# Acceptability and usability of the Planning Advance Care Together (PACT) website for improving patients' engagement in advance care planning

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## ARTICLE INFO

## ABSTRACT

*Objectives:* Most prior advance care planning (ACP) interventions lack integration of the social context of patients' ACP process, which patients indicate is critically important. The current study developed the Planning Advance Care Together (PACT) website to foster inclusion of loved ones in the ACP process.

*Methods:* To provide feedback about the PACT website, patients with advanced cancer ($N = 11$), their caregivers ($N = 11$), and experts ($N = 10$) participated in semi-structured interviews. Patients and caregivers also completed standardized ratings of acceptability and usability.

*Results:* Overall, patient ($n = 11$) and caregiver ($n = 11$) ratings of acceptability and usability of the website exceeded benchmark cut-offs ($\geq 24$ on the Acceptability *E*-Scale and $\geq 68$ on the System Usability Scale). Patients, caregivers, and experts liked the topic of ACP but felt that it could be emotionally challenging. They recommended focusing more on planning and less on end of life. They appreciated being able to include loved ones and recommended adding resources for caregivers.

*Conclusions:* Study findings support the preliminary usability and acceptability of the PACT website. Findings will be used to inform a modified prototype of the PACT website that is interactive and ready for field testing with patients with advanced cancer and their loved ones.

*Innovation:* We utilized a novel application of the shared mind framework to support patients with advanced cancer in engaging their loved ones in the ACP process.

## 1. Introduction

Engaging patients with advanced cancer in advance care planning (ACP) can help to improve quality of life and foster goal-concordant care at the end of life [1,2]. ACP is a patient-centered, voluntary, and ongoing process that supports patients in understanding and sharing their

personal values, life goals, and preferences regarding future medical care [3,4]. ACP consists of having conversations about end-of-life care planning as well as completion of advance directives (ADs). Underlying goals of ACP include respecting individual patient autonomy, improving quality of care, strengthening relationships, preparing for end-of-life, and reducing overtreatment [5]. Due to its critical role in improving patients' outcomes, ACP is incorporated into guidelines for cancer care, including the National Comprehensive Cancer Network, ASCO's Quality Oncology Practice Initiative, and the Centers for Medicare and Medicaid Services Oncology Care Model [6,7].

Engagement in ACP among patients with cancer is associated with reduced hospitalizations and increased use of hospice and palliative care [8]. However, it is important to appreciate the complexities of ACP and the multiple stakeholders involved (e.g. patients, surrogates, community, clinicians, health systems, policy) [9]. Some data on certain ACP outcomes, such as goal concordance and quality of life, are mixed while ACP has had a largely positive influence on improving quality of patient-physician communication, reducing decisional conflict, and improving congruence in preferences between patients and caregivers [9,10]. Completion of ADs, including Do Not Resuscitate (DNR) orders and living wills (LW), are associated with better death preparedness, lower caregiver distress at the end of life, and reduced decisional burden in patients with cancer [11]. Despite its promising benefits, less than half of patients with advanced cancer have ADs in their medical record [12].

Multiple ACP interventions have been developed to improve engagement in ACP, yet there remains limited comprehension and awareness of ACP among cancer patients [13]. A limitation of prior interventions is the lack of direct involvement of patients' personal caregivers into the ACP decision-making process. ACP, including having conversations about end-of-life care and completing ADs, is a social, emotional, and relational decision-making process often requiring the involvement of loved ones [14,15]. Most patients report discussing ACP with loved ones, often at much higher rates than with their physicians (69% versus 8%) [16]. Patients frequently worry about how end-of-life care decisions will affect loved ones, further highlighting the influence of loved ones on patients' engagement in ACP [17-19].

Approaching ACP as a social process, through an iterative process of consulting, sharing, and informing others about ACP decisions, is linked to successful ACP engagement among patients with advanced cancer in prior studies [20]. The shared mind framework, grounded in cognitive neuroscience and communication research, is an interactional approach to decision-making processes between patients, their families, and healthcare providers in which decisions emerge from shared thoughts and feelings [14]. As such, the shared mind framework appreciates that important health decisions are often made in the context of social networks with family, friends, and healthcare providers. This framework has been applied in the context of patient and caregiver sensemaking as they consider bone marrow transplant and in treatment decision-making with patients with inflammatory bowel disease [21,22]. This framework serves as a strong theoretical model to guide integration of loved ones into the ACP decision-making process, in particular to foster exploration, clarification, and co-construction of patients' preferences in complex clinical situations [23].

Engaging with family members during ACP discussions may indirectly motivate individuals to have ACP discussions and increase the likelihood of further conversations between individuals, family members, and members of the healthcare team [24]. Easy-to-use patient-facing ACP websites, such as the PREPARE website, are effective at increasing ACP documentation [25]. However, this website does not directly involve patients' social support system into the process of planning. To address the critical gap of patients' social context in prior ACP interventions, our team applied a shared mind framework to engage patients with advanced cancer and their loved ones in ACP. We developed a preliminary website prototype for Planning Advance Care Together (PACT) that allows for direct virtual engagement in ACP with patients and their loved ones and supports patients in completing their

ADs directly online through an auto-fill document feature. Patients and their loved ones can access the website from any smartphone, tablet device, or computer.

The purpose of this study was to refine the PACT website prototype by incorporating feedback from patients with advanced cancer, their family caregivers/loved ones, and experts (healthcare providers) working with this patient population. We hypothesized that patient and caregiver ratings of the PACT website would meet a priori and standardized benchmarks for acceptability (scores of 24 or higher on the Acceptability *E*-Scale) [26] and usability (scores of 68 or higher on the System Usability Scale or SUS) [27].

## 2. Methods

### 2.1. Participants and procedures

*Patient* eligibility criteria included: (1) diagnosis of poor prognosis advanced cancer defined as locally advanced or metastatic cancer and/or disease progression following at least first line systemic therapy; (2) access to a mobile device;(3) the ability to provide informed consent; and (4) identification and enrollment of a loved one/informal caregiver. *Caregiver* eligibility criteria included: (1) the person (family member or friend) whom the patient identified as an informal caregiver; (2) English speaking; (3) 18 years of age or older; and (4) able to provide informed consent. *Expert (provider)* eligibility criteria included: (1) current clinical practice and/or research with advanced cancer patients, (2) a history of 3+ years working with advanced cancer patients; (3) 18 years of age or older. Providers across disciplines (e.g., social work, oncology) were enrolled. Participants were recruited via provider referral or from the electronic medical record from two participating study sites at academic medical centers in the Northeast and Pacific Northwest.

The study was approved by our Institutional Review Board in accordance with the US Federal Policy for the Protection of Human Subjects (ID: 20–08-355 & ID: 10849. Protocol #: **RG1121852**). Participants provided written informed consent or electronic consent via REDCap. Participants completed a verbally administered questionnaire at the start of the study visit assessing demographics (patients, caregivers, and experts) and health status (for patients). Informed by the Obesity-Related Behavioral Intervention Trials (ORBIT) model for behavioral intervention development (Phase 1b: Refine), patients, caregivers, and experts working with patients with advanced cancer participated in semi-structured interviews to provide feedback about the PACT website [28]. Study visits were conducted in-person or remotely, according to participant preference. Each visit lasted approximately 45 min. Participants were instructed to view the interactive prototype of the PACT website on their own device (smartphone, tablet device, or computer) and were asked questions about its usability and acceptability. The interventionist guided participants from section to section (e.g., "We will review the Questions section now;" "Now let's move on to the Documents section"). Interventionists did not go into detail about the features or functions of the website but rather asked patients about their ability to navigate the website and general feedback on it.

