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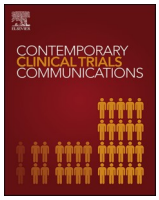

Research paper

Audience segmentation as a strategy for enhancing the use of research registries for recruiting patients into clinical trials

Elizabeth Flood-Grady [a,b,*], Jiawei Liu [c], Samantha R. Paige [a], Donghee Lee [a], David R. Nelson [b], Elizabeth Shenkman [b,d], Deaven Hough [b], Janice L. Krieger [a,b,d,e]

[a] STEM Translational Communication Center, University of Florida, Gainesville, USA
[b] Clinical and Translational Science Institute, University of Florida, Gainesville, USA
[c] School of Journalism and Communication, Jinan University, Guangzhou, People's Republic of China
[d] Department of Health Outcomes & Biomedical Informatics, University of Florida, Gainesville, USA
[e] Department of Advertising, College of Journalism and Communications, University of Florida, Gainesville, USA

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ABSTRACT

Introduction: Health research registries have great potential to increase awareness of research opportunities among diverse patient populations and reduce disparities in clinical trial accrual. However, little research has focused on patients' intentions to participate in clinical trials once they are enrolled in the registry and their intentions to remain in the registry over time.

Methods: Patients ($N = 312$) enrolled in a university-based health research registry (i.e., Consent2Share) in the southeastern region of the US participated in an online survey.

Results: Health research registry knowledge, perceived values, self-efficacy, trust, having chronic health concerns, and consent recall were positively correlated with intentions to remain enrolled in the research registry and participate in future clinical trials. Health research registry consent recall had significant positive associations with registry knowledge, perceived values, trust, registry retention, and participating in future trials.

Conclusion: The process of consenting patients to the health research registry is important for recruitment, registry retention, and participation in future clinical trials. We identified key points of emphasis to expand participation in research registries as a strategy to increase clinical trial enrollment, such as deploying precision messages and tailored interventions.

1. Introduction

Nearly 80% of clinical trials fail to meet accrual goals set forth to establish power for statistical analyses and to avoid study discontinuation [1]. Data suggest that women, racial/ethnic minorities, and older adults are less likely to participate in clinical trials, as compared to their counterparts [2]. Health research registries have great potential to reduce disparities in research accessibility and improve clinical trial accrual [3–5]. By definition, a health research registry is "a systematic collection of a clearly defined set of health and demographic data for patients with specific health characteristics, held in a central database for a predefined purpose" [6]. Research registries enable scientists to quickly identify patient cohorts that meet eligibility criteria for a given study. Once the researcher has gained Institutional Review Board (IRB) approval, research registry participants can be contacted and invited to participate in the clinical trials. Expanding the number and diversity of patients in research registries can increase access and enrollment of diverse patients in clinical research. However, the factors that optimize patients' informed decision-making about research registry enrollment, retention, and participation in subsequent clinical trials remains unknown.

Positive intrinsic value systems and recall of health intervention messages are important to clinical trial recruitment and retention [7–18] and may be associated with research registry recruitment. Drawing from research and theorizing in social psychology, public health, and communication, examples of variables used to measure intrinsic value systems include perceived social values, benefits, barriers, self-efficacy, knowledge, and trust. Perceived benefits and self-efficacy positively

* Corresponding author. University of Florida, STEM Translational Communication Center, College of Journalism and Communications, PO Box 118400, Gainesville, FL, 32611.
E-mail address: efloodgrady@ufl.edu (E. Flood-Grady).

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influence desired behavior changes, while perceived barriers and threat decrease the likelihood of desired behavior changes [7–10]. Trust also plays an important role in clinical trial recruitment. Low perceived trust in healthcare research [11–13], particularly among patients (e.g., mistrust of research, uncomfortable with experimentation), in the protocol (e.g., potential side-effects, trial or treatment has no benefits), and in physicians (e.g., negative effect on doctor-patient relationship), can hinder participation, perpetuating challenges in accrual. However, it remains unknown how participant trust in the healthcare safety monitoring system (e.g., IRB) contributes to clinical trial recruitment.

There are also several important factors that may contribute to clinical trial recruitment for which data are insufficient. The effectiveness of participant knowledge on behavior is mixed [14–17], and it is unclear whether knowledge is a prerequisite of intentional behavior change or not. In addition, though accurate campaign message recall improves public awareness of the health risks [18], little is known about the degree to which consent recall – the extent to which participants remember being recruited (i.e., consenting and enrolling) into the registry – contributes to registry retention and future clinical trial participation.

