4 (36.4%)	1 (50.0%)	
	Married	4 (36.4%)	1 (50.0%)	1.0000
	Divorced/Separated	1 (9.1%)	0 (0.0%)	
	Widowed	2 (18.2%)	0 (0.0%)	
Gender	Female	6 (54.6%)	1 (50.0%)	1.0000
	Male	5 (45.4%)	1 (50.0%)	
Race/Ethnicity	White	3 (27.3%)	1 (50.0%)	
	Black/African American	5 (45.4%)	1 (50.0%)	1.0000
	Hispanic/Latino	3 (27.3%)	0 (0.0%)	
Religious Affiliation	Catholic	5 (45.4%)	0 (0.0%)	
	None	1 (9.1%)	1 (50.0%)	0.4231
	Other	5 (45.4%)	1 (50.0%)	
Employment Status	Employed fulltime	2 (18.2%)	0 (0.0%)	
	Retired	5 (45.4%)	1 (50.0%)	1.0000
	Unemployed	2 (18.2%)	1 (50.0%)	
	Other	2 (18.2%)	0 (0.0%)	
Highest level of Education	9th - 12th grade	9 (81.8%)	1 (50.0%)	
	Some college	1 (9.1%)	0 (0.0%)	0.4231
	College degree	1 (9.1%)	1 (50.0%)	
Economic Class	Lower class	3 (27.3%)	0 (0.0%)	
	Lower-middle class	3 (27.3%)	0 (0.0%)	1.0000
	Middle class	5 (45.4%)	2 (100.0%)	
Born in the US		11 (100.0%)	2 (100.0%)	*N/A*
Language(s) Spoken at Home	English	11 (100.0%)	2 (100.0%)	*N/A*
	Spanish	3 (27.3%)	0 (0.0%)	1.0000
Interpreter Used when Seeing the Doctor	NO	11 (100.0%)	2 (100.0%)	*N/A*
Access to Home Computer with Internet		7 (63.6%)	2 (100.0%)	1.0000

Question: Did you trust what you were seeing in the decision aid?		**Yes (n=11)**	**No (n=2)**	**p-value**
Comfort with Using the Internet	Not at all comfortable	4 (36.4%)	0 (0.0%)	
	Somewhat comfortable	3 (27.3%)	1 (50.0%)	1.0000
	Mostly comfortable	1 (9.1%)	0 (0.0%)	
	Extremely comfortable	3 (27.3%)	1 (50.0%)	
Average *Hours P*er Week Spent on the Internet	Never	4 (36.4%)	0 (0.0%)	
	Less than 5 hours per week	3 (27.3%)	0 (0.0%)	0.5385
	5 to 10 hours per week	2 (18.2%)	1 (50.0%)	
	10 to 30 hours per week	2 (18.2%)	1 (50.0%)	
Type of Insurance	Public insurance (Medicaid, Medicare, VA, etc.	7 (63.6%)	2 (100.0%)	1.0000
	Private insurance (United, BlueCross, etc.	3 (27.3%)	0 (0.0%)	1.0000
Current Living Arrangement	Live alone	2 (18.2%)	0 (0.0%)	
	Live with a spouse or partner	4 (36.4%)	1 (50.0%)	1.0000
	Live with another family member	3 (27.3%)	1 (50.0%)	
	Other	2 (18.2%)	0 (0.0%)	
Self-Rating of Health in General	Very good	2 (20.0%)	0 (0.0%)	
	Good	4 (40.0%)	0 (0.0%)	
	Fair	3 (30.0%)	1 (50.0%)	0.7576
	Poor	1 (10.0%)	1 (50.0%)	
	Missing	1 (10.0%)	0 (0.0%)	
Low Numeracy (defined as > 1 of 5 numeracy questions wrong)		9 (81.8%)	1 (50.0%)	0.4231
Low Terminology (defined as > 1 of 6 Terminology questions wrong)		8 (72.7%)	0 (0.0%)	0.1282
Low ICON ARRAY INTERPRETATION (defined as > 1 of 5 Icon Array Interpretation questions wrong)		7 (63.6%)	1 (50.0%)	1.0000
Lack Comprehension (defined as > 2 of 11 terminology and Icon array interpretation questions wrong)		8 (72.7%)	1 (50.0%)	1.0000

