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Tailored Messages About Research Participation: Using an Interactive Information Aid to Improve Study Recruitment

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Abstract

After a diagnosis of cancer (or other serious disease), patients may be asked to consider joining a clinical trial. Because most people are unfamiliar with the scientific concepts that are necessary to the provision of meaningful informed consent, patient education is necessary. Increasing knowledge alone is not sufficient; understanding how clinical trial participation aligns with personal circumstances and knowledge is central to the decision-making process. In this study, 302 cancer patients and survivors evaluated an interactive information aid (IA) designed to inform their decision to join a research study or clinical trial by providing tailored information to patients' responses to questions pertaining to seven key barriers or facilitators of clinical trial participation. The development of the IA was done with input from the authors' Clinical Translational Science Institute; linked components of the IA were vetted by members and leaders of the institution's NCI-designated comprehensive cancer center. Results of the study indicated that the information aid was successful in significantly reducing fears and increasing knowledge, attitudes, perceived behavioral control, and behavioral intentions about research participation relative to a control condition. Thus, an interactive information aid that provides information that is responsive to patients' values, knowledge, and personal circumstances can help patients to be better prepared to consider a decision about research participation.

Keywords Information aids · Cancer communication · Clinical trials

One of the most devastating pieces of news a person can receive is a diagnosis of a potentially fatal disease, either for themselves or a loved one. As part of treatment decision-making, patients may be asked to consider joining a clinical trial; there is even greater pressure when treatment must begin immediately. At a time when patients and their families feel overwhelmed with information about a disease and the realities of a specific prognosis, they are frequently asked to make a treatment decision that requires a fundamental understanding of difficult scientific concepts including randomization, the role of placebos, and how patients are protected when they participate in research studies. In addition, patients and their families must learn about the risks, potential benefits, and the demands of the specific clinical trials for which a patient might be eligible.

Most of the responsibility for educating patients about clinical trial participation falls on clinical research professionals. The success of clinical research staff in securing meaningful informed consent for research participation depends on a wide variety of factors [1] including the quality of verbal and nonverbal communication behaviors [2–7]. Central to good communication practices that lead to more informed decisions are clear communication [3, 8–10] that avoids overloading patients with excessive detail [11], as well as nonverbal communication that supports comprehension of complex topics, including the appropriate use of eye contact to direct attention and emphasize key points, smiling to convey personal warmth and acceptance, and the appropriate use of physical touch to communicate compassion [4]. Both verbal and nonverbal

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communication "best practices" lead to the development of a relationship between clinical research professionals and patients which in turn provides patients with the motivation needed to learn about clinical trial participation opportunities [6].

However, one-on-one communication with patients is time-intensive. Furthermore, clinical research professionals vary in their ability to communicate well about concepts that patients need to understand thoroughly before consenting to research participation [12]. Well-designed tools that can alleviate some of the demands on clinical research professionals' time while also enhancing patients' understanding of research participation and improve the decision-making process are likely to be welcome.

Researchers who focus on risk and decision-making have developed a variety of decision aids that are designed to help patients and their families. In the context of clinical trial participation, most decision aids provide information that allow patients to choose a specific medical treatment or make a choice about whether to screen for a particular disease in accordance with their values and preferences [13]. A high-quality decision aid has a number of key features: sufficient detail about options, unbiased and understandable presentation of probabilities, values clarification exercises, structured guidance in deliberation, balanced presentation of options, up-to-date evidence with references, disclosed conflicts of interest, and the use of plain language [14]. A recent Cochrane review concludes that decision aids that help patients decide whether to participate in clinical trials for disease screening or medical treatment produce favorable outcomes, including improved decision quality, increased knowledge, more accurate perceptions of risk of participating in research, decisions that are more in accordance with personal values, and reduced decisional conflict [15].

Interestingly, there are other types of interventions that do not meet the criteria for a decision aid but are nonetheless designed to support decision-making by patients, including videos, informational brochures, websites, data visualizations, and animations [16]. Interventions that do not meet the key criteria for decision aids are better termed "information aids" (IAs). Like decision aids, these information aids can be successful in improving knowledge and self-efficacy, and help patients feel prepared to make a decision, and reduce patient anxiety [15, 17, 18]. Importantly, research has shown that information aids that improve patients' sense of self-efficacy and preparation for making decisions can result in increases in actual clinical trial participation [19, 20].