It is important to explicate the language of science to better engage lay audiences in clinical research [19]. Therefore, a primary goal of this study is to identify translational communication strategies to improve public comprehension and accessibility of information surrounding health research registries and clinical trial recruitment. As an important step to achieving this goal, we investigated how participant's intrinsic value systems (i.e., perceived social values, benefits and barriers to health research, self-efficacy, trust in research, doctors, and the IRB) contribute to their willingness to remain in a university research registry and intentions to participate in future clinical trials. We also examined the relationship between participant's intrinsic value systems and their self-reported chronic health concerns and their consent recall.

2. Methods

2.1. Participants and recruitment

From December 2017 through May 2018, patients (N = 3,400) enrolled in the university research registry, Consent2Share (C2S), were contacted via email and asked to participate in an online survey about research participation. C2S is a voluntary research registry of patients in the health system who are willing to have their medical records flagged as someone who is interested in being contacted about future studies for which they may be eligible to participate [20]. Approximately 47,000 patients were enrolled in C2S when we started recruitment.

All study procedures were approved by the local university institutional review board. Patients who were over the age of 18, enrolled in the C2S registry, and had been seen in one of the family practice clinics were eligible to participate in the study. The study team received a random sample of the names and contact details of 3,400 patients who met the study criteria from the university's Integrated Data Repository (IDR). As requested by the study team, the list of registry patients was stratified by age, race, and sex to increase minority representation in the sample. Prospective participants were recruited via email to participate in the study. Email notifications were automated and sent using Qualtrics secure software. Recruitment emails included information about the study (e.g., study description, eligibility criteria) and a link to the consent form and survey. Interested individuals who responded to the recruitment email clicked on the link within the email message that directed them to the consent form and secure survey. All participants provided consent prior to being directed to the survey.

The survey measures assessed participant's knowledge of the registry, perceptions of research studies (barriers, benefits), self-efficacy, trust in medical research, and willingness to participate in future clinical studies. Participants also provided demographic information and responded to questions about their research experiences.[1] Participants who completed the survey were remunerated with a $10 e-gift card. Prospective participants who did not respond to the original recruitment email were re-contacted via email between two and four times over the next six months with reminders to participate in the survey. Two hundred and eighty-six patient email addresses were invalid (i.e., bounced). Thus, 3,154 eligible patients were contacted and reached via email and asked to participate in the study. Of these patients, 454 participants consented, yielding a recruitment rate of 14.4%. Further inspection of the data revealed that approximately 30% of the patients who consented completed less than 10% of the survey. These participants were removed from the analyses, resulting in our final sample (N = 312).

2.2. Measures

Research registry knowledge. Twelve items from the Quality of Informed Consent scale [21] were adapted to assess participant's knowledge of research registry participation. Items were rated on a three-point scale with response options ranging from *disagree* to *agree*. Higher scores indicated higher levels of research registry knowledge (M = 2.64, SD = .30, α = .76).

Perceived social values of health research studies. Five items from Schuber's personal and social value subscale [22] were used to assess the perceived value toward health research studies (e.g. "People who take part in health research studies are helping all of us fight illnesses"). Items were rated on a five-point Likert scale, with responses ranging from *1 = strongly disagree (SD)* to *5 = strongly agree (SA)*. Higher scores indicated higher perceived value of health research studies (M = 4.24, SD = .65, α = .71).

Perceived benefits to health research participation. Four items from Schuber's personal benefits subscale [22] were adapted to assess participants' perceptions of the benefits to participating in health research studies (e.g., "I'd get improved treatment if I took part in a health research study"). Items were rated on a five-point Likert scale, with responses ranging from *1 = SD* to *5 = SA*. Higher scores indicated higher levels of perceived benefits associated with health research participation (M = 2.76, SD = 1.03, α = .90).

Perceived barriers to health research participation. Three items from Schuber's personal barriers and safety subscale [22] were used to assess the perceived barriers to health research participation (e.g., "Taking part in a health research study is a lot more trouble than just getting the usual care"). Items were rated on a five-point Likert scale, with responses ranging from *1 = SD* to *5 = SA*. Higher scores indicated higher levels of perceived barriers to health research participation (M = 2.18, SD = 1.01, α = .97).