After viewing this prototype, participants were asked to draw on their experiences and expertise to provide suggestions on ways to modify and ultimately improve the PACT interactive prototype. All participants (patients, caregivers, and experts) participated in semi-structured qualitative interviews based on standard interviewing techniques termed "verbal probing", to gain an in-depth understanding of their preferences for intervention content and design [29,30]. End users only (patients with advanced cancer and their caregivers) also completed standardized measures of usability and acceptability. Each participant received $35 as compensation for their study participation.

### 2.2. Planning Advance Care Together (PACT)

PACT is an interactive website that provides the following

empirically based features to meet patients' reported need to incorporate loved ones into the ACP decision-making process and thus bolster their social networks. It allows patients to: **Pi**ck one's team of loved ones to be involved in ACP through its shareability feature; **A**ddress common barriers of traditional family meetings (e.g., distance of loved ones, domineering family members) by exploiting the ubiquitous access of a website with the ability to control online ACP meetings; **C**omplete ADs with the engagement and, if desired, input of loved ones through structured question prompts; **T**eam up with loved ones to share one's wishes both informally through care preference messages and formally through shared AD forms.

To develop a preliminary interactive prototype for PACT, Dr. Shen (PI) worked closely with developers and graphic designers. An initial outline of the prototype content was based on: (1) robust prior ACP research; (2) pilot and preliminary data from our prior studies (detailed below) in which patients highlighted desired features of integrating loved ones and providers in ACP; and (3) best practices for designing mobile apps for older adults and seriously ill patients [31]. The PI (Shen) conducted a pilot study (during August 2016 – July 2017) with advanced cancer patients and caregivers to determine with whom patients discussed end-of-life care and ADs and their preferred approaches for communicating about ACP. Results indicated that patients discussed ACP with family members at higher rates than with oncologists, and that patients have a clear desire to engage family members and physicians in ACP and to be able to select who to involve, all of which are the focus of PACT.

Additionally, prior work of our team's NCI funded cohort study of advanced cancer patients and caregivers (Coping with Cancer 2 (CwC2), 2011–2015, PI: Prigerson) asked patients to what extent their treatment preferences are shaped by concerns about their family, in which most patients (70.7%) reported their end-of-life care treatment preferences are shaped 'somewhat' to 'entirely' around concerns about their family. Among all patients, 44.4% reported "entirely." The degree to which family members influenced patients' treatment preferences was significantly associated with actual end-of-life care treatment preferences ($p$ = 0.001). Namely, those who were more strongly influenced by their family had a stronger preference for life-extending (vs. comfort-focused care). These results indicate that not only are most patients influenced by their family members, but these relationships may also directly influence the end-of-life care preferences and choices patients make.

Next, the prototype outline was further developed using stakeholder feedback from expert end-of-life care researchers and providers (oncologists, social workers, and psychologists). Based on this feedback, we developed a preliminary interactive website prototype, which we revised further through a user-centered narrative design approach [32]. The PACT website features were designed to: (1) educate patients about ACP, including terminology, how to select social supports for ACP including picking a health care proxy (HCP) who will support the patients' expressed wishes, and how to communicate wishes to loved ones and providers (Resources section); (2) allow patients to integrate loved ones into the ACP decision-making process (adding loved ones) and in completing advance directive forms (People section); (3) record, store, and share ACP preferences formally through AD documentation and informally through video, audio, and written messages to loved ones (Wishes and Documents sections); and (4) auto-fill questions to complete ADs (living will and health care proxy, Questions section) (see Fig. 1).

### 2.3. Measures

#### 2.3.1. Demographics and clinical characteristics
Patients and informal caregivers reported their age, study site, sex at birth, ethnicity, race, relationship status, religious affiliation, employment status, education, and household income. Additionally, the informal caregiver's relationship to the patient was assessed. Experts reported their age, study site, sex at birth, ethnicity, race, professional discipline, and years of practice. Regarding clinical characteristics, patients self-reported their primary cancer type and current cancer stage.
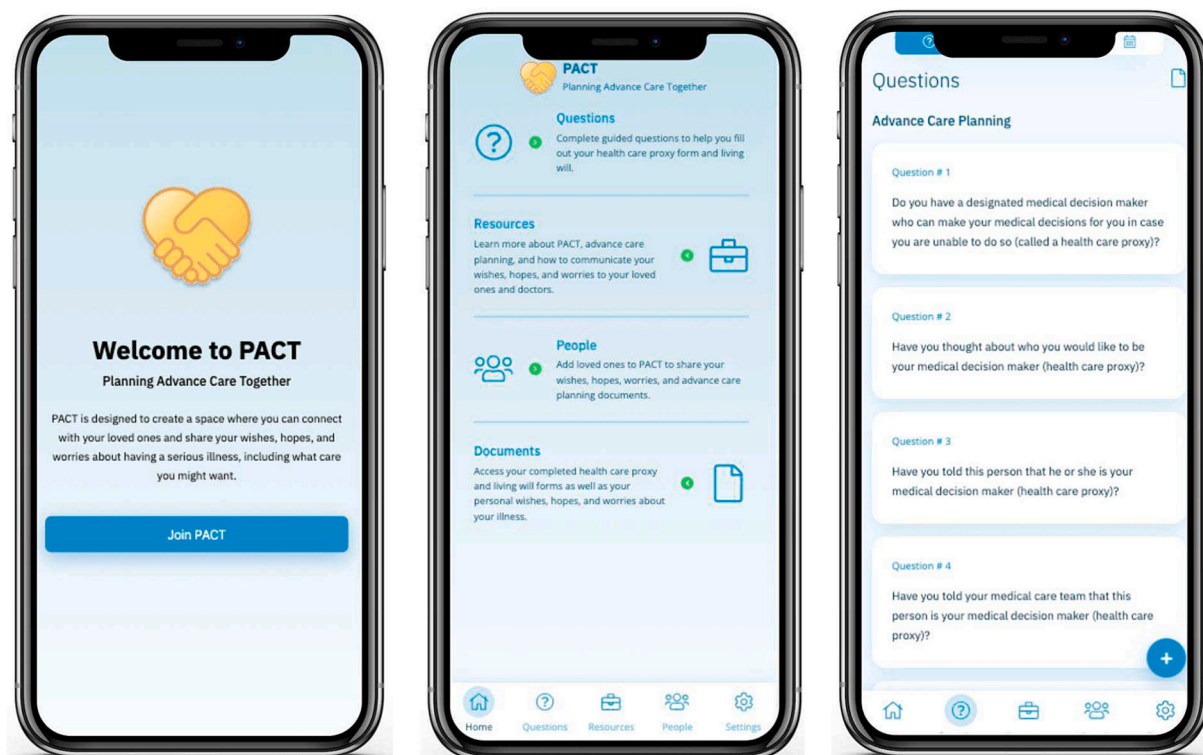


**Fig. 1.** Images from the preliminary PACT website prototype. Images (from left to right) include the PACT homepage, PACT menu, and PACT advance care planning question prompts.

## 2.3.2. Acceptability and usability

Patients with advanced cancer and their informal caregivers assessed the acceptability and usability of the PACT website using two scales: the Acceptability *E*-scale (AES) and the System Usability Scale (SUS).The *Acceptability E-scale (*AES) consists of 6 items and is scored on a 5-point Likert scale [26]. Scores are summed to produce an overall score between 6 and 30. An AES score $\geq$ 24 is considered acceptable for use with patients with cancer and was therefore used as a cutoff in this study [26]. The *System Usability Scale (*SUS) consists of 10 items and is scored on a 5-point Likert scale. Scores are summed and then multiplied by 2.5 to produce a total score ranging from 0 to 100. An SUS score $\geq$ 68 is considered acceptable for use and was therefore used as a cutoff in this study [27,33,34].