There are particular message features of information aids used in interventions centered on research participation that are associated with effectiveness. These message features include the presentation of information in lay language [10–11, 18, 21, simplicity of design [21], the use of visuals [18, 21], and the incorporation of interactivity [18, 21]. While information aids do not rise to the standards of decision aids (as established by bioethicists), they can also avoid some of the potential pitfalls of decision aids. For example, DAs can be lengthy, and the resulting output generally summarizes the information patients provide rather than provide tangible assistance in making decisions. In situations where patients are experiencing information overload, the more focused approach that information aids can provide may actually be more helpful. These findings and principles guided the development of our research participation information aid and form the rationale for the following hypotheses:

- H1: Knowledge about research participation will improve among participants who use an interactive informational aid.
- H2: Attitudes about research participation will improve among participants who use an interactive informational aid.
- H3: Fears and worries about research participation will decrease among participants who use an interactive informational aid.
- H4: Perceived behavioral control will increase among participants who use an interactive information aid.
- H5: Intentions to participate in a research study will increase among participants who use an interactive informational aid.

Methods

Procedures

A Qualtrics panel of cancer patients and survivors were asked to complete a pretest survey and then randomly assigned to either an online information aid relative to an online information aid focused on flu vaccine. After interacting with the information aid, participants completed a posttest. All participants were required to be over the age of 18, have a cancer diagnosis at any point in their lives, and be living in the USA at the time of study participation.

Participants

A total of 460 individuals participated in a parent study of message design strategies for clinical trial information aids; 302 participants in two conditions of this quasi-experiment were used to test the hypotheses advanced for this study. Approximately 73% of our sample was female; the majority (86.3%) were white. The age of participants ranged from 18 to 87, with a mean of 56 years ($SD = 14$ years). Median household income was reported as $40,000 USD/year, with a range of $0 to $400,000. Almost 50% of the sample were stage I or

stage II at the time of diagnosis. Additional demographic information about participants appears in Table 1.

Measures

Knowledge Knowledge about clinical trial participation was evaluated using a 9-item assessment developed by Cameron and colleagues [22]. Example items include "In a clinical trial, a patient will always get the experimental drug" and "Doctors personally receive money if I join a clinical trial." Participants indicated whether they thought each statement was true, false, or that they did not know. Correct responses were coded as "1." Mean score on the scale was 0.51.

Attitudes Attitudes toward clinical trial participation were assessed with a 4-item scale that was adapted from Jenkins and Fallowfield [23]. Items included "I think clinical trials offer the best treatment available for cancer" and "I feel that others with my illness will benefit from the results of a clinical trial." The scale showed good reliability, $M = 4.81$, $SD = 1.01$, Cronbach's alpha = 0.80.

Table 1 Participant characteristics

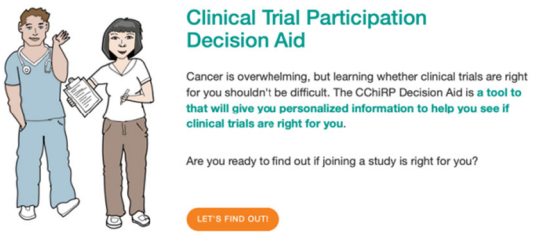
Variable	Category	*N* (%)
Race/ethnicity		
	Hispanic	18 (3.9%)
	Non-Hispanic	435 (94.6%)
	Prefer not to say	7 (1.5%)
	African-American	34 (7.4%)
	Asian or Pacific Islander	4 (0.9%)
	Hispanic/Latinx	8 (1.7%)
	White	397 (86.3%)
	Multiracial	3 (0.7%)
	Other/prefer not to say	9 (2.0%)
Sex		
	Female	336 (73%)
	Male	124 (27%)
Education level		
	Some high school	11 (2.4%)
	High school	79 (17.2%
	Some college	168 (36.5%)
	College	127 (27.6%)
	Master's degree	63 (13.7%)
	Doctoral degree	3 (0.7%)
	Professional degree	4 (0.9%)
	Other	5 (1.1%)
Cancer stage at diagnosis		
	0	36 (7.8%)
	I	127 (27.6%)
	II	97 (21.1%)
	III	62 (13.5%)
	IV	40 (8.7%)
	Not sure/N/A	98 (21.3%)

Fears and Worries Ten items from Manne et al.'s Clinical Trials Barriers Scale [19] were selected to measure anxiety about research participation. Sample items include "I think that being on a clinical trial is dangerous" and "I am afraid that taking part in a clinical trial would make me sicker than I am now." The scale was reliable, $M = 3.90$, $SD = 1.28$, Cronbach's alpha = 0.95.