Self-efficacy. Eight items from O'Connor and LeBlanc et al.'s decisional conflict measures [23,24] were adapted to assess participant's perceived self-efficacy with their decision to enroll in the research registry (e.g., "I was aware of the choices I had to participate in Consent2Share"). Items were rated on a five-point Likert scale, with responses ranging from *1 = SD* to *5 = SA*. Higher scores indicated higher levels of self-efficacy among participants (M = 3.97, SD = .84, α = .87).

Trust in the research process. Four items from Hall et al.'s medical trust scale [25] were adapted to assess participant's trust in the research process (e.g., "It would be safe for me to join a health research study"). Items were rated on a five-point Likert scale, with responses ranging from *1 = SD* to *5 = SA*. Higher scores indicated higher levels of trust in the research process (M = 4.06, SD = .82, α = .79).

Trust in the IRB. Four items from Hall et al.'s medical trust scale [25] were adapted to assess participant's trust in the healthcare safety monitoring system (i.e., IRB) (e.g., "IRB who oversee research care only

[1] Full survey available from the first author upon request.

about what is best for each patient"). Items were rated on a five-point Likert scale, with responses ranging from *1 = SD* to *5 = SA*. Higher scores indicated higher levels of trust in the IRB ($M = 3.93$, $SD = .80$, $\alpha = .78$).

Trust in doctors. Four items from Hall et al.'s medical trust scale [25] were used to assess trust in doctors (e.g., "I completely trust doctors who do medical research"). Items were rated on a five-point Likert scale, with responses ranging from *1 = SD* to *5 = SA*. Higher scores indicated higher levels of trust in doctors ($M = 3.94$, $SD = .83$, $\alpha = .82$).

Research registry consent recall. A single item was developed to assess consent recall among participants (i.e., "I remember agreeing to participate in Consent2Share clearly"). This item was rated on a ten-point Likert-type scale, with responses ranging from *1 = I do not remember agreeing to participate* to *10 = I remember agreeing to participate very clearly*. Higher scores indicated greater recall of their enrollment in C2S ($M = 5.96$, $SD = 3.61$).

Inspection of the data during preliminary analyses showed that the data were non-normally distributed and that separating responses into tertiles was the best way to continue with the analysis. In data analysis, participants were categorized into three groups based their consent recall: participants who selected '10′ were placed in the 'clearly remembered enrolling group' (group 1), participants who chose a response between "2–9" were placed in the 'somewhat remembered enrolling group' (group 2), and participants who selected '1,' were placed in the 'Do not remember enrolling group' (group 3).

Willingness to remain in the research registry. A single item developed to assess willingness to remain in the research registry among current participants (i.e., "I would like to remain in this research contact registry"). Items were rated on a 5-point Likert scale, with responses ranging from *1 = SD* to *5 = SA*. Higher scores indicated greater willingness to remain in the registry ($M = 4.25$, $SD = .88$).

Future clinical trial participation. A single item was developed to assess participants' intentions to participate in future studies (i.e., "If contacted again, I will participate in another research study hosted by this research contact registry"). This item was rated on a five-point Likert scale, with responses ranging from *1 = SD* to *5 = SA*. Higher scores indicated greater likelihood of participating in a future study ($M = 4.22$, $SD = .85$).

2.3. Analysis strategy

Data were analyzed using SPSS 25. Pearson correlation tests were used to explore the associations among the intrinsic value systems, consent recall, willingness to remain in the research registry, and intentions to participate in future clinical studies. Two-sample *t* tests were conducted to examine potential differences in these variables among participant's with and without self-reported chronic health conditions. A one-way analysis of variance (ANOVA) was used to examine if differences in consent recall led to more favorable attitudes about research participation, greater registry knowledge and trust, as well as stronger intentions to remain in the research registry and to participate in future clinical trials. Significance for all analyses was set a priori at $p < 0.05$.

3. Results

3.1. Sample characteristics

Participants were 19–80 ($M = 47.3$, $SD = 14.2$) years old, predominantly white ($N = 183$, 61%), and female ($N = 182$, 60.7%). Among respondents, 63% ($N = 182$) identified themselves as having at least one chronic health concern (e.g., cancer, mental illness, diabetes, etc.). See Table 1 for full details on demographic characteristics.