## 2.3.3. Interview guide

The qualitative interview included structured questions on concrete characteristics of the PACT website such as needed features (removal of current features and/or addition of needed features); design features; understandability; usability; and acceptability.

## 2.4. Statistical analyses

### 2.4.1. Quantitative analyses

Descriptive statistics related to patient, informal caregiver, and expert demographics/clinical characteristics were examined for all participants who completed the study. Continuous variables were expressed with means (SD) and categorical variables were expressed with frequency counts/percentages. All descriptive statistics and data visualizations were performed in RStudio 4.3.0.

### 2.4.2. Qualitative analyses

All qualitative semi-structured interviews were audio recorded and coded by study staff. Coders either listened to the interview recording or used the interview transcription when available. Qualitative Description (QD) was used to analyze the data capturing participants' experience using the PACT website [35-37]. The codebook was developed based on the organizing categories of the semi-structured interview guide: (1) positive feedback, (2) negative feedback, and (3) suggestions for changes. All transcripts were coded separately by two individual coders. Upon completion, two independent researchers extracted major themes from coded transcripts and met together to resolve discrepancies and to create a comprehensive list of feedback to share with the developers to inform revisions to the website. The comprehensive listing was further analyzed according to content, formatting, and functionality (see Table 4).

## 3. Results

### 3.1. Demographics and clinical characteristics

A total of $N = 11$ patients, $N = 11$ informal caregivers and $N = 10$ experts completed the study. Detailed information on participant recruitment at both study sites can be found in Fig. 3. Patient and informal caregiver characteristics were as follows (see Table 1). Two dyads were recruited separately. The informal caregiver for one of the dyads completed their interview but the patient never completed theirs. For the other dyad, the patient completed their interview, but their primary informal caregiver never completed theirs. Patients had a mean age of 63.7 years (SD 14.17), were majority female (54.5%), White (72.7%), and married/partnered (72.7%). Patients most commonly reported their primary cancer site to be lung (54.5%) and 'other' (18.2%), and the majority reported having Stage IV cancer (54.5%). Caregivers had a mean age of 63.4 years (SD 17.04), were majority female (72.7%), White (81.8%), and married/partnered (81.8%). Experts had a mean age of 42.5 years (SD 7.91), were majority female (70.0%), White (100.0%), and predominately worked as oncologists (50.0%) (see Table 2).

**Table 1**

Sociodemographic data and clinical characteristics, PACT Aim 1 study. Data is from all patients ($N = 11$) and caregivers ($N = 11$) who completed their interview.

| | Patients ($N = 11$) | Caregivers ($N = 11$) | Overall ($N = 22$) |
|---|---|---|---|
| **Mean (SD)** | | | |
| Age (years) | 63.7 (14.17) | 63.4 (17.04) | 63.5 (15.29) |
| **N (%)** | | | |
| **Study Site** | | | |
| Fred Hutch | 7 (63.6%) | 7 (63.6%) | 14 (63.6%) |
| Mount Sinai | 4 (36.4%) | 4 (36.4%) | 8 (36.4%) |
| **Gender** | | | |
| Male | 5 (45.5%) | 3 (27.3%) | 8 (36.4%) |
| Female | 6 (54.5%) | 8 (72.7%) | 14 (63.6%) |
| **Hispanic/Latino** | | | |
| Yes | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) |
| No | 11 (100.0%) | 11 (100.0%) | 22 (100.0%) |
| Missing | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) |
| **Race** | | | |
| White or Caucasian | 8 (72.7%) | 9 (81.8%) | 17 (77.3%) |
| Black or African American | 2 (18.2%) | 2 (18.2%) | 4 (18.2%) |
| Asian | 1 (9.1%) | 0 (0.0%) | 1 (4.5%) |
| American Indian or Alaskan Native | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) |
| Native Hawaiian or Other Pacific Islander | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) |
| Multi-Racial | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) |
| Other (Hispanic or Latino) | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) |
| Other | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) |
| **Relationship Status** | | | |
| Married/partnered | 8 (72.7%) | 9 (81.8%) | 17 (77.3%) |
| Not married/partnered | 3 (27.3%) | 2 (18.2%) | 5 (22.7%) |
| **Religion** | | | |
| Catholic | 5 (45.4%) | 3 (27.3%) | 8 (36.4%) |
| Baptist | 1 (9.1%) | 0 (0.0%) | 1 (4.5%) |
| Protestant | 1 (9.1%) | 1 (9.1%) | 2 (9.1%) |
| Jewish | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) |
| Muslim | 1 (9.1%) | 1 (9.1%) | 2 (9.1%) |
| Pentecostal | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) |
| Atheist | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) |
| Agnostic | 1 (9.1%) | 0 (0.0%) | 1 (4.5%) |
| Other/missing | 2 (18.2%) | 6 (54.5%) | 8 (36.4%) |
| **Employment Status** | | | |
| Employed, full time | 2 (18.2%) | 3 (27.3%) | 5 (22.7%) |
| Employed, part time | 2 (18.2%) | 2 (18.2%) | 4 (18.2%) |
| Not employed | 7 (63.6%) | 6 (54.5%) | 13 (59.1%) |
| **Highest Education Level Completed** | | | |
| Graduated high school or equivalent | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) |
| Some college | 1 (9.1%) | 0 (0.0%) | 1 (4.5%) |
| Graduated college | 4 (36.4%) | 5 (45.4%) | 9 (40.9%) |
| Some postgraduate/ professional courses | 1 (9.1%) | 2 (18.2%) | 3 (13.6%) |
| Completed post-graduate/ professional degree | 5 (45.4%) | 4 (36.4%) | 9 (40.9%) |
| | **Patients ($N = 11$)** | **Caregivers ($N = 11$)** | **Overall ($N = 22$)** |
| **Total Household Income (Annual)** | | | |
| Less than $21,000 | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) |
| $21,000 - $39,999 | 1 (9.1%) | 1 (9.1%) | 2 (9.1%) |
| $40,000 - $65,999 | 1 (9.1%) | 0 (0.0%) | 1 (4.5%) |
| $66,000 - $105,999 | 2 (18.2%) | 3 (27.3%) | 5 (22.8%) |
| $106,000 or more | 6 (54.5%) | 6 (54.5%) | 12 (54.5%) |
| Refused/ don't know | 1 (9.1%) | 1 (9.1%) | 2 (9.1%) |
| **Insurance Status (Loved One's Insurance Status)** | | | |
| Insured | 11 (100.0%) | 11 (100.0%) | 22 (100.0%) |
| Not insured | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) |
| **Primary Informal Caregiver Relationship** | | | |
| Spouse/Partner | 7 (63.6%) | – | – |
| Son or Daughter | 1 (9.1%) | | |
| Sibling | 0 (0.0%) | | |
| Parent | 1 (9.1%) | | |
| Aunt or Uncle | 0 (0.0%) | | |
| Cousin | 1 (9.1%) | | |
| No caregiver | 1 (9.1%) | | |
| **Clinical Characteristics (Self-reported by Patient)** | | | |