Perceived Behavioral Control Two items adapted from Umphrey [24] were used to assess perceived behavioral control: "I am confident in my ability to enroll in a clinical trial" and "I feel well-informed about how to enroll in a clinical trial." The scale was reliable, $M = 5.39$, $SD = 1.34$, Cronbach's alpha = 0.91.

Intention to join a study was assessed using one item from Cameron et al. [22]: "If I had the option, I would definitely consider joining a clinical trial") as well as an additional item developed for this study: "If a cancer study were offered to me, I would agree to take part in it." The scale was reliable, $M = 4.84$, $SD = 0.1.45$, Cronbach's alpha = 0.86.

Stimuli



The Culture Change in Research Participation (CChiRP) Information Aid includes tailored messages in response to a set of seven questions (plus demographics), based on the literature on the most significant barriers to clinical trial participation as well as data from a series of formative research studies. These include whether a patient has health insurance, a patient's level of trust in cancer doctors and researchers, and whether a patient tends to have a strong treatment preference for either established treatments or the newest treatments. Multiple iterations of the developed scripts, branching logics, and interactive interface were reviewed by leadership of the authors' Clinical Translational Science Institute (CTSI), oncologists at the institution's NCI-designated comprehensive cancer center, as well as clinical research coordinators who recruit patients for clinical trials. The branching logic for each participant's response provides specific messages that acknowledge the validity of patients' attitudes and available

resources, provides a frank assessment of whether or not these circumstances are compatible with study participation, and then provides additional information that is relevant to patient concerns. For example, the IA cautions patients without insurance that clinical trial participation is often more difficult, but that trials exist that offer coverage of all treatment costs. (The actual health care system implementation of the IA, which is in progress, will refer patients interested in a clinical trial to a patient navigator for assistance.) At the end of the set of tailored messages, the CChiRP IA offers a short report with specific details about participants' (in)compatibilities between their specific circumstances and values and the prospect of research participation. The IA can be viewed at http://cancerresearch.miami/decision-aid/ (please see Appendix for sample screenshots of customized text responses and the summary report.)

A *Flu Vaccine Interactive Informational Aid* was developed by healthwise.org (https://www.healthwise.net/ohridecisionaid/Content/StdDocument.aspx?DOCHWID=tb1913) and served as the control condition for this study. This decision aid was of similar length as the CChiRP information aid, focused on a common health topic of general interest, and prepared participants to make a decision that impacted their own health (or the health of a family member or loved one).

Results

The first hypothesis predicted that participants who interacted with the interactive CChiRP information aid would be more knowledgeable about research participation than those who were assigned to the control condition. An ANCOVA was performed to assess the impact of the information aid on participants' knowledge about research participation, controlling for pretest knowledge scores. Participants in the intervention condition did not have significantly better knowledge scores ($M = 0.50$, $SD = 0.18$) than participants in the control condition, $M = 0.52$, $SD = .18$, $F(1, 301) = 2.12$, $p = 0.15$. Follow-up analyses were performed to see whether extraneous items in the 9-item knowledge scale created "noise" that concealed the impact of the intervention. While pretest scores on individual items did not differ significantly, posttest scores on three items showed significant differences between the intervention and control stimuli. These include "A standard treatment will be withheld if a placebo is given" ($t(301) = 2.27$, $p = 0.02$); "Once I sign a consent form, I must do everything in the clinical trial until my doctor tells me I'm done" ($t(301) = 1.93$, $p = 0.05$); and "Doctors personally receive money if I join a clinical trial" ($t(301) = 2.90$, $p = 0.004$). One other item showed a marginally significant higher score in the intervention condition: "Clinical trials of experimental drugs are monitored for safety by the government" ($t(301) = 1.71$, $p = 0.09$). New pretest and posttest knowledge scores were computed based on these items, and the ANCOVA was run again. Factoring out pretest scores, participants in the CChiRP intervention condition ($M = 1.80$, $SD = 1.21$) scored higher than control participants ($M = 1.32$, $SD = 1.04$), $F = 17.24$, $p < 0.001$, partial $\eta^2 = 0.06$. These results provide partial support for hypothesis 1.

The second hypothesis predicted that the interactive information aid would result in more favorable attitudes toward research participation. As expected, after controlling for pretest attitude scores, the intervention was effective in improving attitudes toward research participation ($M = 4.66$, $SD = 0.84$) relative to the control condition ($M = 4.28$, $SD = 0.90$), $F(1, 300) = 426.90$, $p < 0.001$, partial $\eta^2 = 0.15$, supporting hypothesis 2.