Table 1
Sample characteristics ($N = 312$).

	n	%
Age[a]	47.3(14.2)	
Gender		
Male	118	39.3
Female	182	60.7
Ethnicity		
African Americanrowhead	99	29.7
American Indian/Alaska Native	1	0.3
Asian	2	0.7
Hispanic/Latino	11	0.3
White	183	61.0
Multi-ethnic[b]	20	6.7
Other	4	1.3
Education		
Some high school	4	1.3
High school graduate	23	7.7
Some College credit, but less than 1 year	20	6.7
1 or more years of college, but no degree	37	12.3
Associate degree (e.g., AA, AS)	56	18.7
Bachelor's degree	75	25.0
Master's degree	57	19.0
Professional degree (e.g., MD, DDS, DVM, LLB, JD)	9	3.0
Doctorate degree	19	6.3
Income		
Less than $20K/year	47	16.4
$20K - $39,999K/year	71	24.7
$40K - $59,999K/year	55	19.2
$60K - $79,999K/year	36	12.5
$80K - $99,999K/year	23	8.0
$100K - $119,999K/year	24	8.4
$120K - $139,999K/year	13	4.5
More than $140K	18	6.3
Self-reported chronic health concerns		
Cardiovascular	17	5.9
Cancer	20	6.9
Chronic obstructive pulmonary disease (COPD)	3	1.0
Diabetes	17	5.9
Mental illness	14	4.8
Multiple health concerns (e.g., cancer and diabetes)	51	16.3
Other health concerns[c]	60	20.8
None	107	37.0

Note. Due to missing data, category totals may be less than 312.
[a] M(*SD*) for age.
[b] Participants reported two or more ethnicities (e.g., African American and Asian).
[c] Other health concerns reflect participant's self-identified health concerns that were included as response options on the survey (e.g., Hypertension, High Blood Pressure, and Chron's Disease).

3.2. Research registry retention and intention to participate in clinical trials

Participant's willingness to remain in the research registry was positively associated with research registry knowledge ($r = .27$, $p < .001$), perceived social value toward health research studies ($r = .50$, $p < .001$), self-efficacy ($r = .45$, $p < .001$), trust in the research process ($r = .40$, $p < .001$), trust in the IRB ($r = .39$, $p < .001$), trust in doctors ($r = .41$, $p < .001$), intentions to participate in future clinical trials ($r = .78$, $p < .001$), and consent recall ($r = .19$, $p < .01$). Findings also demonstrated that willingness to remain in the research registry ($r = -.17$, $p < .01$) and intentions to participate in future clinical trials ($r = -.13$, $p < .05$) were negatively related to perceived barriers toward health research studies (See Table 2).

3.3. Effects of self-reported chronic health concerns among registry patients

Participants with self-reported chronic health concerns had higher research registry knowledge ($M = 2.69$, $SD = .26$), higher self-efficacy ($M = 4.10$, $SD = .76$), a greater willingness to remain in the research

Table 2
Pearson correlation matrix for variables ($N = 312$).

		1	2	3	4	5	6	7	8	9	10	11
1.	Research registry knowledge											
2.	Perceived social value toward health research studies	.43***										
3.	Perceived barriers toward health research studies	-.13*	-.32***									
4.	Perceived benefits toward health research studies	.18**	.14**	.27***								
5.	Self-efficacy	.42***	.34***	-.16**	.16**							
6.	Trust in the research process	.32***	.65***	-.55***	-.02	.34***						
7.	Trust in the IRB	.34***	.54***	-.41***	.09	.31***	.71***					
8.	Trust in doctors	.35***	.55***	-.40***	.05	.38***	.74***	.81***				
9.	Willingness to remain in the research registry	.27***	.50***	-.17**	.08	.45***	.40***	.39***	.41***			
10.	Future clinical trial participation	.26***	.44***	-.13*	.09	.39***	.32***	.32***	.37***	.78***		
11.	Consent recall	.26***	.20**	-.19**	.01	.28***	.24***	.28***	.30***	.23***	.19**	

***Correlation was significant at the 0.001 level (2-tailed).
**Correlation was significant at the 0.01 level (2-tailed).
*Correlation was significant at the 0.05 level (2-tailed).

registry ($M = 4.36$, $SD = .73$), and greater intentions to participate in future clinical trials ($M = 4.34$, $SD = .72$) than participants who did not self-report chronic health concerns (research registry knowledge: $M = 2.61$, $SD = .35$, $p < 0.05$; self-efficacy: $M = 3.83$, $SD = .92$, $p < 0.01$; willingness to remain in the registry: $M = 4.08$, $SD = 1.03$, $p < 0.01$; future clinical trial participation: $M = 4.04$, $SD = .98$, $p < 0.01$). See Table 3 for details.