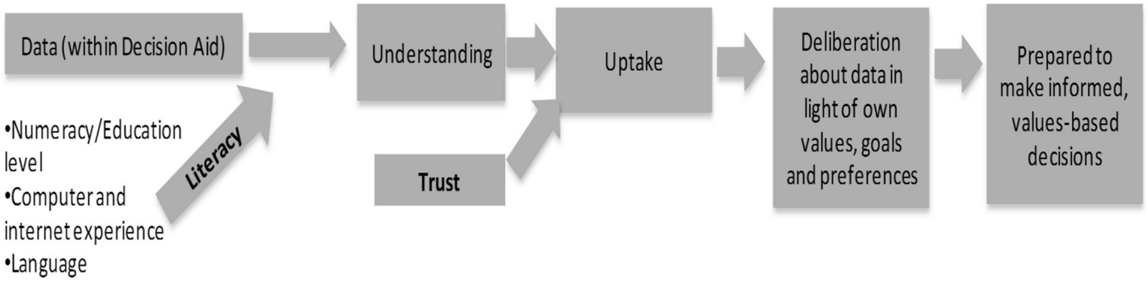

Data (within Decision Aid)
•Numeracy/Education level
•Computer and internet experience
•Language
Literacy
Understanding
Trust
Uptake
Deliberation about data in light of own values, goals and preferences
Prepared to make informed, values-based decisions

Figure 1.

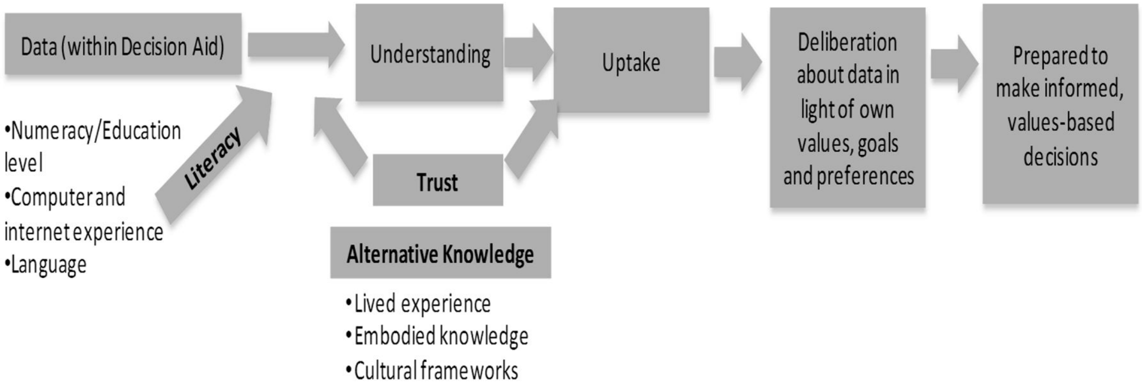

Data (within Decision Aid)
Understanding
Uptake
Deliberation about data in light of own values, goals and preferences
Prepared to make informed, values-based decisions
•Numeracy/Education level
•Computer and internet experience
•Language
Literacy
Trust
Alternative Knowledge
•Lived experience
•Embodied knowledge
•Cultural frameworks

Figure 2.

Table 1

Patient and Surrogate Participant Characteristics (Descriptive)