The third hypothesis predicted that fears and worries about research participation would be less among participants in the CChiRP condition than in the control. An ANCOVA controlling for pretest scores showed that participants who interacted with the informational aid reported less anxiety about research participation ($M = 3.69$, $SD = 1.32$) relative to the control ($M = 4.03$, $SD = 1.34$), $F(1, 301) = 22.76$, $p < 0.001$, partial $\eta^2 = 0.07$. These results support hypothesis 3.

The fourth hypothesis predicted that participants in the intervention condition would report greater perceived behavioral control related to research participation. As predicted, an ANCOVA controlling for pretest scores demonstrated that the intervention improved participants' perceptions of behavioral control about research participation ($M = 5.57$, $SD = 1.10$) significantly more than the control ($M = 5.17$, $SD = 1.12$), $F(1, 302) = 14.25$, $p < 0.001$, partial $\eta^2 = .05$. These results support hypothesis 4.

The fifth hypothesis predicted that participants who used the CChiRP information aid would be more likely to report future intentions to participate in a research study. Indeed, participants who used the interactive informational aid reported greater intentions to participate in research ($M = 4.94$, $SD = 1.36$) relative to the control ($M = 4.66$, $SD = 1.56$), $F(1, 302) = 11.05$, $p = 0.001$, partial $\eta^2 = 0.04$. Thus, hypothesis 5 was supported.

Discussion

Our interactive information aid was designed to help patients and their families learn about key concepts related to research participation and to get acquainted with the most common issues that support or inhibit participation. In essence, the information aid is intended to help individuals prepare for interactions with physicians and/or clinical research professionals where they would be approached with the opportunity to participate in a research study. The interactive information aid does not present information about any specific study

which would involve an informed consent process. The information aid, then, helps patients to be better prepared to consider a decision about research participation at a more abstract level.

This study demonstrates the value of using an interactive information aid to address patients' concerns about participation in clinical trials and research studies. Strong effect sizes indicate that the CChiRP information aid increases favorable attitudes toward research participation, reduces anxiety about research participation, increases perceived behavioral control (aka self-efficacy), and increases intentions to participate in research studies in the future. However, the nonsignificant difference between scores on the original knowledge measure among participants in the intervention versus control condition are quite mysterious in light of the impressive magnitude of effects on other dependent measures (attitudes, fears and worries, perceived behavioral control, and behavioral intentions). A closer examination of individual knowledge items revealed that significant changes in three items (with a fourth item being marginally significant) were masked by unchanged scores on the other five items. There are two possibilities for this. First, it is possible that not all knowledge about clinical trial participation matters to cancer patients and that their attitudes, intentions, and fears and worries are related to just a few key points of knowledge. The second possibility is that the information aid only addressed certain facts about research participation; it is not reasonable to expect the information aid to shift knowledge about facts that were not discussed. Future research should insure that measures used to evaluate the effect of an intervention are matched to the content of the intervention. Otherwise, the measure cannot be deemed to be a valid or fair assessment.

While this study demonstrates the efficacy of the information aid, it is not clear what is driving these effects. Future research should examine whether interactivity, for example, creates a more positive response to information, perhaps by creating greater cognitive engagement. Nonetheless, we believe that the findings from the current study, when taken together with results from other studies point to some key principles that can be applied to the development of future information aids. Information aids should be patient-centered (i.e., developed through formative research with members of the targeted population) and focused on factors that actually matter to the patient and their family members. Additionally, aids should use simple language, incorporate supporting visual information, be engaging, and be as brief as possible in order to avoid information overload. The ultimate goal of an information aid should not simply be to inform patients, but rather should provide tangible assistance in reducing anxiety, prepare patients for an in-depth discussion with a physician or clinical research coordinator, and even provide useful insights tailored to the patient about whether research participation is a good fit with their values and goals.

An additional limitation of the study is the use of behavioral intention as a key-dependent measure. Actual enrollment in a research study is most definitely not the same as being willing to enroll, just as self-reported behavior is not as reliable as verified behavior. Prospectively, assigning patients randomly to conditions and then assessing the rates at which patients in each group actually enroll in research studies and clinical trials would be the best way of evaluating impact of messages. This requires a significant commitment of resources at the level of a health care system, but may ultimately prove to be a worthwhile investment.

Finally, we are concerned about the lack of racial and ethnic diversity in our sample. Over 94% of our respondents were white; given the urgent need for greater diversity among clinical trial participants, it is important that tools designed to address patient concerns are tested by members of diverse populations. Future research should take care to secure more diverse patient populations.