*(continued on next page)*

**Table 1** (*continued*)

|  | Patients (*N* = 11) | Caregivers (*N* = 11) | Overall (*N* = 22) |
|---|---|---|---|
| **Primary Cancer** |  |  |  |
| Pancreaticobiliary cancer | 0 (0.0%) | – | – |
| Esophagogastric cancer | 0 (0.0%) |  |  |
| Hepatocellular carcinoma | 0 (0.0%) |  |  |
| Lung cancer | 6 (54.5%) |  |  |
| Gynecologic cancer | 1 (9.1%) |  |  |
| Colorectal cancer | 0 (0.0%) |  |  |
| Head and neck cancer | 1 (9.1%) |  |  |
| Liver cancer | 1 (9.1%) |  |  |
| Bladder or renal cell carcinoma | 0 (0.0%) |  |  |
| Lymphoma or sarcoma | 0 (0.0%) |  |  |
| Other | 2 (18.2%) |  |  |
| **Current Cancer Stage** |  |  |  |
| Early stage (Stage I) | 0 (0.0%) | – | – |
| Middle stage (Stage II) | 1 (9.1%) |  |  |
| Late stage (Stage III) | 2 (18.2%) |  |  |
| End stage (Stage IV) | 6 (54.5%) |  |  |
| Don't know | 2 (18.2%) |  |  |

**Table 2**
Sociodemographic characteristics for N = 10 experts, PACT Aim 1 Study.

| Sociodemographic characteristics |  |
|---|---|
|  | Experts (*N* = 10) |
| **Mean (SD)** |  |
| Age (years) | 42.5 (7.91) |
| **N (%)** |  |
| **Study Site** |  |
| Fred Hutch | 5 (50.0%) |
| Mount Sinai | 5 (50.0%) |
| **Gender** |  |
| Male | 3 (30.0%) |
| Female | 7 (70.0%) |
| **Hispanic/Latino** |  |
| Yes | 1 (10.0%) |
| No | 9 (90.0%) |
| Missing | 0 (0.0%) |
| **Race** |  |
| White or Caucasian | 10 (100.0%) |
| Black or African American | 0 (0.0%) |
| Asian | 0 (0.0%) |
| American Indian or Alaskan Native | 0 (0.0%) |
| Native Hawaiian or Other Pacific Islander | 0 (0.0%) |
| Multi-Racial | 0 (0.0%) |
| Other (Hispanic or Latino) | 0 (0.0%) |
| Other | 0 (0.0%) |
| **Professional Discipline** |  |
| Social worker | 2 (20.0%) |
| Psychologist | 0 (0.0%) |
| Psychiatrist | 0 (0.0%) |
| Oncologist | 5 (50.0%) |
| Nurse | 2 (20.0%) |
| Other | 1 (10.0%) |
| **Mean (SD)** |  |
| **Years in Professional Discipline** | 12.5 (5.99) |

### 3.2. Acceptability and usability ratings

Acceptability and usability ratings were assessed individually for patients and caregivers, as well as combined (see Table 3). Average mean patient AES scores were right below the cut-off value of 24.0 (M = 23.6, SD 4.74), but mean caregiver AES scores exceeded the cutoff (M = 25.4, SD 3.17). Overall, 54.5% of patients' and 63.6% of caregivers' AES scores were over the cut-off value. Informal caregivers expressed interest in more caregiver focused resources on the website and noted that the questions were too negative and too focused on death. Patients expressed that they did not see the value of the meetings section and that the wishes section was confusing and/or irrelevant. Mean patient and

**Table 3**
Acceptability and usability data, PACT Aim 1 Study. Data is from all patients (*N* = 11) and caregivers (*N* = 11) who completed their interview. Any missing sub-score values were replaced using median imputation.

|  | Patients (*N* = 11) | Caregivers (*N* = 11) | Overall (*N* = 22) |
|---|---|---|---|
| **Acceptability *E*-Scale** |  |  |  |
| Total possible score range: 6–30 |  |  |  |
| Range | 16–29 | 21–29 | 16–29 |
| Mean (SD) | 23.6 (4.74) | 25.4 (3.17) | 24.5 (4.03) |
| **SUS Scale** |  |  |  |
| Total possible score range: 0–100 |  |  |  |
| Range | 50.0–97.5 | 62.5–87.5 | 50.0–97.5 |
| Mean (SD) | 72.0 (12.49) | 73.2 (7.75) | 72.6 (10.16) |

informal caregiver SUS scores were both above the accepted cut-off value for usability of 68.0, (M = 72.0, SD 12.49; M = 73.2, SD 7.75, respectively). A total of 72.7% of patients' SUS scores and 63.6% of informal caregivers' SUS scores were above the normed cut-off for acceptable usability scores. Overall, acceptability and usability benchmark cut-offs were exceeded (see Fig. 2).

### 3.3. Qualitative findings

Patients, informal caregivers, and experts provided both positive and negative feedback about the PACT website. We organized feedback according to content, formatting, and functionality of the PACT website as reported by patients, informal caregivers, experts, and overall/combined (see Table 4). In addition, study participants provided specific suggestions for desired changes to the PACT website (see Table 5). Direct quotes from study participants are labeled by their group (e.g., patient, caregiver, or expert) with their corresponding participant ID number.

#### 3.3.1. Patients

Regarding content, patients felt that the website aided in understanding of ACP and communication of ACP preferences to loved ones, such as "*It makes you think about medical decisions. Loved ones will know exactly what care you want*" (Patient 2001). They noted that some medical terms were difficult to understand and that some sections of the website could be improved (e.g., questions section was overwhelming and hard to navigate). The resources section was the most liked, with comments such as "*The topics covered are important. Having conversations about the care you want is important*" (Patient 2005). Some patients did not feel that they would use the meetings section and felt that the function of it needed to be described more clearly. For formatting, they liked the color scheme and felt that the website was easy to use, but some pages were too busy, and some questions were redundant. In terms of functionality, they appreciated time-saving features (e.g., auto-populate of ACP documents), noting "*it's good that the app auto-fills the document so that you don't have to worry about filling it out again*" (Patient 2007). The purpose of certain functions was unclear (e.g., it was unclear that information they filled out in the questions section was being auto-populated into ACP documents). Suggestions for changes included adding additional content (e.g., dialogue guidance for conversations around ACP), modifying the formatting (e.g., arrange by topics instead of sections), and improving functionality of the website (e.g., expand document offerings). Patients recommended guided questions and prompts to initiate a conversation such as, "This is where I am at currently, and where it appears I am going", and "This is how you can help".