3.4. Effects of research registry consent recall

One-way ANOVA tests examined if differences in consent recall (i.e., the extent to which participants remember consenting and enrolling in the registry) were related to attitudes toward health research participation, registry knowledge, trust, willingness to remain in the research registry, and intentions to participate in future clinical trials. Participants with different levels of consent recall demonstrated significantly different levels of research registry knowledge ($F_{2,321} = 13.67, p < .001$), perceived social values toward health research studies ($F_{2,300} = 5.47$, $p < .01$), self-efficacy ($F_{2,323} = 15.62$, $p < .001$), trust in the research process ($F_{2,298} = 7.56$, $p < .01$), trust in the IRB ($F_{2,303} = 12$, $p < .001$), trust in doctors ($F_{2,308} = 11.94$, $p < .001$), willingness to remain in the research registry ($F_{2,297} = 7.99$, $p < .001$), and intentions to participate in future clinical trials ($F_{2,296} = 5.8$, $p < .01$).

Post-hoc analyses revealed that participants who "clearly remembered" enrolling in the C2S registry had significantly higher levels of research registry knowledge ($M = 2.74$, $SD = .03$), perceived social value toward health research studies ($M = 4.41$, $SD = .07$), self-efficacy ($M = 4.28$, $SD = .08$), trust in the research process ($M = 4.3$, $SD = .08$), trust in the IRB ($M = 4.22$, $SD = .08$), trust in doctors ($M = 4.23$, $SD = .08$), a greater willingness to remain in the research registry ($M = 4.52$, $SD = .09$), and greater intentions to participate in future clinical trials ($M = 4.45$, $SD = .09$) than participants in the other two conditions. There were no differences in the perceived benefits toward health research based on the different levels of consent recall among participants. See Table 4 for more details.

Table 3
Differences in variables among participants with and without self-reported health concerns.

	With self-reported chronichealth concerns ($n = 107$)		Without self-reported chronic health concerns ($n = 182$)				
	M	SD	M	SD	*t*	*df*	*p*
Research registry knowledge	2.61	.35	2.69	.26	−2.11.	276	.04*
Perceived value toward health research studies	4.22	.68	4.27	.63	-.64	279	.52
Perceived barriers toward health research studies	2.20	.99	2.15	1.02	.37	283	.72
Perceived benefits toward health research studies	2.64	.97	2.84	1.05	−1.57	283	.12
Self-efficacy	3.83	.92	4.10	.76	−2.71	278	.007*
Trust in the research process	4.06	.80	4.12	.80	-.65	278	.52
Trust in the IRB	4.00	.78	3.93	.80	.84	282	.40
Trust in doctors	3.92	.82	4.03	.77	−1.12	286	.26
Willingness to remain in the research registry	4.08	1.03	4.36	.73	−2.63	287	.009*
Future clinical trial participation	4.04	.98	4.34	.72	−2.97	286	.003*
Consent recall	5.85	3.37	6.58	3.48	−1.74	286	.083

*Correlation was significant at the 0.05 level (2-tailed).

4. Discussion

Our goal was to identify translational communication strategies to improve public understanding and support for clinical research. As an important step, we examined the extent to which health research registry member's perceived social values toward health research studies, registry knowledge, self-efficacy, trust in research, and consent recall contribute to their intentions to remain in the research registry and enroll in future clinical trials. Research registry knowledge, perceived social values, self-efficacy, consent recall, and trust in research (i.e., in the process, IRB, and doctors) were positively associated with participant's willingness to remain in the registry. Willingness to remain in the research registry was significantly and positively correlated with intentions to participate in future clinical trials among current registry patients. Results confirm the importance of participant's perceived social values, self-efficacy, trust, and knowledge to participating in health research [7–18] and extend the significance of these variables to registry retention and participation in future clinical trials among patients currently enrolled in a health research registry.

4.1. The importance of building trust

We found that trust in the research process, the IRB, and in the doctors conducting studies was positively associated with participant's willingness to remain in the research registry and intentions to participate in future clinical trials. Our findings confirm the importance of patient trust in physicians and in the research process to clinical trial recruitment [11–13]. Importantly, our study extends the significance of patient trust in the IRB, the research process, and in the individuals (e.g., doctors, researchers) conducting studies to patients' intentions to remain in a research registry and participate in future clinical studies.