Conclusion

It is our hope that short, simple interactive information aids can serve as a stimulus for discussing research participation. Research participation is extremely low, largely because patients are not offered the opportunity to join a study [25]. Unfortunately, the reality of most health care systems is that there are not enough resources devoted to the hiring and training of clinical research professionals who are generally expected to present research information. An interactive information aid that provides information tailored to patients' own circumstances (such as the one that is described in the current study) would allow patients to receive accurate, consistent information that provides a number of the same benefits of face-to-face discussions with clinical research professionals. By addressing the most common concerns and potential barriers to participation, this type of interactive information aid can prepare patients and their family members for subsequent discussions about specific research studies. Based on the findings from this study, we believe that the provision of information customized to patients' circumstances and preferences will prove to be important features of an intervention. As Woolfall and colleagues state, "Providing trial information that is tailored to what [patients] consider important in making a decision about a clinical trial may improve recruitment practices and ultimately benefit evidence-based…medicine" [26].

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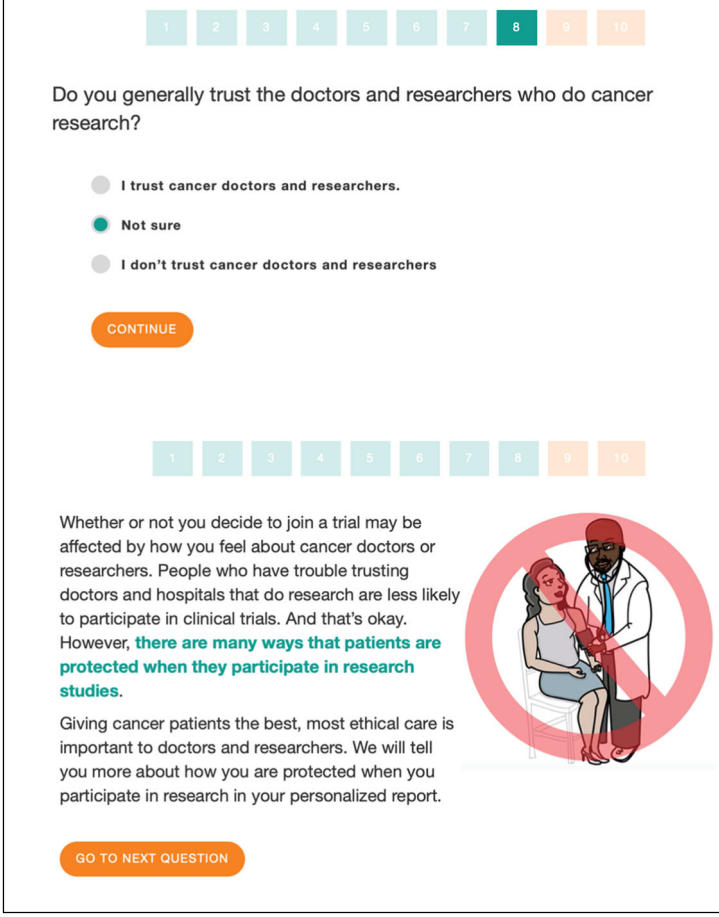
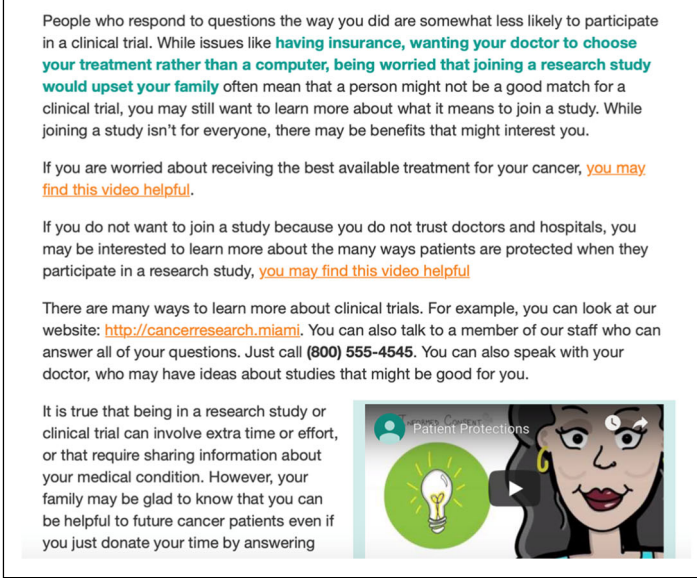
Appendix

Screenshots from clinical trial participation information aid

Sample response to medical mistrust question



Screenshot of summary report



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