#### 3.3.2. Informal caregivers

For content, informal caregivers shared that PACT was a valuable tool and that it included good questions to consider and discuss about ACP, noting that "*It does a good job steering for those who might not be as familiar*" (Caregiver 3005). However, they wanted more caregiver-focused questions and resources about ACP. They described, "*I don't*
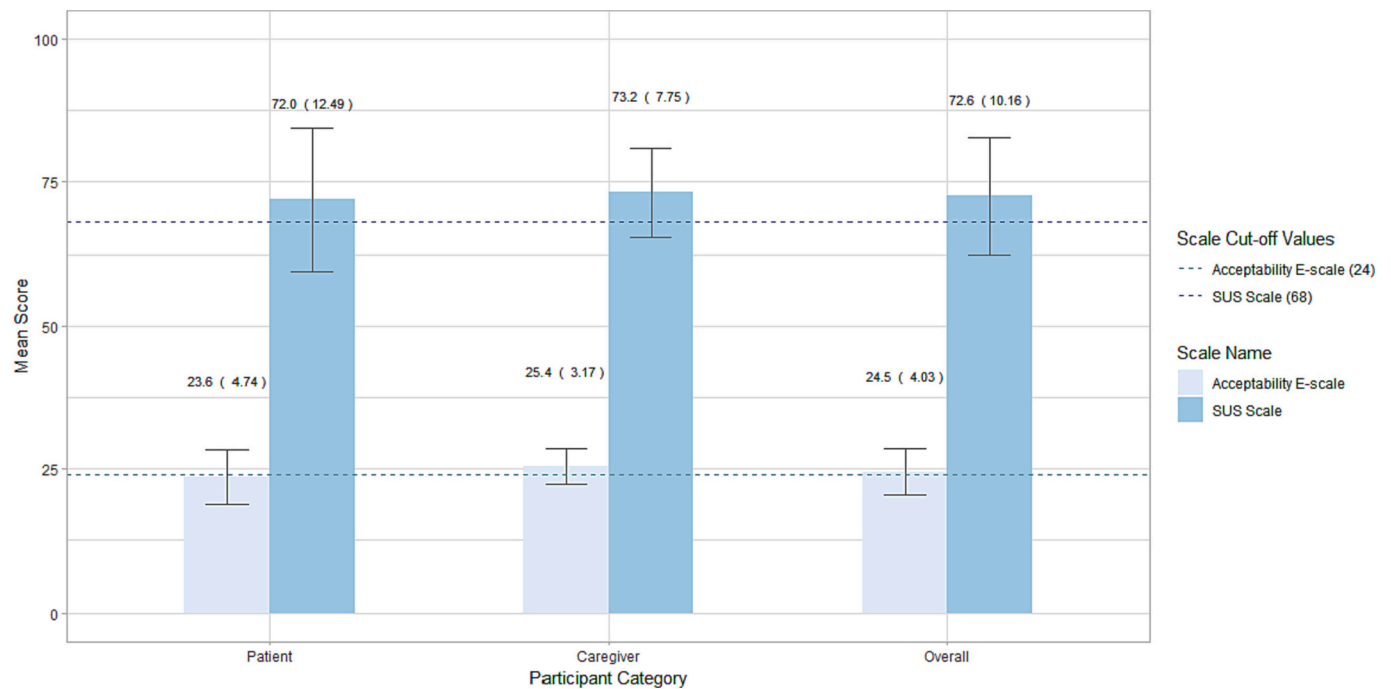
**Fig. 2.** Acceptability and Usability Ratings from Patients, Caregivers, and Overall. For the Acceptability *E*-Scale, a total score of ≥24 is considered acceptable for use and is used as the cutoff in this study. For the System Usability Scale, a score ≥ 68 is considered above average usability and is used as the cutoff in this study. Data is from all patients ($N = 11$) and caregivers ($N = 11$) who completed their interview.
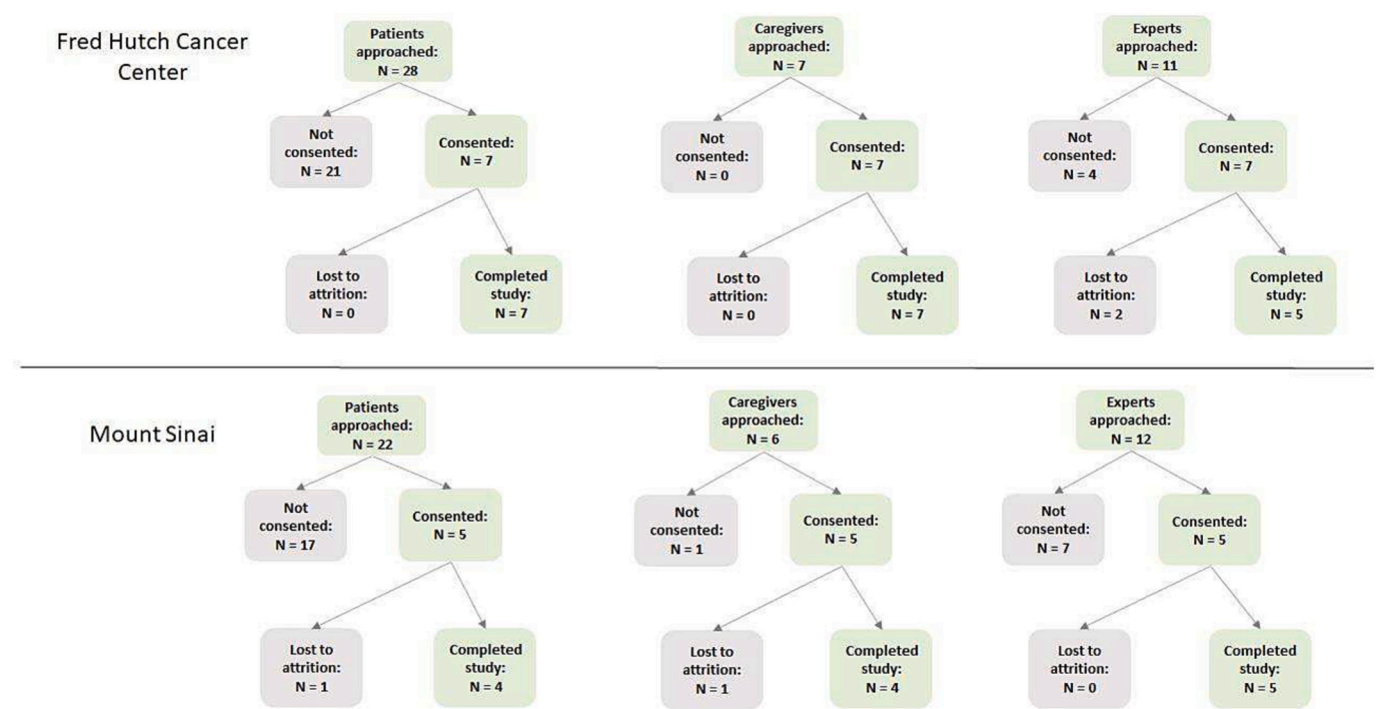


**Fig. 3.** Study Recruitment Flowchart. This flowchart outlines the recruitment, consent, and study completion counts for each participant group at each study site.

*like having to scroll through a lot of questions that only apply to patients to get to relevant ones for me*" (Caregiver 2001). With respect to formatting, they found the website to be simple and user-friendly. They noted however, that it could be improved with better design and flow. Certain features were unclear (e.g., it was unclear that section titles under "Resources" could be clicked on for more information). In terms of functionality, informal caregivers found value added in including loved ones but were unsure who to add and what information would be shared. They suggested changes to improve the content (e.g., make questions more positive), formatting (e.g., add a progress bar), and functionality of the website (e.g., add ability to communicate with medical team).