		patients (n=13)	**surrogates (n=5)**
Age		58.3 ± 11.0 (median=62.0)	54.6 ± 10.7 (median=59.0)
Marital Status	Unmarried	8 (61.5%)	4 (80.0%)
Sex	Female	7 (53.9%)	3 (60.0%)
Race/Ethnicity	White	4 (30.8%)	2 (40.0%)
	Black/African American	6 (46.1%)	1 (20.0%)
	Hispanic/Latino	3 (23.1%)	1 (20.0%)
	Other	0 (0.0%)	1 (20.0%)
Highest Level of Education	9th – 12th grade	10 (76.9%)	1 (20.0%)
	Some college	1 (7.7%)	1 (20.0%)
	College degree	2 (15.4%)	3 (60.0%)
Economic Class	Lower class	3 (23.1%)	1 (20.0%)
	Lower-middle class	3 (23.1%)	2 (40.0%)
	Middle class	7 (53.8%)	1 (20.0%)
	Upper-Middle class	0 (0.0%)	1 (20.0%)
Language(s) Spoken at Home	English	13 (100.0%)	4 (80.0%)
	Spanish	3 (23.1%)	2 (40.0%)
Access to Home Computer with Internet		9 (69.2%)	5 (100.0%)
Comfort with Using the Internet	Not at all comfortable	4 (30.8%)	0 (0.0%)
	Somewhat comfortable	4 (30.8%)	1 (20.0%)
	Mostly comfortable	1 (7.7%)	2 (40.0%)
	Extremely comfortable	4 (30.8%)	2 (40.0%)
Average *Hours* Per Week Spent on the Internet	Never	4 (30.8%)	0 (0.0%)
	Less than 5 hours per week	3 (23.1%)	0 (0.0%)
	5 to 10 hours per week	3 (23.1%)	2 (40.0%)
	10 to 30 hours per week	3 (23.1%)	2 (40.0%)
	Over 30 hours per week	0 (0.0%)	1 (20.0%)
Self-rating of Health in General	Very good	2 (15.4%)	3 (60.0%)
	Good	4 (30.8%)	1 (20.0%)
	Fair	4 (30.8%)	1 (20.0%)
	Poor	2 (15.4%)	0 (0.0%)
	Missing	1 (7.7%)	0 (0.0%)
Lack comprehension (defined as > 2 of 11 terminology and Icon array interpretation questions wrong)		9 (69.2%)	2 (40%)
Low numeracy (defined as > 1 of 5 numeracy questions wrong)		10 (76.9%)	3 (60%)
Low terminology (defined as > 1 of 6 Terminology questions wrong)		8 (61.5%)	0 (0.0%)

		patients (n=13)	**surrogates (n=5)**
Low ICON ARRAY INTERPRETATION (defined as > 1 of 5 Icon Array Interpretation questions wrong)		8 (61.5%)	2 (40.0%)
COPD		11 (84.6%)	4 (80.0%)

Table 2

Clinician Participant Characteristics (Descriptive)

		Clinicians (n=8)
Age		45.3 ± 10.6 (median=45.0)
Gender	Female	3 (37.5%)
Years Since Residency Completion		13.5 ± 11.9 (median=10.0)
Race/Ethnicity	White	4 (50.0%)
	Hispanic/Latino	1 (12.5%)
	Caribbean or West Indian	2 (25.0%)
	Missing	1 (12.5%)
Born in the US	Yes	6 (75.0%)
How many patients treated with severe COPD?	Some	1 (12.5%)
	About half	6 (75.0%)
	Most	1 (12.5%)
How many of clinician's patients with severe COPD have advance directives?	Very few	4 (50.0%)
	Some	2 (25.0%)
	Most	1 (12.5%)
	Almost all	1 (12.5%)
How many of clinician's patients with severe COPD patients have they talked to regarding planning in case they need to make decisions about mechanical ventilation?	Very few	1 (12.5%)
	About half	1 (12.5%)
	Most	3 (37.5%)
	Almost all	3 (37.5%)

Table 3

Variation in patients’ and surrogates’ preferences for information and emotional reactions to the information contained in the decision aid

Timing of when to use	“I think it should be given at the beginning when they find out they have COPD.” (**Surrogate**)	“I would say… when your COPD began to – when your doctor notice that it’s beginning to get severe.” (**COPD Patient**)
Tone and level of sensitivity of information	“it was a slap in the face” (**COPD Patient**)	“tell it like it is” (**Surrogate**)
Reaction to the Images	Image of intubated patient “too graphic” (**Surrogate**)	“I just loved that it’s so graphic” (**Surrogate**)
Depth of Information	“As far as I was concerned, as long as you put those numbers up there, with you know, anything else beyond that was [unnecessary].” (**COPD Patient**)	“I liked it the fact that they were upfront about the personal things, the financial stability of your family, these things because when you’re really sick, you’re not thinking about these things.” (**COPD Patient**)