Table 4
Mean levels of variables associated with consent recall among participants.

	Clearly remembered (G1)	Somewhat remembered (G2)	Did not remember (G3)	Difference G1-G2	Difference G1-G3	Difference G2-G3
Research registry knowledge	2.74(.03)	2.63(.02)	2.50(.04)	.11**	.24***	.13**
Perceived social value toward health research studies	4.41(.07)	4.18(.05)	4.09(.09)	.23**	.32**	.09
Perceived barriers toward health research studies	2.05(.10)	2.16(.08)	2.44(.14)	-.13	-.42**	-.29
Perceived benefits toward health research studies	2.76(.10)	2.78(.08)	2.65(.14)	-.03	.11	.13
Self-efficacy	4.28(.08)	3.90(.06)	3.58(.10)	.39***	.7***	.31*
Trust in the research process	4.30(.08)	4.03(.07)	3.78(.11)	.27*	.52***	.25
Trust in the IRB	4.22(.08)	3.85(.06)	3.62(.11)	.36***	.6***	.24
Trust in doctors	4.23(.08)	3.86(.07)	3.61(.11)	.36***	.62***	.26*
Willingness to remain in the research registry	4.52(.09)	4.14(.07)	4.02(.12)	.38**	.5**	.12
Future clinical trial participation	4.45(.09)	4.11(.07)	4.06(.12)	.34**	.39**	.05

Note: *significant at $p < .05$, ** significant at $p < .01$; *** significant at $p < .001$.

The positive associations between trust and willingness to remain in the registry and intentions to participate in future clinical trials underscore the importance of transparency in the research process and the need for positive perceptions of the individuals, institutions, and systems involved in research to increase registry enrollment, retention, and study accrual.

Research trust was negatively associated with perceived barriers to participating in research (e.g., time, perceived risks, effort to participate in studies). Common barriers to research participation include limited awareness of study opportunities, competing life demands (e.g., time, limited support from social networks), and mistrust in medical research [26]. To increase transparency and trust in research among registry participants, research teams should customizemessages about registry recruitment and research participation to reflect prospective participants perceived social values toward research, the individual benefits to participation, and safety protection plans. Future studiesshould explore how trust and barriers to research participation enhance or impede recruitment and study participation among individuals enrolled in a registry compared to individuals who are recruited directly into clinical studies.

4.2. Recruitment communication and consent recall

Participant's recollection of the registry recruitment and consent process (consent recall) was positively correlated with registry knowledge, perceived values toward research, research trust, willingness to remain in the research registry, and intentions to participate in future clinical trials and negatively correlated with perceived barriers to research participation. It may be that patients who clearly recall the consent process have greater knowledge, perceived social values toward research, and research trust, fewer perceived barriers, as well as a stronger interest (willingness) to remain in the registry and participate in future research of all registry participants. It is also possible that participant's ability to clearly recall the registry consent process increases registry knowledge, values toward research, trust, and decreases perceived barriers to research participation, ultimately improving intentions to remain in the registry and participate in future clinical trials. Future studies should examine the causal relationships between participant's intrinsic values toward health research and consent recall and their actual retention in the registry and participation in clinical trials.

4.3. Patient health concerns, registry retention, and future study participation

Participants who self-identified as having at least one chronic health concern (e.g., diabetes) had greater research registry knowledge, higher self-efficacy, as well as greater intentions to remain in the research registry and to participate in future clinical trials than participants who did not self-identify as having chronic health concerns. Patient perceptions of their illness identity (e.g., being a patient with cancer) can influence how they process health information (e.g., treatment options) [26,27]. Greater registry knowledge among registry patients with chronic health concerns may have resulted from their additional experiences receiving and processing information about their illness.

The positive association between having chronic health concerns and self-efficacy regarding participant's decision to enroll in the registry suggests that patients with self-reported chronic illnesses may be more likely to engage in certain disease management behaviors, such as enrolling in a registry or participating in future , compared to those without chronic health conditions. However, the reliability and validity of patient's self-reported engagement in certain health behaviors (e.g., smoking, cancer screening) is mixed [28,29]. In the future, researchers should consider linking data from patient electronic health records (EHR) to survey responses to validate self-reported diagnoses and to confirm the extent to which self-identifying as a having chronic health concern is associated with registry knowledge, self-efficacy, remaining in the research registry, and participating in future trials. Future studies should also examine potential differences in attitudes and beliefs about research among patients with specific chronic diseases or conditions (e.g., compare differences among patients with cancer and diabetes).