**Table 4**
Feedback about the website from patients with advanced cancer ($N = 11$), caregivers ($N = 11$), and experts ($N = 10$).

| Feedback type | Feedback source | | | |
|---|---|---|---|---|
| | Patients | Caregivers | Experts | Overall/Combined |
| **Positive** | | | | |
| | **Content** | **Content** | **Content** | **Content** |
| | • Aided in communication of ACP preferences to loved ones<br>• Aided in awareness & reflection<br>• Resources section was most liked/ would be used<br>**Formatting**<br><br>• Liked the color scheme<br>• Well organized, intuitive, easy-to-use<br>• Documents section very professional and organized<br>**Functionality**<br><br>• Auto-populate of ACP documents was helpful<br>• Log-in/registration was easy<br>• Liked communication aspect of the resources section | • Valuable tool<br>• Good questions to consider and discuss<br>**Formatting**<br><br>• Simple, user friendly<br>• Font was easy to read, even on a mobile device<br>• Liked some images (e.g. hands with heart, LIVE phrase)<br>**Functionality**<br><br>• Easy log-in/registration<br>• Value added in including loved ones (People section)<br>• Liked that ACP documents would auto-populate from questions section | • Good questions to consider for ACP<br>• Resources section good for patients and caregivers<br>• Document section would be helpful if completed<br>**Formatting**<br><br>• Easy to use, intuitive design<br>• Easy log-in/registration<br>**Functionality**<br><br>• Auto-fill of ACP questions was good<br>• Nice to have ability to add family members (People section) | • Liked topic of ACP<br>• Resources section clear and provided good information<br>• Documents section was clear and organized<br>**Formatting**<br><br>• Easy to use, intuitive<br>• Liked color scheme<br>**Functionality**<br><br>• Auto-fill feature of documents was helpful<br>• Value in adding family members/loved ones to keep people involved |
| **Negative** | | | | |
| | **Content** | **Content** | **Content** | **Content** |
| | • ACP and medical terms were difficult to understand<br>• Questions section was overwhelming, too much<br>• Did not see the value of the meetings section<br>• Resource videos were too simple/ irrelevant/'white'<br>• Wishes section was confusing and/or irrelevant<br>• Make the function of the meetings section more clear (would not use)<br>**Formatting**<br><br>• Some pages were too busy/hard to notice features<br>• Too many questions/redundant questions<br>**Functionality**<br><br>• Unclear that information from the "Questions" section was being populated into ACP documents<br>• Invitation process for adding collaborators was unclear | • Wanted more caregiver-focused questions and resources<br>• Questions too negative/too focused on death<br>• Unclear how results/answers would be used<br>• Unsure what 'collaborator' meant<br>**Formatting**<br><br>• Seemed busy, could have better flow<br>• Graphics too simple or "childish"<br>• Too many clicks required to answer questions<br>• Unclear that section titles could be clicked on for more information<br>**Functionality**<br><br>• App would timeout without warning<br>• Unsure who to add and what would be shared (People section)<br>• Unclear that question responses would populate documents section | • Some ACP terms too complicated<br>• Disliked question content/ amount of questions<br>• Could add Physician Orders for Life Sustaining Treatment (POLST) and other documents<br>**Formatting**<br><br>• Icons unclear and/or too small<br>• Hard to navigate<br>• Free text after questions is unclear<br>**Functionality**<br><br>• Unclear who has access to answered questions<br>• Physician referral code process unclear<br>• Lacks clear outline of what to do with documents | • Too depressing, harsh, and/or focused on end-of-life<br>• Videos were too simple, not diverse, too "childish"<br>• Needed instructions on next steps for advance directives<br>**Formatting**<br><br>• Questions were difficult to interact with<br>• Not easy to find specific features of the app<br>• Unclear documents were auto-filling from questions<br>**Functionality**<br><br>• App would timeout with no warning<br>• Needed improvements (e.g. documents section would not open in app, unable to upload advance directives) |

### 3.3.3. Experts

For content, experts indicated that overall PACT had good questions to consider for ACP but expressed that some questions were worded too negatively (e.g. too focused on dying). One provider described "*Patients will come away with the feeling that they're dying*" (Expert 204). For format, they found the website intuitive but noted some improvements that could make it easier to navigate (e.g., auto advance to next question, include section headings). They noted, "*Add links to complete the documents discussed in each section. It would be frustrating for patients to learn about them and not have access to them*" (Expert 303). For functionality, they liked the auto-fill feature of ACP questions and the ability to share with loved ones, but they noted certain features were unclear (e.g., who has access to patients' answered questions). They suggested changes to content including focusing more on planning, not 'end-of-

**Table 5**
Suggestions for changes to the website.

| Patients | Caregivers | Experts | Overall/Combined |
|---|---|---|---|
| **Content** | **Content** | **Content** | **Content** |
| • Provide dialogue guidance for conversations around ACP<br>• Diversify video participants<br>• Replace videos with PowerPoint slides<br>• Expand focus to include end-of-life healthcare, palliative care, financial health<br>• Provide more guidance and clarification about collaborators<br>• Provide examples/clinical scenarios for questions<br>• Make wishes section clearer and provide more guidance or remove<br>• Add a 'worries' section<br>**Formatting**<br><br>• Arrange by topics (instead of sections)<br>• Enlarge font<br>• Add more images to liven it up<br>• Reiterate that you can click on questions to access resources<br>• Reduce the number of questions (e.g. auto-advance feature)<br>**Functionality**<br><br>• Expand document offerings/functionality (e.g. option to upload previously completed advance directive documents)<br>• Clarify that answers are being populated into a living will | • Make questions more positive<br>• Clarify the term 'collaborator' or change to 'loved one'<br>• Add additional information/resources<br>• Add instructions on next steps after filling out documents<br>• Provide a summary sheet of all documents needed<br>**Formatting**<br><br>• Enlarge font<br>• Add a time estimate or progress bar<br>• Make resources section first<br>**Functionality**<br><br>• Add ability to communicate with medical team<br>• Allow collaborators to add their phone number | • Focus website more on planning not 'end of life'<br>• Use clinical scenarios rather than value statements<br>• Add links to relevant published resources<br>• Simplify questions and question flow<br>• Provide more explanations/instructions of documents<br>• Consider removing 'Death with Dignity' section<br>• Diversify and simplify videos<br>• Add Physician Orders for Life Sustaining Treatment (POLST) and other documents<br>**Formatting**<br><br>• Enlarge font<br>• Add more infographics<br>• Streamline to reduce number of external links<br>• Add closed captions in videos<br>• Simplify questions and question flow<br>• Share all questions with collaborators rather than individual items<br>**Functionality**<br><br>• Allow for upload of advance directives<br>• Add meeting invite to scheduler<br>• Add feature that will auto-populate clinic contact information | • Focus more on planning and less on end-of-life<br>• Provide examples/clinical scenarios to clarify questions<br>• Add a 'worries' section to wishes<br>• Provide more information about who to invite and change wording (e.g. collaborator to loved one)<br>• Improve videos (e.g. diversify participants, make less cartoonish)<br>• Add summary sheet of documents needed<br>• Add resources for caregivers<br>• Add resources/external links related to advance care planning<br>**Formatting**<br><br>• Enlarge font<br>• Include more images/infographics<br>• Add a time estimate or progress bar<br>• Make functions within sections clearer<br>• Reduce redundancies and number of questions<br>**Functionality**<br><br>• Allow for upload of current documents<br>• Add ability to share completed documents with others |

life' and including more information (e.g., explanations of documents, links to relevant published resources), formatting (e.g., add more infographics), and functionality (e.g., allow for upload of advance directives).

### 3.3.4. Overall/combined

Taken together, patients, informal caregivers, and experts appreciated learning more about ACP but also felt that it could be an emotionally challenging point of conversation. They found the website easy to use but indicated that the formatting of the website, and the questions section specifically, could be improved (e.g., questions were difficult to interact with/answer). In terms of functionality, they appreciated being able to add loved ones to keep people involved and the auto-fill feature of documents but noted some desired improvements around these features (e.g., ability to upload advance directives).

### 3.3.5. Revisions to the website based on user feedback

The study team and web developers refined the PACT prototype based on patient, informal caregiver, and expert feedback. The study team included revised the general content (e.g., provide examples/clinical scenarios to clarify questions), formatting (e.g., make clearer who patients are sharing information with and what information they are sharing, provide instructions on how to complete Ads), and functionality (e.g., make questions auto-advance and more streamlined, clarify that question answers auto-populate documents). To specifically address the emotionally challenging nature of the ACP process, the study team created a tailored video in collaboration with an expert in palliative care and oncology discussing how to think about ACP when facing a serious illness. Additional changes made by the developers included formatting (e.g., make font bigger, add more images where possible) and functionality around the use of documents and features of the website (e.g., add ability to share completed documents with others, make the referral code link to the 'clinical team' rather than physician).

## 4. Discussion and conclusion

### 4.1. Discussion

Study findings support the preliminary usability and acceptability of the PACT website for patients with advanced cancer. Individual patient, informal caregiver, and overall mean usability scores exceeded the accepted cut-off value. For acceptability, patients mean acceptability score was right below the cutoff value and the mean informal caregiver acceptability score exceeded the cutoff. Patients, informal caregivers, and experts appreciated the ACP content and valued the opportunity to include loved ones in the ACP process.

Patients and caregivers in our study sought more information and clarification about ACP, and in particular dialogue guidance for conversations about ACP and next steps after filling out ACP documents. Patients with advanced cancer often perceive limited access to psychosocial services for ongoing conversations about prognosis and future care [38], which may limit their ability to engage in ACP conversations. Furthermore, ACP discussions may occur late in the care trajectory if left until a palliative care referral. Definitive tools and resources that support ACP can help ensure these conversations occur in a timely manner [38]. Integration of tools such as Physician Orders for Life Sustaining Treatment (POLSTs), as recommended by some experts involved in this study, may help to ensure that treatment preferences are met, especially among those lacking the knowledge or connections that facilitate the use of more traditional ACP tools [39].

Consistent with emerging research supporting the importance of family involvement in ACP and its potential role in enhancing individuals' willingness to progress in the ACP process [24], patients noted that the PACT website would aid in communication preferences of ACP to loved ones, caregivers noted that there was value added in including loved ones, and experts said it was nice to have the ability to

add family members. Family members frequently report wanting more information about patients' end of life care preferences to serve as surrogate decision-makers [40]. Most patients with advanced cancer report having healthy, supportive social relationships which are associated with higher quality of life [41]. Informing patients about how to choose and engage these supportive loved ones into the ACP process could significantly reduce family conflicts at end of life, thus increasing rates of goal-concordant end of life care. Whether family involvement contributes to goal-concordant care will be studied in future trials of PACT.

### 4.2. Strengths and limitations

This study helps to inform the evidence-base for interventions targeting ACP among patients with advanced cancer. Application of the "shared mind" framework in intervention design supports empirically based features in the PACT website to meet patients' reported need to incorporate loved ones into the ACP decision-making process. Inclusion of patient, informal caregiver, and expert perspectives with a user-centered design approach offers unique insights and helps to optimize the website features and design, yet the small sample size limits the generalizability of these findings. In future testing of the PACT website, we will also include assessments of patients' health literacy and digital literacy to ensure accessibility for those with limited health literacy and lower digital health literacy [42,43]. The PACT website is currently in English only, limiting its generalizability and reach both in terms of language but also in its ability to reach diverse racial and ethnic groups. Consistent with this, the sample was limited in demographic characteristics such as race and ethnicity, also limiting generalizability.

Future research aims to develop and tailor PACT to be available in multiple languages (e.g., Spanish) to ensure broader reach to a diverse patient population. Given that racial and ethnic differences in engagement in ACP may contribute to disparities in end-of-life care [44,45], this is critically important to consider in the future development of PACT as a tool to improve engagement in ACP. To enhance recruitment of minoritized groups in future studies, we will utilize provider referral and community-based outreach. We will culturally tailor recruitment materials by aligning recruitment messaging with language preferences and motivations for study participation [46]. We will partner with our Office of Community Outreach and Engagement to promote the PACT website at health fairs and other community events. As future iterations of PACT include additional languages, we hope to host workshops and training sessions in multiple languages to familiarize patients and informal caregivers with the PACT website. We envision that the PACT website could be shared by peers in the cancer community and clinicians alike. Additionally, future research aims to test the dissemination and implementation efforts of the PACT website.

### 4.3. Innovation

We utilized a novel application of the shared mind framework in developing PACT. This framework notes that individuals tend to make major decisions such as those around medical treatment with the support of feedback from loved ones. Specifically, we applied the shared mind framework to ACP in order to support patients with advanced cancer in engaging their loved ones in the ACP process [14]. This novel website provides comprehensive information about ACP and enables patients to reflect upon, design, and engage with the social environment of their ACP processes.

An understudied barrier to engagement in ACP that we also sought to address in the design of PACT is the emotionally challenging nature of ACP. We developed tailored support resources for patients and informal caregivers, such as a video which includes an oncologist discussing how to think about ACP when facing a serious illness, to address the emotionally challenging nature of this context. Additionally, the original design of this study (including future trials) is to include a social worker interventionist to oversee patients' and informal caregivers' use of the

website. This will allow them to address any resulting distress and help mediate any potential family conflicts that may arise.

### 4.4. Conclusions

Study findings support the preliminary usability and acceptability of the PACT website for patients with advanced cancer. The PACT website addresses a critical gap in ACP interventions by acknowledging ACP as a social, emotional, and relational decision-making process. Study findings will be used to inform a modified prototype of the PACT website that is interactive and ready for field testing with patients with advanced cancer and their loved ones.

**Ethics approval**

This study was approved by the Fred Hutchinson Cancer Center Institutional Review Board, the Weill Cornell Medicine Institutional Review Board, the Mt. Sinai Institutional Review Board, and the BRANY Institutional Review Board.

**Patient consent**

Informed written consent was obtained from all study participants.

**CRediT authorship contribution statement**

**Casey A. Walsh:** Conceptualization, Writing – original draft, Writing – review & editing. **Sarah J. Miller:** Investigation, Supervision, Writing – review & editing. **Cardinale B. Smith:** Investigation, Writing – review & editing. **Holly G. Prigerson:** Conceptualization, Investigation, Writing – review & editing. **Daniel McFarland:** Investigation, Writing – review & editing. **Sarah Yarborough:** Data curation, Formal analysis. **Claudia De Los Santos:** Project administration, Writing – review & editing. **Robert Thomas:** Project administration, Writing – review & editing. **Sara J. Czaja:** Investigation, Writing – review & editing. **Arindam RoyChoudhury:** Formal analysis, Investigation, Writing – review & editing. **Eloise Chapman-Davis:** Investigation, Writing – review & editing. **Mark Lachs:** Investigation, Writing – review & editing. **Megan J. Shen:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Resources, Supervision, Writing – original draft, Writing – review & editing.

**Declaration of Competing Interest**

The authors declare no conflicts of interest.

**Data availability**

Data are available upon reasonable request to the principal investigator.

**Appendix A. Supplementary data**

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pecinn.2023.100245.

# References

[1] Garrido MM, Balboni TA, Maciejewski PK, Bao Y, Prigerson HG. Quality of life and cost of care at the end of life: the role of advance directives. J Pain Symptom Manage 2015;49(5):828–35.

[2] Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. Bmj. 2010;340:c1345.

[3] Goswami P. Advance care planning and end-of-life communications: practical tips for oncology advanced practitioners. J Adv Pract Oncol 2021;12(1):89–95.

[4] Sudore RL, Lum HD, You JJ, et al. Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. J Pain Symptom Manage 2017;53(5):821–32. e821.

[5] Fleuren N, Depla MFIA, Janssen DJA, Huisman M, Hertogh CMPM. Underlying goals of advance care planning (ACP): a qualitative analysis of the literature. BMC Palliat Care 2020;19(1):27.