4.4. Practical implications

Our findings have important implications for designing and disseminating materials about research participation and registries to improve recruitment, consent recall, and clinical trial participation. Discrepancies in consent recall among participants suggest that the "one size fits all" approach to recruitment may be ineffective at enrolling and retaining certain patients in health research registries. To improve registry recruitment and retention, health practitioners and researchers should engage theoretically-driven strategies to make the consent process more memorable. First, audience segmentation – dividing a prospective population into groups whose members are more similar to each other than members of other segments [30,31] – may be an important step to increasing consent recall and recruiting patients into registries. Our results suggest that segmenting prospective registry participants by self-rated health status (e.g., having a chronic health concern) and psychographic composition (e.g., attitudes toward health research) and targeting individuals for recruitment based on these attributes may increase recall and recruitment.

Second, customizing (i.e., tailoring, personalizing) messages about recruitment and consent on the basis of prospective participant's beliefs, attitudes, needs, and preferences can improve recruitment and consent procedures. Message customization enhances message attention and promotes intentions to engage in positive health behaviors [32]. Thus, incorporating patient perspectives (e.g., interests, values, feedback) into the development of messages and information about registry participation and recruitment should increase message attention, consent recall, and sustained registry enrollment. Adding visuals (e.g., pictures) with written or spoken information also increases attention and recall of

health education information [33], and may be effective for research registry recruitment. Developing videos that explain the registry and including them as part of the informed consent process should give patients a clearer understanding of registries and may increase registry recruitment and consent recall.

4.5. Strengths and limitations

We addressed two important knowledge gaps regarding clinical recruitment and research participation among research registry patients. This study was among the first to examine how trust in the research process, IRB, and doctors is associated with health research registry enrollment, retention, and intentions to participate future clinical studies. Second, results demonstrate the importance of consent recall on registry retention and on registry patient's intentions to participate in future clinical trials. Overall, our findings underscore the consent process as an important communication event and suggest that developing broad research trust and making the consent process more memorable may improve registry recruitment and future study accrual.

Another strength of this study is the diversity of the sample. We oversampled ethnic and racial minorities, which resulted in approximately 40% of the sample participants identifying as non-White (e.g., African American, multiple races). Although our sample includes a higher proportion of females than males, which may limit the generalizability of some findings, women are less likely than men to enroll in treatment studies [34]. Therefore, it is important to oversample women to understand their motivations for participating in research registries and studies to enroll them into future treatment trials.

As with any study, this one is not without limitations. First, this study is limited by its design. We did not measure the length of time that has passed since participants enrolled in the registry nor did we examine how previous contact history (e.g., frequency with which patients were contacted about research opportunities) was associated with study outcomes. Because participant's ability to recall details of the consent process may be affected by time and previous contact history, these variables should be included in future studies on recruitment and consent recall. Second, our data are descriptive rather than predictive and our findings do not denote causal relationships between variables. The study is also limited by our examination of patients' intentions to remain in the research registry and participate in future clinical trials. Although the strongest predictor of a person's behavior is their reported intention to engage that behavior [35,36], intentions may not translate into real-world activity when opportunities are presented. Participant attrition and missing data are also limitations, as approximately 30% of participants were removed from the analysis due to missing or incomplete data. Finally, as participants in this study were all enrolled in C2S, our university registry, our findings may not be generalizable to participants in other research registries. However, understanding participant's motivations for enrolling in a health system registry can be applied to optimize recruitment and consent procedures across the research spectrum.

5. Conclusion

Understanding patient perspectives on research participation is important to ethically recruiting individuals into health research registries and fostering autonomous, informed decisions about participating in clinical trials. Among participants, perceived values, research registry knowledge, trust, self-efficacy, and consent recall were associated with intentions to remain in the registry and participate in future clinical trials. Study participants with self-reported chronic health concerns had greater knowledge and self-efficacy, as well as stronger intentions to remain in the research registry and participate in future clinical trials than participants without chronic health concerns. Positive associations between consent recall and participant's perceived values, knowledge, trust, and intentions to remain in the registry and participate in future clinical trials underscore the recruitment consent process as a significant communication event. Study findings can be applied to improve recruitment consent procedures, health research registry retention, and clinical trial participation rates.

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