[6] Bestvina CM, Polite BN. Implementation of advance care planning in oncology: a review of the literature. J Oncol Pract 2017;13(10):657–62.

[7] Dans M, Kutner JS, Agarwal R, et al. NCCN guidelines® insights: palliative care, version 2.2021. J Natl Compr Canc Netw 2021;19(7):780–8.

[8] Berkowitz CM, Wolf SP, Troy J, Kamal AH. Characteristics of advance care planning in patients with cancer referred to palliative care. JCO Oncol Pract 2021; 17(2):e94–100.

[9] McMahan RD, Tellez I, Sudore RL. Deconstructing the complexities of advance care planning outcomes: What do we know and Where do we go? A scoping review. J Am Geriatr Soc 2021;69(1):234–44.

[10] Malhotra C, Shafiq M, Batcagan-Abueg APM. What is the evidence for efficacy of advance care planning in improving patient outcomes? A systematic review of randomised controlled trials. BMJ Open 2022;12(7):e060201.

[11] Falzarano F, Prigerson HG, Maciejewski PK. The role of advance care planning in Cancer patient and caregiver grief resolution: helpful or harmful? Cancers (Basel) 2021;13(8).

[12] Schubart JR, Levi BH, Bain MM, Farace E, Green MJ. Advance care planning among patients with advanced Cancer. J Oncol Pract 2019;15(1):e65–73.

[13] Spelten ER, Geerse O, van Vuuren J, et al. Factors influencing the engagement of cancer patients with advance care planning: a scoping review. Eur J Cancer Care (Engl) 2019;28(3):e13091.

[14] Epstein RM, Street Jr RL. Shared mind: communication, decision making, and autonomy in serious illness. Ann Fam Med 2011;9(5):454–61.

[15] Johnson S, Butow P, Kerridge I, Tattersall M. Advance care planning for cancer patients: a systematic review of perceptions and experiences of patients, families, and healthcare providers. Psycho-oncology. 2016;25(4):362–86.

[16] Singer PA, Martin DK, Lavery JV, Thiel EC, Kelner M, Mendelssohn DC. Reconceptualizing advance care planning from the patient's perspective. Arch Intern Med 1998;158(8):879–84.

[17] Winzelberg GS, Hanson LC, Tulsky JA. Beyond autonomy: diversifying end-of-life decision-making approaches to serve patients and families. J Am Geriatr Soc 2005; 53(6):1046–50.

[18] Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA. 2000;284(19):2476–82.

[19] Steinhauser KE, Christakis NA, Clipp EC, et al. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. J Pain Symptom Manage 2001;22(3):727–37.

[20] Michael N, O'Callaghan C, Clayton J, et al. Understanding how cancer patients actualise, relinquish, and reject advance care planning: implications for practice. Support Care Cancer 2013;21(8):2195–205.

[21] Fadem S. Investigating and supporting patient and caregiver Sensemaking in complex medical decisions using participatory design. MDM Pol Pract 2023;8(1). 23814683231164988.

[22] Siegel CA. Shared decision making in inflammatory bowel disease: helping patients understand the tradeoffs between treatment options. Gut. 2012;61(3):459–65.

[23] Epstein RM, Gramling RE. What is shared in shared decision making? Complex decisions when the evidence is unclear. Med Care Res Rev 2013;70(1 Suppl): 94s–112s.

[24] Kishino M, Ellis-Smith C, Afolabi O, Koffman J. Family involvement in advance care planning for people living with advanced cancer: a systematic mixed-methods review. Palliat Med 2022;36(3):462–77.

[25] Sudore RL, Boscardin J, Feuz MA, McMahan RD, Katen MT, Barnes DE. Effect of the PREPARE website vs an easy-to-read advance directive on advance care planning documentation and engagement among veterans: a randomized clinical trial. JAMA Intern Med 2017;177(8):1102–9.

[26] Tariman JD, Berry DL, Halpenny B, Wolpin S, Schepp K. Validation and testing of the acceptability E-scale for web-based patient-reported outcomes in cancer care. Appl Nurs Res 2011;24(1):53–8.

[27] Usability.gov. System Usability Scale. https://www.usability.gov/how-to-and-tools /methods/system-usability-scale.html; 2023.

[28] Czajkowski SM, Powell LH, Adler N, et al. From ideas to efficacy: the ORBIT model for developing behavioral treatments for chronic diseases. Health Psychol 2015;34 (10):971–82.

[29] Willis G. Cognitive interviewing. In: Thousand Oaks, California; 2005. https: //methods.sagepub.com/book/cognitive-interviewing [Accessed 2023/06/14].

[30] Willis GB, Royston P, Bercini D. The use of verbal report methods in the development and testing of survey questionnaires. Appl Cognit Psychol 1991;5(3): 251–67.

[31] Czaja SJ, Rogers WA, Fisk AD, Charness N, Sharit J. Designing for older adults: Principles and creative human factors approaches. CRC Press; 2009.

[32] Norman DA, Draper SW. User Centered System Design: New Perspectives on Human-Computer Interaction. 1988.

[33] Bangor A, Kortum PT, Miller JT. An empirical evaluation of the system usability scale. Int J Human–Comp Interact 2008;24(6):574–94.

[34] Bangor A, Kortum PT. Determining What individual SUS scores mean: adding an adjective rating scale. J Usabil Stud 2009;4(3):114–23.

[35] Sandelowski M. What's in a name? Qualitative description revisited. Res. Nurs. Health 2010 Feb;33(1):77–84.

[36] Sandelowski M. Whatever happened to qualitative description? Res Nurs Health 2000;23(4):334–40.

[37] Sullivan-Bolyai S, Bova C, Harper D. Developing and refining interventions in persons with health disparities: the use of qualitative description. Nurs Outlook 2005;53(3):127–33.

[38] Toguri JT, Grant-Nunn L, Urquhart R. Views of advanced cancer patients, families, and oncologists on initiating and engaging in advance care planning: a qualitative study. BMC Palliat Care 2020;19(1):150.

[39] Carr D, Luth EA. Advance care planning: contemporary issues and future directions. Innov Aging 2017;1(1).

[40] Rennke S, Yuan P, Monash B, et al. The SDM 3 circle model: a literature synthesis and adaptation for shared decision making in the hospital. J Hosp Med 2017;12 (12):1001–8.

[41] Breen CM, Abernethy AP, Abbott KH, Tulsky JA. Conflict associated with decisions to limit life-sustaining treatment in intensive care units. J Gen Intern Med 2001;16 (5):283–9.

[42] Nouri SS, Barnes DE, Volow AM, et al. Health literacy matters more than experience for advance care planning knowledge among older adults. J Am Geriatr Soc 2019;67(10):2151–6.

[43] Faux-Nightingale A, Philp F, Chadwick D, Singh B, Pandyan A. Available tools to evaluate digital health literacy and engagement with eHealth resources: a scoping review. Heliyon. 2022;8(8):e10380.

[44] Lenko R, Voepel-Lewis T, Robinson-Lane SG, Silveira MJ, Hoffman GJ. Racial and ethnic differences in informal and formal advance care planning among U.S. older adults. J Aging Health 2022;34(9–10):1281–90.

[45] Crooks J, Trotter S, Clarke G. How does ethnicity affect presence of advance care planning in care records for individuals with advanced disease? A mixed-methods systematic review. BMC Palliat Care 2023;22(1):43.

[46] Cunningham-Erves J, Kusnoor SV, Villalta-Gil V, et al. Development and pilot implementation of guidelines for culturally tailored research recruitment materials for African Americans and Latinos. BMC Med Res Methodol 2022;22(1):248.